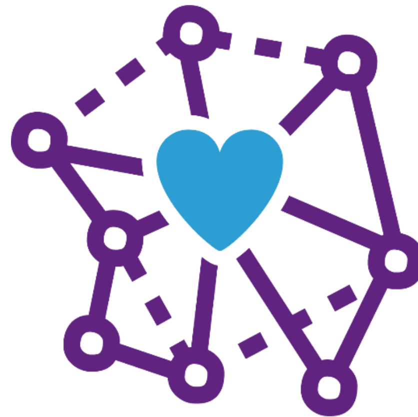

Deliverable 2.5: Collective autonomy. An ethnography of open care services.

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Introduction

The opencare project explores how communities of any kind provide health and social care, when neither states nor businesses can or will serve them. Data are gathered from an online forum where individuals share and discuss their experiences of community-provided care. At the time of writing, the forum consists of 657 discussion threads, normally started by a long-form post followed by one or more replies. Overall, the opencare corpus contains 3,910 posts for a total of 824,000 words, mostly in English, authored by 336 unique informants. These were uploaded onto the online forum in the period between January 2016 and October 2017. This corpus was enriched with 6,299 annotations, employing 1,282 unique codes.

This ethnographic report outlines key findings from opencare. It is titled "Collective Autonomy" because the central finding that spans the project topics is that people, when seeking care, need to be empowered to solve their own problems but need a community-based framework in order to most successfully do so. Put another way, people need networks of other people to teach them how to solve their own problems and live autonomously. Solutions that treat people as dependent and helpless, or that remove them from a community context, are likely to fail. Instead, it is the solutions that connect people with others with compatible skills, or strengthen care networks in communities, that have been the most useful to people seeking care outside of existing health and social care systems.

This finding is visible across multiple topic areas generated by opencare participants:

1. Mental Healthcare: The most effective mental health solutions involve empowering people to be active of their own volition and engaged members of their communities, as feeling autonomous and purposeful is central to mental well-being.
2. Migration and Refugee Care: Refugees often feel like their autonomy has been stripped from them, so although providing for basic needs is important, returning a sense of control over one's life is vital to successful care in the refugee crisis.
3. Building Resilient Communities: Resilient care projects link people together in the physical space of their communities, allowing people to share skills and offer social support to one another. Linking diverse groups within the community leads to strong and resilient care networks.
4. Open Source Design Interventions: Existing health and social care system failures have made open source technology a promising solution, but social networks are key to the success of these projects, since many of the barriers to creation and uptake are socio-political, not technological.

In short, care comes from communities. Both self-care and institutionally-based care can only take people so far, as they do not always connect individuals with social support systems that integrate with their pre-existing social worlds. If communities are the locus of most people's care practices, it is vital to invest time and energy into community-building and community-based care initiatives.

In what follows, we first explicate opencare's research methods, then detail each finding and provide examples from the opencare conversation. The expression "opencare" denotes the projects of this name; the expression "open care" denotes forms of care based on open source knowledge and organisational forms that make it easy for self-selected individuals to step up into the role of carer.

Ethnographic Methods in opencare

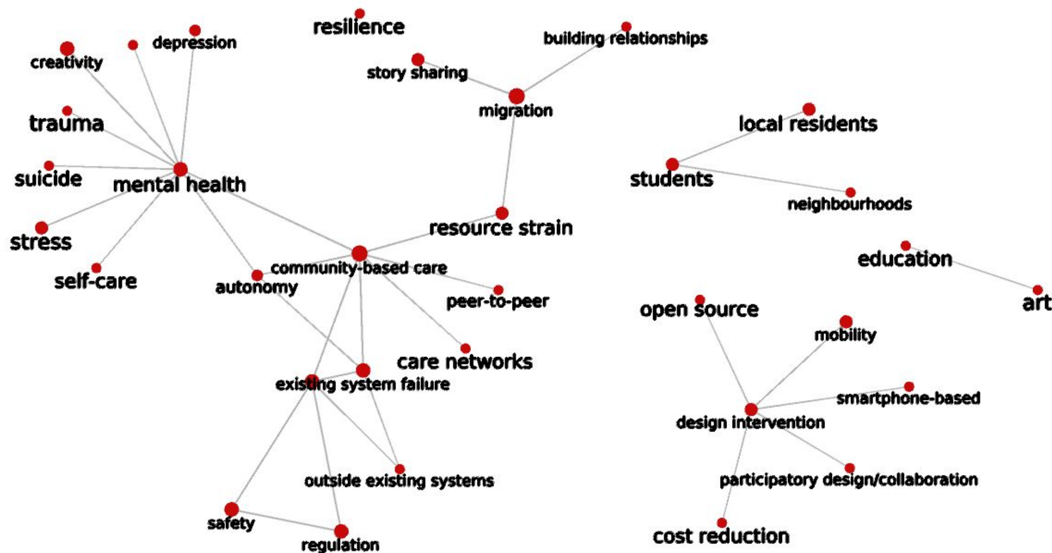

Figure 1. The map of the strongest associations in the opencare conversation. In the graph, ethnographic codes are connected if they co-occur on at least seven different contributions.

Ethnographers study individuals as community members: how people with their own unique worldviews and life experience live together and act in social groups. Ethnography is a qualitative research technique aimed at discovering how a certain group of humans perceives a set of issues. Its unique value lies in that its findings encode the culture and worldview of the group being studied. Social and cultural meanings that arise organically from human interactions are the main objects of research rather than pre-conceived, researcher-imposed analytical categories.

Ethnography takes informants (the disciplinary term used to describe research participants) embedded in communities as its object of study, seeking analytical depth through long-term engagement with informants (Geertz 1973; Abu-Lughod 1991). Ethnographers conduct interviews, hang out with informants, and write field notes about observed social behaviour. They then assign codes to that written material, which form an ontology of concepts relevant to describe the problem at hand. These codes emerge from the ethnographer's embeddedness in the community she studies, gleaned through extended participant-observation which contextualises interview data in informants' larger environment (Emerson 2013; Goffman 1989).

In opencare, we convened an online conversation specifically to discuss health and social care issues, and treated those conversations as ethnographic data. In this approach, informants co-construct and sustain visible themes of conversation through interaction with the researcher and community managers. When an

ethnographer is synchronically doing research with informants, she can contextualise the temporal unfolding of information rather than getting lost in noise as in other methods that analyse aggregated digital data after the fact (Coleman 2010). This approach relates to works such as participant-observation with UNIX user-groups (Kelty 2008), online research with Anonymous hackers (Coleman 2015), and fieldwork in virtual worlds like World of Warcraft (Nardi 2010) and Second Life (Boellstorff 2008). In these studies, anthropologists conducted long-term ethnography, interacting with informants in-setting, asking questions, and generating context-specific data that evolved through interactions with informants over time. Some projects included offline components (Kelty 2008), while others were completely undertaken online (Boellstorff 2008), but all pay close attention to the ways informants make sense of their own worlds and define their terminology.

OpenCare similarly commits to engagement with informants, but also convenes the environment within which conversations unfold. This allows researchers to code data directly on the OpenCare site, resulting in a rich overlay of quantitative data over the qualitative data generated by informants and coded by ethnographers. It is from this long-term engagement that these conclusions emerge.

