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opencare

Deliverable 4.6: Using collective intelligence to improve care - an empirical study on best practice in the care sector

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1. Introduction

The provision of health and social care is central to any well-functioning human community. Health care alone accounts for 10% of GDP in Europe, and 17% in the United States [Sanandaji and Lakomaa, 2016]. Besides its quantitative dimension, it performs a very important function of spreading risks across the population.

In most countries, care costs are growing faster than GDP, putting provision systems under financial stress. The causes of this dynamics have been investigated elsewhere. In this paper, we focus rather on a related, but different, phenomenon: the rise of care services funded and delivered neither by the state nor by the private sector, but rather by *communities.* By this term we denote unformalized groups of humans who recognise a common goal, and have sufficient trust and capacity to attempt to attain that goal.

The phenomenon is, of course, nothing new. Unformalized communities have been the default providers of care for most of human history. Even the buildup of sophisticated systems delivering professional care services is not new. Care has long been a terrain of contention – or at least of interplay – between top-down state intervention ("with the goal to preserve the social order") and bottom-up mutualistic systems [Liebart and Manca 2017] .

What is new is how these fundamental societal drivers interact with the technological developments of the last few decades. The Internet connects instantly billions of humans, creating – at least in principle – an unprecedented space for mass collaboration. And freely available, cheap, open source technologies promise to put technological prowess in the hands of the skilled amateur, allowing her to produce high-tech goods and services. The combination of these two forces is yielding a democratisation of innovation. It is estimated that as many as 6% of consumers engage in product innovation alone [Von Hippel 2017]. The average innovator is a consumer.

In principle, we could have community-provided care services that are powered by modern science, high technology and open source knowledge sharing. Following Sanandaji and Lakomaa we call these "open care" for shorthand, whereas "opencare" denotes the project of the same name. opencare set out to explore:

1. Whether open care services have actually been developed.
2. Whether they can co-exist in harmony with formal care institutions[1].

At this point of the opencare project, we have tentatively answered "yes" to question 1. We have indeed detected, and engaged with, a large community of bottom-up innovators in the domain of health and social care. The answer to question 2 is, as expected, far less clear-cut.

The purpose of this document is to provide empirical evidence to health and social care reformers, as they venture into the specifics of question 2. Elsewhere, the opencare project

[1] Question 2 is more jurisdiction-specific than question 1. We are most interested in addressing it in the context of the European Union.

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has suggested models: ways of thinking about whether, and how, open care initiatives might be bolstered to take some of the load off formal care institutions. Furthermore, it has collected hundreds of experiences of open care initiatives, as perceived not from analysts, but from their protagonists. Here, we put these two pieces together, offering would-be reformers an array of real-life initiatives arranged along an analytical grid.

Our goal in doing this is to encourage reformers to maintain an open passageway between reform design, models and evidence. That is, to give them easy access to the (messy and idiosyncratic, but incredibly rich) wealth of experience of the people trying to make open care services work. This experience should be used during reform design to continuously test how watertight their models are.

We proceed as follows. Section 2 describes the data we use as sources, and it explains how to interpret results. Section 3 recalls and summarises the results of the analyses performed in the course of the opencare project. Section 4 contains the actual evidence, arranged along the analytical grid of Section 3. Section 5 concludes.