Given that the opencare project has such a strong social networking element, it is essential that people are to interact with neither mediation nor delay, so as not to dampen interaction and feedback. As a result, the language of opencare is Euro English. This is an inclusive, connecting language which allows for spelling and grammar mistakes, and focuses on mutual intelligibility rather than perfect correctness. Native English speakers are asked to make an effort to keep their language simple and clear. Those uncomfortable using any version of English are welcome to use their own language, and people interact by running the text through Google translate, responding in Euro English when possible. This commitment breeds an atmosphere of tolerance and patience, with a focus on understanding others, reaching for the underlying ideas, and asking for further clarification when needed.

Finally, community members are mentioned by name if they provided it on the platform when sharing their story. Otherwise, they are mentioned by username (e.g. @trythis, @woodbinehealth) as this is the form that their contributions took on the platform.

We have grouped our findings into four key areas based upon the most heavily discussed topics in the opencare conversation. Section 1 discusses issues around mental health and healthcare. Section 2 focuses on migration and refugee care. Section 3 explores what it takes to build resilient communities. Section 4 details debates around open source design interventions and obstacles to their production and uptake.

Mental Health

Figure 2. The ego network of the "mental health" code (2 co-occurrences or higher). Node size maps to number of connections.

Key Finding 1: The most effective mental health solutions involve empowering people to be active of their own volition and engaged members of their communities, as feeling autonomous and purposeful is central to mental well-being. Self-care is not sufficient as issues are often too big to cope with alone, but paternalistic solutions are not useful either as sharing one's story and connecting and mutually supporting others is central to the healing process. These findings mean that community-based care initiatives are a powerful way to support those with mental health problems outside of existing health and social care systems.

"Mental health" is one of the most frequently used codes used to describe the opencare conversation. It co-occurs with codes like gardening, art, food sharing, intergenerational connection, and peer-to-peer, indicating that mental healthcare can be found in unexpected places. These co-occurrences (which emerge directly from the stories of community members) also suggest that seeing the individual as the unit of analysis when dealing with mental health issues overlooks a large aspect of what makes mental illness survivable or not: a person's connection to their wider community and the actions they undertake in it. Helping others, for example, was a way that community members boosted their own mental health and well-being.

At the same time, code co-occurrences shed light on the sources of mental health issues: widespread experiences of crisis, precarity (tied to labour loss and economic instability), and displacement that cause mental health issues have been shared on the platform. Trauma is rife after such experiences, and community members have been trying to find ways to heal themselves mentally as well as physically. Feeling useful and purposeful is important to people's mental health, according to community members, so treating them like patients is often counter-productive.

As a result self-care has been an emergent theme, though community members across various topics have made clear that going it alone is not a viable option in many circumstances. Discussion has also shown that sometimes people do need trained professionals---- there is a limit to how much peers can help in certain medical situations. There is a serious lack of available mental health professionals despite this fact. Though there are a lot of ways people can improve mental health outside of institutions, mental health issues must not be trivialized or stigmatized and often require professional care.

Since holistic healthcare is so important to so many members of the community, however, trained professionals are only one aspect of mental healthcare. In dealing with trauma especially, connecting people in different places, sharing support and resources, has been crucial. Some have found group therapy and online support groups useful, while others have found that alternative therapies like meditation and acupuncture help them cope and heal. Gardening can be the key to happiness and healing sometimes, according to community members, as can artistic expression.

Some opencare community members have fought mental health issues through a commitment to living life a little differently. Many community members have identified sources of stress that emerge from trying to measure success by someone else's metric, or taking on expectations at work that far exceed or are completely different from their own desires. Sometimes mental health issues come from sources that cannot be healed through labour or lifestyle changes--- certain types of depression result from a chemical imbalance in the brain that require medical attention --- but some sources are identifiable, and community members have been inventing creative ways of attaining happiness even in the face of precarity. There is a powerful link between creating a life in which someone is able to express themselves creatively and finding mental well-being.

Labour

Mental health issues are strongly tied to labour, and the struggles people have finding work, imagining their employment futures, managing stress in the workplace, and feeling fulfilled and happy at their jobs. As Sharon puts it in her story on "Kindness and Connection":

Unfortunately, we live in a society that places huge stigma around mental health issues so in terms of employment, people are encouraged to cover up any such issues. The past few years have really been a very harsh eye opener for me, into the affects an

economic crisis has on people's lives. It has detrimental impacts on people's health, welfare, living conditions and psyches.

Nele shares the same sentiment, citing work-related stresses as central to mental health issues:

It was the logic of efficiency that I began to see everywhere. Peers trying to "get it all right", to "avoid failing". To master their own life as it was some kind of stress test. And to always be ready for the next job interview, a smooth and pleasing CV at hand. I was and I am a part of that. And it strikes me that this kind of neoliberal thinking of "your life (and your success/failure) is your responsibility" leads us sometimes to very harsh assumptions about ourselves and our peers.

I can now see all of that in a broader socio-economic context of destabilized markets and societies. We are all, in a way, facing much more uncertain futures than our parents did (while it is extremely difficult to get a full understanding of how this is just a perceived thing or really the case).

Sharon goes on to discuss potential solutions to these labour-related issues, stressing connection with one's community:

The other side of the coin is, that I have fortunately come to discover, the absolute profound healing and joy that comes from people around us, the hearts and minds of people who genuinely care. That sense of community and connection is the most important aspect to life and has certainly helped me and my family to cope through the last few years. There is a dire need for an extension of this supportive community, in tackling the many varied and complex social issues of our time. The most recent suicide and cancer statistics, highlight the absolute urgency, in finding alternative ways, of connecting and supporting the people who are struggling within our communities.

Nele puts forth a similar solution, suggesting that story sharing might have healing potential, and that there are dangers in trying to cope with one's problems alone:

Against this backdrop, the topic of mental and emotional resilience seems really a thing we should put our minds to. What does "real" self-care mean when we are all trained to function? … I think sharing our vulnerabilities and insecurities around failing, missing out and not wanting anymore is crucial at this point. Although there are already some great projects bringing these issues into awareness it seems that for a majority of people the stigma around for example mental illness, burnout etc. is still too big to cope with on their own.

Alan, in his story "Losing and Gaining Hope", agrees that human supports are crucial, but highlights a key issue: that people already close to you are not always the most equipped to offer continuous support. Thus communities must be actively built and cultivated around the notion of support for mental illness:

Supports are very important. I have always had great support from my family and friends. However it can sometimes be very difficult to discuss some of these topics with family and friends and I worry about burning them out by talking about the same old

issues over and over. This is why I joined a mutual support mental health group called GROW.

Echoing this need for more organized social support in tackling mental health issues, other community members have formed groups that allow people to help one another. MAZI Greece is an organization that seeks to fight depression together (Mazi means together in Greek), committing to avoid either “expert lectures” or “self-pity parties”. Community-building is an important part of what they do, but they also ensure that the group is actively empowering members to take control of their lives and feel autonomous. They focus on providing “an environment of emotional support, which reduces isolation and alienation, moderates despair and increases optimism, personal responsibility and self-acceptance” and support members in “regaining control and improving the quality of their lives and relationships” as well as help them “learn and practice new, more effective and satisfactory ways of relating to others.”

Medical professionals have also caught on to people’s need to share their experiences. We Mental Health Nurses host regularly scheduled Twitter chats around mental health. The topics of these conversation emerge from previous conversations with the community. Their goal is to facilitate “broader conversation in a democratised digital space, where everyone can have a voice, regardless of positional authority” and focus on “discussing the everyday implications of policy on mental health nursing practice.”

Alternative Living Arrangements

Co-living solutions will be discussed in more depth later in the report, but they have been put forward as a solution to social isolation. The opencare conversation has made clear that social isolation and loneliness are a huge issue across contexts. This feeling, community members have articulated, is alleviated through gestures of social solidarity: having someone to talk to and knowing you are not alone. As Pauline puts it in her story “Under Pressure”:

The greatest help for me was just someone being there and giving me a hug. Telling me that they know it sucks and just sharing a little bit of the suckiness in that moment.

Maria talks about a co-housing initiative in the Netherlands that helps facilitate these kinds of connections:

In an effort to save on rent, some Dutch college students are living at nearby nursing homes. In exchange for 30 monthly volunteer hours, the students get free housing in vacant rooms. It seems to be a win-win for everybody. Not only are the students living in better accommodations than student housing and not racking up as much student debt, but they’re providing a better quality of life for the eldest residents by socializing, helping them with tasks, and teaching them tech-savvy skills like using email, social media and Skype.

@asimong also describes the psychological benefits of co-living with a community that self-consciously protects minority rights and thinks critically about the

aforementioned normative stressful living situations (as exemplified by the above community member contributions):

Sharing some non-mainstream values, and a vision that is not yet shared by the majority of people...we will provide a safe space for "people like us", a haven from the strain of being minorities who are disregarded, or even criticised, elsewhere. This need for a sense of psychological safety does appear in various ways, sometimes surprisingly. This is often hidden in the rest of society...We need now to care for each other's resources of time, energy and good will.

Mental Health Activities

Activities were central in the boosting of mental health. Artistic expression is one such activity that people found useful. As Alex puts it, in support of a larger discussion on the positive impacts of art on mental health:

There are certainly studies that show that engagement with the arts have a sustained and positive benefit on all aspects of mental health, and I've also seen brilliant theatre work that works across a variety of disciplines.

Community gardening, food sharing, art, and building/making are all ways in which community members have actively sought to boost their mental health.

Gehan of GalGael in Glasgow has come up with a particularly innovative activity for those who have battled worklessness, depression, addiction, and other mental health issues: wood/stone/metalworking. People craft furniture, process timber, work at events and cook. GalGael focuses on helping people build skills and engaging them in activities, building "architectures of love" and a "learning community" alongside the material outputs. The focus is less on the training and more on the cooperative development and learning process. Participants build "personal capacity and resilience" through hands-on activity.

Trauma

Finally, mental health issues were also connected to traumatic experience, especially from displacement and conflict. Kate works with the Trust for Indigenous Culture and Health, who developed a program with survivors of the Nyayo House Torture Centre and other Centres in Kenya. According to Ngala, who runs the program, survivors often have to suffer alone since social isolation after experiences with trauma is prevalent. He says that most problems can be solved through sharing: "when survivors are given opportunities to share their stories, they heal fast." Networked technologies, in his view, can help facilitate this sharing, letting people decide whether they wanted to write or record their stories to share later. As Kate puts it:

There is a huge amount of trauma recovery material and contexts for group psychology that I do not know about. It is challenging terrain. As much as it's essential to tread carefully, it is also necessary to create. The outpouring of emotional pain, anger and concern after the American election makes clear a need for strong communities of action and bold ways for participating in new stories. As worrying as is the prospect of

making mistakes around mental health, the more worrying prospect is not creating networks to meaningfully connect up alienated, isolated or suffering individuals. Local actions, online networks and communities are all growing this November: each network has a different focus. Involving digital technology to reimagine group psychology and care (beyond Facebook) is just one of the potentials to help these evolving networks support themselves.

Ngala's experience, Kate thinks, shows that "targeted and bold ventures can reboot the community's ability to support" and that through this community-based care, even the most traumatic experiences can be healed.

These creative solutions link people who are struggling up with one another and give them space to share their stories, strengthening social ties and reintegrating them into communities.

Community members' experience with the refugee crisis has also illuminated how important social supports are to coping with trauma. Alex describes the grim mental health situation for both refugees and volunteers in Calais in his story "Care on the Camp":

Mental health for the volunteers is a concern. Everyone lives on a knife-edge...Everyone experiences some form of trauma. Most experience exhaustion. Often trauma comes from being in scary situations that you aren't trained to deal with. In the end there is either hope, or hopelessness; Chance or no Chance. Both suffocate you and the refugees. It clouds all your conversations and interactions. In the end you start to live like the refugees on the camp: day-to-day, expecting the unexpected, desperate to get away to the 'real world' but somehow unable to move on.

Alex stresses that volunteers also need care as they live in a challenging situation:

Most volunteers self-finance their time working in Calais. They live frugally, stretching their money out. This means they end up living on top of each other. The warehouse team has a caravan park attached to the building. Volunteers with no money can stay there. Living up to 6 people in a caravan, with limited access to hot water and personal space. Volunteers who live in this enclave have a different experience to those who stay in private accommodation or hostels.

@ybe runs a program called Trauma Tour, in which she takes her psychology practice on the move. As articulated by Alex, many refugees suffer from mental health issues such as PTSD, but are mobile and do not have access to consistent healthcare. @ybe seeks to give them more support by bringing medical practice to them. She feels like existing mental health services have failed a large segment of the population:

We, psychotherapists, stay in our daily practices. We don't move. We don't reach out and explain things to people. We do things with individuals - why not try to work with a group, and talk to a group? This is what I'd rather do. The more I thought about it, the more sense it made.

Alex stresses the need for such mental health resources, but laments that they are often not reaching the people that they need to:

Occasionally volunteer social workers, therapists and psychologists stop by the volunteer camps. They offer their services for free. As always, the people who need it the most are most likely to not take advantage of these services.

In short, mental health issues are a serious concern across topic areas, and community members are devising creative ways to collectively cope. Following from these discussions, the next section dives deeper into migration issues and autonomy and solutions to the problems that community members like Alex raise in this section.

Migration

Figure 3. *The ego network of the "migration" code (2 co-occurrences or higher). Node size maps to number of connections.*

Key Finding 2: Refugees often feel like their autonomy has been stripped from them, so although providing for basic needs is important, returning a sense of control over one's life is vital to successful care in the refugee crisis. In situations of need, people are more likely to reach out for other people to find support, rather than technology. Since displacement often weakens communities and strips away social ties, restoring human connection through story and skill sharing proved invaluable to refugees across the platform. Further, refugees know best about the kinds of help and support they need, so any kind of aid that does not include their opinions will likely fail to be effective.

Migration and refugee hardships pervade the opencare stories: migration is another highly frequent code. The typical solution offered by institutions of giving goods and temporary habitation is decent (when those resources actually make it to refugees, which they often do not) but not as good as giving very competent and capable people the ability to shape their own world, connect with other people, and do things for themselves. As seen in the previous section, refugees also need psychological care and therefore need access to non-material resources as well as clothes and food.

Existing System Failures

Aid organizations and governments frequently make decisions without consulting refugees or people with expertise in refugee issues, so often resources go to waste and people do not get the kind of materials they need. Aravella finds this in her research into refugees' material needs:

Local authorities and their services operated superficially while the government was obviously unprepared. On the other hand, citizens reacted vigorously and passionately ....without surprise, no one reached out to experts from the clothing sector for professional advice and assistance. Moreover both government and UNHCR ignored any proposals or contact efforts.

In her story "Backpacks for Refugees", she describes how

large amounts of food, clothing, medicines and a lot of useless things were being carried around Greece like a giant pinball machine. Unnecessary shipments, aid wasted, corrupted by mold, insects or still remain in inappropriate warehouses. A serious waste of resources.

Franca also calls for tailoring solutions to refugees' specific contexts:

It's not possible to speak about refugees in general when trying to be of real help. We have to think about the countries where we are and where they come from (for example 90% of Syrian refugees that arrived in Italy decided not to ask asylum here, but in other north EU countries), the migration routes, the particular war conditions, but also the economical ones.

Several community members also lamented attempts to use technology as a cure-all for refugee problems. As Noemi asks:

How do we stop building apps and start building communities?

Attempts to provide care that are not localised and do not consult displaced people themselves, in short, do not serve refugees' needs best. Tomma found this when visiting camps. In her story "Fostering Productive Potential in Refugee camps", she observes how refugees are creatively using limited resources to transform their living spaces:

We were shown the little gimmicks to improve the bare rooms where they are living in at the moment: How they pulled out screws and nails from the walls to make clothing hooks; how you make a wall-mounted phone holder with just duct tape and a piece of wood; where to store the food; they showed us how they hack the beds to create more privacy and how to shield the light falling onto the upper beds with merely pieces of wood and a blanket to a point where one could create an entire ceiling with just white cloth. We learnt quickly that the ideas of how to use the space could never occur to someone who has never been in that exact position.. It was evident that they know best about the needs and necessities in their very situation and environment.

Autonomy and Skill Sharing

Those community members with intimate knowledge of refugee issues stressed that fostering autonomy was vital to improving living situations. Camps, as evidenced in the last section, can be very challenging places to live, and there is often nothing for refugees to do day-to-day. This lack of autonomy and feeling of helplessness causes mental health issues. Franca, in her story "Teaching Languages to Refugees", maintains that the key question is "to create opportunities for people to be really active (refugees as #nospectators)." When asked what projects can really make a difference, she answers:

Projects that work on the concept of resilience*... opening workshops where people can create something (for ex. FabLabs, Makerspaces..) using open technologies (like Raspberry Pi) could become new ways to take care of people in really big troubles, with strong vulnerabilities and help them to start again*.

Franca's lessons then become workshops, where participants work together to construct their own language-learning methods (through art, music, and plays, for example). She says this builds a strong community around the language acquisition, restoring some of the social ties that were lost during experiences of displacement.

This idea of teaching refugees concrete skills and giving them the materials to decide what they want to make spans different stories. Asnada is a space for refugees to learn languages, but Sara emphasizes that refugees need more than that:

Our schools are the places where we try to build up familiar relationships and a sense of community, but also the place where we try to understand, together, the contradictions of the world we live in. The learning group has here an essential role because it's the context in which every single student find his place, support and the courage to express himself. The variety of writing and speaking levels we look for in the student group is meant to lead to a free and informal circulation of knowledge and language skills, creating a context where the directory of teaching is also transversal, not only vertical.

Asnada's ethos focuses on restoring a sense of community, sharing skills, and enabling refugees to take joy in life. Loss of community, as seen in the previous section, can take a toll on one's mental health. Therefore, building up social ties and providing a space for fun social events is a crucial care practice when it comes to displaced people. Freedom to express oneself in one's own way is a central part of Asnada's community building:

In order to allow everybody to have the opportunity to express himself or herself, we don't only use the spoken and written language: theatre exercises, songs, handcraft workshops, games, silent books, pictures and images, silk-screen printing, short films are the means through which explore the new language and ourselves.

Many opencare initiatives receive no support from public authorities or institutions. They are peer-to-peer.

Similarly, Nina from RefugeesWork focuses on teaching programming skills to enable refugees to get freelance jobs. Freelancing, she maintains, helps refugees gain some freedom, both from discrimination and in terms of financial independence.

Tomma finds that young men are not taken care of in refugee camps, and often feel a sense of uselessness. Through building furniture and selling it, people become more involved in daily goings-on and are motivated to do things, reintegrating into the community and restoring a sense of capability:

[Helping people] improve their living situation by building their own furniture is a first step in that direction [as it] motivates people and gives them the feeling of doing something useful for them and the community.

Her goal is to expand this work to other camps as well.

Building Relationships

This desire for expansion work was articulated by other community members. Aravella stresses the need for solidarity networks:

The refugee crisis gave rise to a strong solidarity network and also an opportunity for local communities and the society in total. An innovative strategic plan seems to be a necessity, in order to coordinate and manage all the available resources successfully. We should focus on organizing and training ourselves for cases of emergency. Based on the strength of these sharing communities, we should work, in innovative ways, which could bring people together around common concerns, recognize and increase their skills and knowledge and instill in them a belief that they can make a difference.

In a similar vein, @christinsa helps run a cooperative project that seeks to strengthen ties between refugees. It is called "'Refugees to Refugees (R2R) Solidarity Call Center' and it is a project "run by refugees for fellow refugees." Refugees give information and advice about issues that other refugees face in Greece, related to transit, temporary stay, or settlement. The project's aim is to:

[…] create linkages between refugee communities and the wider solidarity movement, in order to break the exclusion and isolation that refugees are feeling, as a result of being crammed in concentration camps.

It also mobilises pre-existing solidarity networks in communities, in which:

[…] teams of lawyers, doctors, translators and networks of families offering hospitality in their homes, are offering voluntary support and practical solutions, whenever needed.

She stresses that when it comes to social care:

[…] it is important to create links between the social movements, in a way they continuously support and feedback to each other, finding solutions that are creative, radical and practical at the same time.

In conclusion, care that is 1) localised and community-based, leveraging existing social networks, building new social ties, and taking into account the day-to-day lived experience of refugees, 2) empowers refugees to affect change in their own ways, and 3) builds connections across communities works most effectively to combat the refugee crisis. Existing system failures make clear that alternative ways of coping, spearheaded by community members and based upon the premise that refugees need healthy social spaces as well as material goods, must be taken on board.

Resilient Communities

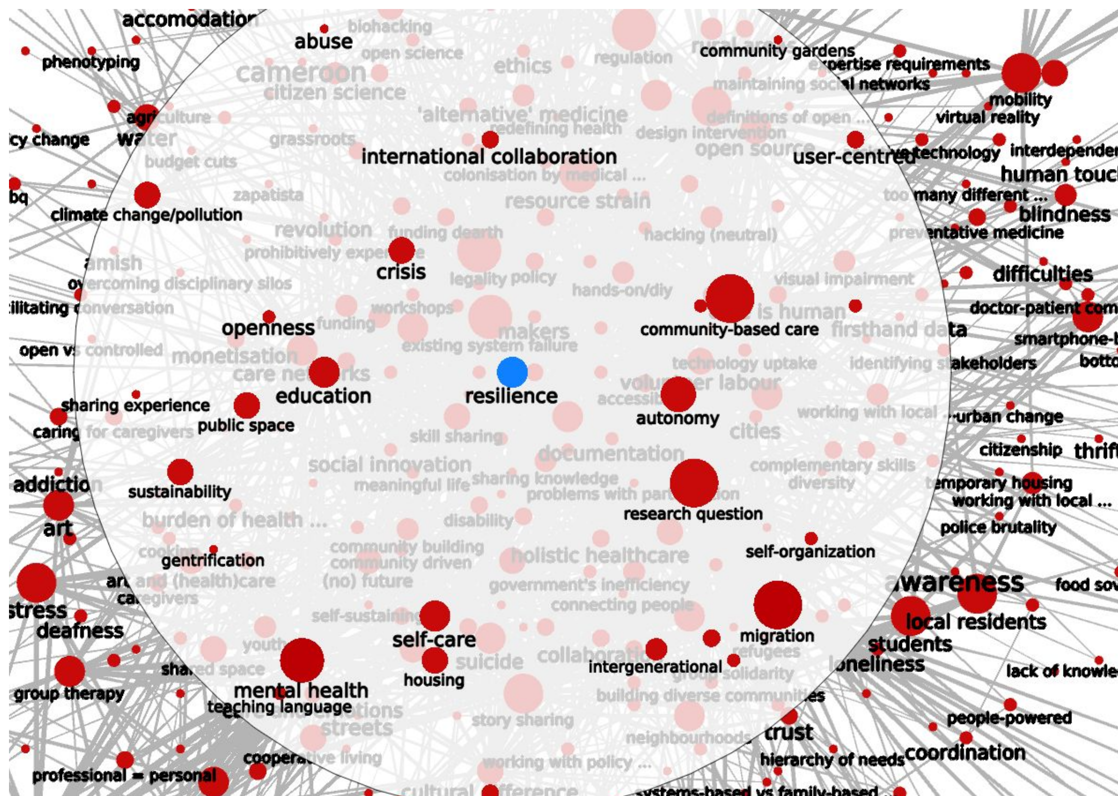

Figure 4. The ego network of the "resilience" code (2 co-occurrences or higher). Node size maps to number of connections.

Key Finding 3: Resilient care projects link people together in their communities, allowing people to share skills and offer social support to one another. Linking diverse groups within the community so that the community can be autonomous from failing systems leads to strong and resilient care networks.

A key topic of discussion in opencare has been how to build resilient communities capable of withstanding the collapse of institutionalised health and social care services. Concerns around resilience span several interrelated concerns: crisis, neighbourhoods, building diverse communities, and sustainability.

Crisis

Crisis has been a key theme across the platform, whether it be the financial crisis in countries like Greece or the refugee crisis that has led to mass migration. Community members have been devising ways to maintain resilience, trying to balance preservation of old ways of life (like neighbourhoods, or safeguarding the elderly's stores of valuable knowledge) while being open to new community members arriving from other shores (through intercultural exchange, and overcoming language barriers).

Crisis also comes in the form of precarity: decreased opportunities for employment/labour, rising housing prices, and youth seeing a lack of a future for themselves. These kinds of crises have been answered by community-based care, the umbrella for so many interactions that have been documented on opencare: through co-habitation, skill-sharing and skill-building, building or repurposing space for living, and many other creative living arrangements. Places are at the heart of communities, whether those places be neighbourhoods or homes, cities or rural areas. Connections across disparate geographical terrains have occurred (sharing drugs across national borders, or online support groups), and international networks have been formed --- these have lead people to meet up offline, and to strengthen the spaces in which they live and work. Despite claims that the internet is radically removing the need for place, offline spaces remain crucially important to communities in opencare.

Crisis takes another form as well: climate change and pollution have created concerns among community members, prompting the need for greater resilience in the face of natural disasters and environmental disruptions, and creating sustainable solutions has been a key factor in conversations across topics.

Yannick, of Huis VDH (discussed further below), has this to say about crisis:

One big challenge we will be facing in the next couple of years is to use our talent to organize ourselves within crisis. Big problems are ahead and we need to build up resilience to react quickly to an ever changing surrounding. Huis VDH is trying to take that challenge inside our own development. For us resilience can be developed on four levels: knowledge, vulnerability, out of the box exercise, and modification.

As Matteo, a policy officer in Milano, articulates:

Cities are experiencing a growing social crisis: lacking in social cohesion; insufficient public services; decreasing support by traditional social forms (as families and neighbours); growing sense of loneliness. The gap between the growing demand and the shrinking offer of care is the basis of the present care crisis. To overcome this crisis a brand-new care systems has to be imagined and enhanced. It is possible to imagine communities of care and their socio-technical enabling ecosystems, capable to sustain and coordinate people's caring and collaborating capabilities and doing so, creating new forms of care-related communities.

Working outside existing systems is therefore not always the path chosen by community members. Many community-based care initiatives look to work with policy-makers, or form public-private partnerships, to realise their visions or get the resources they need to deliver them to the people who need them. The desire to rejuvenate urban spaces and revitalise neighbourhoods has been a key space of collaboration between different stakeholders. Change in each case is needed, but the implementation of that change can take different forms depending on the issues at hand.

Patrick, in his story "Caring for Life", situates his desire to make autonomous care homes in the current healthcare crisis in the UK:

The demand for care is growing rapidly due mainly to an ageing population, with increasingly complex conditions, a breaking down of traditional community-provided care, and higher expectations amongst the elderly. At the same time, the ability of government-funded institutions to meet those needs is diminishing. They lack the resources, the responsiveness and the political will to deal with the population's increasingly complex care needs. At the same, escalating asset prices are putting pressure on traditional providers, and attracting hedge funds and private equity looking for the "growth opportunities". The result is that many care home are being run as a business more than as a service, meaning that profit and shareholder value is prioritised over the needs and well-being of residents or staff.

The effect of corporate interests is discussed in more length in the next section, but the crisis created by the failure of current health and social care systems to meet needs prompts innovation by those both inside and outside the system. Solutions to these crises have been community-based: they involve 1) strengthening place-based care in neighbourhoods (instead of having to travel to other delimited health and social care spaces) and 2) building relationships between diverse groups inside communities.

Place-Based Care

Yannick of Huis VDH in Brussels is "fascinated by the concept of public space and how to bring it back in the center of everyday life in the city." His project tries to transform vacant spaces into multifunctional temporary living spaces "for people that are drowning in a sea of complexity of city life". Huis means 'home' in Dutch. Transforming semi-public spaces like this helps to build resilience and strengthen neighbourhoods, in Yannick's opinion. Like many initiatives of open care, this attempt draws from an open source ethos and seeks to exist outside monetary systems, to stand on its own through community support and skill sharing alone. As Yannick puts it:

Huis VDH wants to give time and resources to people to experiment, try, fail and succeed around new models for the present and future of Brussels. We are convinced that the magic happens by connecting citizens' skills and needs. We aim to become a laboratory for urban change hosting citizens in search of anchor.

To do so, he argues, requires the building of collective trust:

When working in a collective environment, we tend to show our better self, hiding our flaws in the first place. But a strong collective group is as strong as its weakest link, and therefore we find it important that we are open and honest to each other. Having personal problems is something common, but sharing them is less. We try to create a trust field around Huis VDH where personal development is as important as the common goal of the organization. Caring about each other as a human being before seeing it as a resource for a project. In order to bring this theory into practice, we have made the first floor as cosy as possible, so people can just hang around and talk freely to each other. We make meetings short and efficient so there is time to discuss at the bar the more intimate stuff, not with all, but with whom we trust.

Starting from the views of those living in the neighbourhood, the Living Streets project in Ghent similarly tries to engage residents to reimagine their public spaces. Pieter's Living Streets story, like Yannick's, is committed to transforming public space for community-building purposes:

We started engaging people with the question "What if?"; mapping the ideas and also the interests of people. "How do I look at my neighborhood?" from the perspective of social security, traffic, safety, more green in the streets,... For each remark we mobilize our network and creativity to support initiators from each street to find solutions. After that process is done, the people come up with a vision for their living street, that will be implemented in practice. Evaluation is an ongoing process, so things can be changed during it.

The project yielded the building of safe playgrounds, green meeting spaces, and communal activities. It has been going on for 4 years and has involved 25 streets. The project was a temporary one, but the ultimate goal endures: "exploring a new approach of public space, finding alternatives for street parking and reworking people's relationship with city officials" and is "driven by communities in the city."

Continuing the theme of healthcare professionals taking matters into their own hands, Street Nurses have responded to crisis by bringing care to people who for various reasons cannot bring themselves to treatment. They take to the streets and "meet patients directly in their environment, without asking for payment." Like other initiatives discovered in the course of opencare, they seek to motivate people to "take charge of their personal care and health." They do so by caring for them, earning their trust, "accompanying them to specific care facilities, by actively listening to their needs and giving them advice.

Similarly, Zoe in her story "Care beyond the Clinic" advocates for health and social care services that take place in the community itself, and are community-driven:

Ninety five percent of healthcare happens outside hospital or the doctor's surgery - in the home, and in the community. Collaborative service networks are emerging- from child care, to dementia support - that empower people to work in equal and reciprocal relationship with professionals and without needing hospitals....health and wellbeing are properties of social-ecological-context and not a something you "deliver" like a pizza. Communities need to be nurtured and supported and it's by being "in them", not by doing things "to them" that change happens.

Patrick is also interested in re-thinking existing care homes, pushing for networks of independent care homes that are integrated with the local community. These care homes would exist for the health and well-being of community members, and would not exist to "maximise profit" or be "subject to the whims of governments" unlike existing care homes, which he feels have failed local communities.

A key response to institutional collapse has been to build relationships within communities. Students in Milano's Bovisa neighbourhood have linked up with residents to try and make the neighbourhood livelier. As articulated in the "Networks of Care" story, "connection between people and the space they live in

plays a huge role in the development of any area." Yet Bovisa lacks street life, since it used to be an industrial area. Linking up diverse groups within the community is one solution:

We consider collaboration between students and locals as the strong tool to achieve this goal. Our concept starts with the platform where locals communicate their needs to the specific spaces in the neighbourhood with the professors who are in charge of the workshop. Locals would define problematic spaces, spaces that can be transformed and improved. Professors will choose few places to be developed and launch the workshop.

As articulated in the previous section, co-living has also been a way of building diverse communities: having the elderly live with college students, or creating cooperative living spaces where residents mutually support one another.

Sustainability

Sustainability is a key feature of resilient communities. Food and water sustainability and security are important aspects of this push for sustainability in the opencare community.

Alberto Rey, an artist, has created an exhibition to promote sustainability and awareness of water pollution. The project aims to raise awareness as well as build connections and share best practices between diverse communities:

Our hope is that, by touring the exhibition and by combining it with site-specific exhibitions, audiences can create connections between their region and other global communities. There is a good deal that can be learned from the history of the Bagmati as well as from the grassroots efforts that created the Saturday Bagmati River clean-up program and the successful community health initiatives supported by the non-government organizations.

His initiatives also include a program to take community members fly-fishing, as a way of "reconnecting people to their local environment" so they can reap "educational and therapeutic benefits" as well as strengthening a commitment to steward their natural resources. His holistic approach connects science, art, and literature and he actively teaches others to do the same.

Marco, a community activist, works on an urban gardening project in a densely populated, underprivileged Berlin neighbourhood. The Prinzessinnengarten is a communal garden in Berlin that is not owned by any resident: it is entirely public, built in Berlin's public space. Marco theorizes that the garden does not just provide food. It promotes the health and well-being of the community through promoting "the development of a culture of mutual help, sharing and empowerment." Like some of the aforementioned projects, it is financially self-sustaining and supports 15 full-time jobs. The garden is able to provide healthy, environmentally sustainable food to residents and is a "locus of social exchange and mutual learning." Marco calls the garden a "laboratory for resilient forms of urban development", as it emerges from collaboration with local institutions, universities, and international partners:

In a pragmatic manner, we have been asking questions on how to deal with urgent issues such as climate change, dwindling resources, food sovereignty and the loss of biodiversity. The answers being experienced and experimented on all strive toward the creation of a resilient city, not only taking global challenges such as climate change into consideration but also incorporating local actors in the building of practical and local solutions.

A community-based approach to these issues has benefits and drawbacks, according to Marco:

Community groups often focus on single questions, spaces, conflicts. They often react under economic and time pressure to immediate problems. They act within marginalized or weak political and economical communities. They deal with institutions and stakeholders with more time, much power, and resources whereas they rely on limited personal resources or precarious funding. Simultaneously there are a lot of joy, learning and personal empowerment involved as well as a sense of a meaningful life and community relations. However, the risk of failing is high, which can lead to frustration and disintegration.

Community care structures can help to ease this stress not only in giving support but also in a form of what we call "collective learning". They can work as an archive for the knowledge, the experiences and know-how being created in grassroots and community initiatives. Thus, they allow activists to see themselves not only as part of a singular local fight that you might win or lose but as contributors to a collective living memory.

With a similar focus, Jenny works on a Community Supported Agriculture Network project called "Real Food Utopia", which seeks to create self-sustainable communities ("ecovillages"). The project maps alternative food systems in Thessaloniki and runs workshops on "alternative economies, peri-urban gardening, refugees and food" by implementing a "participatory procedure between people who belong to informal initiatives all around the city." The workshops not only disseminate information, but teach skills like participatory video creation. Her ultimate goal is to

[...] create self-sufficient farmers and viable, circular economies that not only do not pollute, but actually create more resources instead of depleting them.

Woodbine Health provides perhaps the most poignant example of autonomous community-building in the face of failing health and social care institutions. The Woodbine Health Autonomy Resource Center in New York stresses community, pushing back against individualising health discourses:

Disease becomes individualized as "health" and "wellness" becomes commodified. If we refuse this logic, begin to express the anger necessary for a health that recognizes the truly horrific nature of the time we're living in and develop shared practices of care that diffuse that isolation, we can begin to grow the collective backbone we so desperately need. Apart from a critique of modern theories on health, we as a community have lost all control over our health. Our individualized

choices to workout, eat right, not smoke, etc are important, but wholly insufficient to answer the demands of this century.

The center has a workshop, library, kitchen and meeting space in which people "focus on efforts to self-organize, connect, create infrastructures, and develop greater individual and collective efficacy." Rather than trying to rebuild collapsed institutions, the center tries to "rebuild the idea of community and shared mental health as models" to overcome isolationism.

In all these projects the twin themes of autonomy and community intertwine to create resilience. Projects stress community members' ability to diagnose their own problems and the connections required between diverse stakeholders to build strong communities in the face of myriad crises.

The next section focuses on specific design interventions in opencare and the challenges they face.

Design Interventions

Figure 5. The ego network of the "design intervention" code (2 co-occurrences or higher). Node size maps to number of connections.

Key Finding 4: Existing health and social care system failures have made open source technology a promising solution, but social networks are key to the success of these projects, since many of the barriers to creation and uptake are socio-political, not technological. Though technology can help people innovate around problems, corporate greed and bloated regulatory bodies often stand in the way. Ensuring people's safety while working quickly to better people's lives can be difficult. It is problematic to focus on the individual as the locus of health interventions in part because it is often not the individual is broken: it is the material world and social conditions that disable individuals. Technologies that are co-designed with people work better to solve their problems.

This final section focuses on the design interventions that opencare community members have innovated to overcome failing systems. Issues in this conversational sphere include: 1) proprietary blocks due to corporate interests 2) tensions between regulation/legality and safety and 3) funding open source solutions. Continuing the theme of promoting collective autonomy, design solutions which engage stakeholders and allow users to participate in the making process were more effective at solving their health and social care issues.

Proprietary blocks

Although opencare community members come from a variety of countries and socioeconomic backgrounds, a similar theme emerges across the platform: how the increasing privatization of healthcare systems across the globe leaves ordinary people vulnerable to the logics of supply and demand, rendering them unable to access medical care. In these contexts, hacking (in this case, tapping into proprietary systems or creating alternative open source systems that circumvent these proprietary systems altogether) can literally be a life-saving practice. As @dkfo articulates:

Open source methods of production are relevant not just to aligning incentives and improving the economics of software development, but also to scientific reproducibility and transparency, and in both software and science, open source can enable more participation and progress than trying to hold secrets close. In medicine in general, and diabetes treatments in particular, I think it holds one of the keys to breaking through the barrier between promising research and a stagnant market of treatments available to patients, just as it made software much more efficient to produce and use and enabled a great deal more innovation than was otherwise possible.

This decision to be closed and non-interoperable (and therefore not amenable to changes by users) "stems not from a lack of technical sophistication, nor is it an "accident" of complexity, but is a deliberate assertion of economic and political power" (Kelty 2008:74). When large corporations have what amounts to a monopoly over medical supplies, they are not incentivized to make life better for patients, as long as they are upholding their baseline legal obligations. Even further, existing proprietary practices can literally give rise to life-threatening situations when people cannot afford to access the care resources they need. Open source solutions strive to subvert these harmful proprietary logics.

This proprietary blockage is the target at which the Open Insulin project aims its intervention. Open Insulin is a collaboration between biohackers at Counter Culture Labs in Oakland and the DIYbio space ReaGhent in Ghent. Both groups are trying to create open source insulin, as dfko explains, toward three important goals:

first, by making insulin production more economical at a smaller scale, and opening up manufacturing to much more competition, it could improve cost and access for patients. Second, we hope the protocol will serve as a basis for future research into improvements to insulin - variants that are longer acting, shorter acting, more temperature stable, and so on - that address different concerns that arise in treatment. Third, we hope it might serve as a basis for research and production of other proteins by small groups, and open up participation in research and development to accelerate progress in other aspects of diabetes treatment besides insulin and other areas of science and medicine besides diabetes treatment.

Nightscout, an open source software created by parents of children with Type 1 Diabetes who felt their relationships with their children were being negatively affected by constantly having to ask them for their glucose level readings, provides

another example of circumventing a proprietary block. Hacking into the pump itself allows for remote monitoring of glucose levels, resulting in a shift in focus away from a loved one's condition. As one parent put it:

It is such a change in your relationship when the first question out of your mouth when you talk to your son, your daughter, your spouse, your brother, whatever, is no longer, 'Hey, what's your number?' It's 'How was math class? How was work? What are you up to today?'

Having access to one's own data can make a medical difference since an individual (and their community of caretakers) is more intimately aware of what is normal and abnormal for their own body. Open source hacks allow others to build upon and tailor software to their own needs, as they emerge from their personal experiences with their conditions and their particular relationship to a given medical device. As @dfko describes hacking:

Hackers are people who seek to modify things to serve their own purposes, instead of just accepting them as being limited to their originally intended purposes. It's an approach that emphasizes the philosophical concepts of phronesis and techné, which describe an embodied, contextualized, practical approach to things, applied to science and technology. Biohackers are people who take a practical approach to understanding and engineering biological systems, and look beyond appearances and inside the black boxes of commercial products to understand the substance and true implications of things.

To subvert legal frameworks that stop people from getting access to medicine, some community members have created international care networks to distribute medical resources. Sabina of the Cytostatics network is one such person, transporting medicine across borders:

Yes, I travelled home with medicine, calmly taking them through security and bringing them to Valeriu, the taxi driver that distributed them to the ones in need. More important was the fact that doing a simple thing, an easy gesture, meant helping someone's health and fighting a system that seemed not to care about the people. Everyone I talked to about the network felt the same: it is the least we can do! I got involved because I knew what it means to be helpless against a disease and I will remain involved for as long as I will live.

Legality, Regulation, Safety: working Outside Existing Systems

Yet many of these practices are deemed illegal. Legal dangers arise due to the difficulty of reconciling the public good of open and free solutions in medical care and the private good of closed and expensive medical supplies. Working at the margins of or outside existing systems carries legal risk. Questions surrounding the risk of design interventions that operate outside or at the margins of existing systems rotate around the twin spokes of legality and safety. A community member will ask something along these lines: how can we get around stringent regulations

that stop people, usually people without resources like money or the ability to travel, from accessing vital medical interventions? As Noemi articulates:

While building trust in the service while offering affordability and humane treatment is definitely a plus, the questions remains and it's for us to try to answer in the future: what happens when a number of such care services become available? We have great insights, yet risk running completely unprotected. The more they grow effective or meet a growing demand, the more attention they draw, the more competitive they become, the more they risk being antagonised by systems on more-or-less valid concerns.

Then, generally, another community member will bring up the issue of safety, especially around clinical trials. These regulations are there for a reason, the community member(s) argue back, to keep people safe from harm. Take Marco, for example:

Registrations/certifications/licensing are in place as fences, one of the tools in the arsenal of safety in healthcare…there are no shortcuts.

Rune, who has put together a "Legal Evasion Guide for Humans Helping Out", responded:

I though the OpenCare proposal was to shortcut. Shortcut waitlinglists. Shortcut ineffective bureaucracy. Shortcut documents that separates people and not connecting them.

Rune starts the legal evasion guide with a quote from Woodbine Health Autonomy Center:

practice may involve working outside the structure of licenses, certifications and insurance.

He sees the essence of opencare as "breaking out of failed institutions while staying clear of trouble", a goal that resonates with the Open Insulin group and the Metropolitan Community Clinic at Helliniko. The Clinic is technically illegal, as it has no legal existence and is autonomous of existing governments or institutions, yet it provides much needed care to community members in need.

@steelweaver, who runs a community acupuncture clinic outside the commercial model of delivery, has mixed feelings about regulation and safety:

I am conflicted on this - on the one hand, I recognise that some degree of regulation of healthcare is probably desirable to avoid malpractice and protect patients (or at least it was desirable before networked reputation economies became a possibility - who knows what alternative models might be possible now?). On the other hand, I was certainly struck by the degree to which stepping outside the commercial model of delivery freed me up to do things differently. It's also made it far easier to get 'buy-in' from the community so that they think of it as something that belongs to them, that they can collaborate with. The terms of interaction defined by our habits of commercial consumption go deep, and having some way to differentiate yourself from it seems very important in encouraging people to think and act differently.

Winnie, who runs the Ghent operations of the Open Insulin project, articulates a version of both questions:

- *Legal frameworks and patents. How to make things reusable for everyone regarding regulatory and patent framework?*
- *Reliability and safety. How can you ensure that the community with its contributions (the sum of all) are good quality and safe?*

Collectively, therefore, the community has generated a more nuanced question: how to work outside existing systems to give people access to vital technologies of care, while also keeping them safe? The answer seems to lie in self-regulation, in ethics and ethical commitments to good, safe practice. Making rules for spaces is another way in which this happens, as people collectively agree on best practices. Open processes are another way this is managed, with commitments to open notebook science, open source and open hardware, which maintain transparency and keep everyone honest and accountable.

Funding

When trying to make design interventions that are open and free, funding is an issue. As @dfko articulates:

While we are a group of talented and curious folks, most of us are learning challenging lab protocols from scratch, and second, we're working with limited amounts of time and money, fitting the work into gaps in our schedules left by work or school, and mainly relying on surplus equipment and reagents that add delays and uncertainties to our work. So progress can be slow and involve a lot of detours on top of those implied by the already uncertain nature of scientific investigation, and we have to dig deep to figure out what to do next when something goes wrong. We do our best to learn fast, but it's difficult to follow up on everything we should with our limited time and resources and background knowledge. There's a lot of practical wisdom around making insulin that doesn't show up directly in the papers published in scientific journals, and we're learning these nuances of making things work as we go. Much of the value we hope to provide to the community is documenting as much of this practical wisdom as we can, and perhaps eventually automating the kind of work we're doing by hand right now.

These design interventions operate in an existing capitalist framework that makes it difficult to successfully distribute open and free medical resources. The opencare fellowships helped somewhat, but funding is a key issue that must be addressed to further these useful innovations. Almost every single project on the opencare platform cited funding as an obstacle to successful implementation.

Co-operative Making

Many more people than expected suffer from incurable/untreatable/permanent conditions, some visible, some invisible. These conditions make the world harder to navigate. To address this issue, community members are designing technologies to make life better for people. Fixing or working around an external world is a

productive response to being told to fix one's body when one cannot. Thus life can be improved for people through technological engagement.

Allergo Ki is a mobile application which allows people with a food allergy to find a restaurant where they are guaranteed to be served safe food, choose a safe dish from the menu, order that dish online, choose their arrival time at the restaurant, and find the food ready. Because food allergies can prohibit people from socializing, this intervention empowers people to be active and eat out.

Similarly Open Rampette, a project undertaken by those at the WeMake makerspace, seeks to improve access for mobility impaired people in Milan. Constantino of WeMake describes the process:

Small iterations, user research, interviews are few elements that guided our design process. While those concepts and tools are well accepted in the world of the industry..., in the domain of policymaking, regulations, and administration of city they haven't been quite discovered yet. We believe that some of the techniques we adopted can be translated in the exciting domain of the city regulatory system.

Working around bureaucratic systems to implement change is common across opencare stories, yet one that does not preclude working with policy makers.

Open Rampette illustrates the kinds of cooperative design work that happen across the platform, taking up a disability activist anthem: nothing about me without me. Co-design processes require identifying and mobilising all the stakeholders involved in a task (in this case, building ramps across Milan):

One of the criteria for the successes now being achieved through Open Rampette seems to be process design and deliberate steps to include all stakeholders; those holding different roles within the public administration, at various levels of seniority as well as shopkeepers and business owners and of course members of the public with mobility issues impacted by the lack of access to shops and other facilities. A particular challenge seems to have been engaging all the 'actors' within the public administration - something that was only achieved through persistent engagement to form the necessary relationships. Shopkeepers were another distinct stakeholder group - when the project team started talking to them they found that by and large they were willing to comply with the regulation and make their shops accessible, but they couldn't afford technical expertise to implement a solution. This was another role that WeMake were able to fill. They helped facilitate a process of co-design to include all the stakeholders in finding technical solutions, including a means by which those with mobility issues could contact the shopkeepers to alert them to their arrival.

Rune at WeHandU found similar success with commitments to co-design in the desire to provide community-driven assistive technology:

Could we leave people with a physical handicap to become a maker, create their own assistive technology? Would it be possible for, for example, researchers to help people living with a disability to hack a dropped foot correcting device like connecting an Arduino with an extension board? That would mean that people should take responsibility for their own rehabilitation devices. They would have full ownership.

Clearly they must be guided by healthcare professionals and experts without conflict of interests to ensure that everything is done ethically, safe and sound. Maybe if we reunite people living with physical challenges with researchers they would both benefit and research becomes action and functionally useful to the society?

Community-based making practices gather together stakeholders like clinicians and people with physical handicaps to co-design solutions that actually work for them in practice. Alexander puts forth a similar model:

We propose a laboratory where people living with motor impairment due to e.g. multiple sclerosis (MS), stroke or spinal cord injury (SCI) can meet and collaborate with other people. There will be mentors (physiotherapists, engineers and designers etc.) and together we will create solutions to personal needs in form of assistive devices. A cooperative model where citizens with various skills can work together on realizing devices for use in everyday life, that will improve or maintain individual functional capabilities. This model will explore ways to transfer research results directly to users (target participants). New and existing ideas will be challenged and transformed into methods and assistive technology for activities of daily living.

In short, cooperative design in health and social care that engage actual users produces effective solutions. Though obstacles like funding, legality, and regulation exist, community members remain committed to designing technology that brings people together and helps them navigate often debilitating health and social care issues.

Conclusion

opencare community members have a strong desire for autonomy: to be independent from failing systems, to be mobile on their own, to be self-sufficient even when in a liminal space like a refugee camp, to be treated like adults by their governments and public services, to have the power to effect change in their worlds. Myriad design interventions have addressed mobility issues, allowing people to regain control over their motor functions. Other initiatives have promoted, through skill-sharing and education, the ability of refugees to be self-sufficient despite unfavourable circumstances and temporary living situations. It is important to be in control of one's own life instead of being at the mercy of institutions that often do not consult people about what they want and how they care to live.

That being said, communities are interdependent and strong as a result of that interdependency. Community members support each other, share resources, build common spaces, and teach each other new skills. More importantly, they believe this should be the case: communities should be at the heart of health and social care practices, according to OpenCare community members. In the face of crisis and in a state of precarity, where you are living life on the edge, any and all resources make a difference. Small acts and resource exchanges, small skill acquisitions, are really not so small after all.

Resilient communities are those that celebrate their interdependency and care for one another, while also allowing each other to flourish in their own individual ways. How to achieve this balance has been an ongoing topic of conversation, since it is not only the collapse of public systems that has troubled opencare community members, but the collapse of informal support systems like extended family units and vibrant communities as well. How do we take care of communities and strengthen informal ties in the face of increasing collapse of formal systems of care? Or, perhaps the better question is how to improve both, since opencare community members seem deeply committed to improving both forms of care.

Finally, the community as a whole has a strong commitment to egalitarianism, whether it be in the form of cooperative living, transparent and flat governance, distribution of resources, maintaining open processes, fighting against corrupting of corporate greed, or creating alternatives to existing systems of inequality. How to manage equality while also creating systems that work and are effective has been an ongoing topic of conversation, and will continue to be. How do we make rules for spaces and enact shared governance while being fair to everyone? How do we overcome and/or reform systems that seem hell-bent on perpetuating inequality?

So, how to create conditions for initiatives of open care? Gehan asks this question herself in her work with GalGael Trust in Glasgow:

actively generating a healthy culture is perhaps more effective in achieving in an anchored way the "good intentions" of policy. Strong values guide actions, decisions and behaviour, influence language and how we treat one another.

Focusing on building architectures of love, in short, is her answer to building resilient communities.

These are the concerns of opencare community, and as has been demonstrated, community members have come up with a wide range of innovations to address these concerns and to strengthen their communities. These interventions provide roadmaps for future change beyond the opencare project. The conversation has been so rich and generative as a result of community members' commitment to bettering their communities through engaged practices of care, building architectures of love to withstand the storms of crisis.

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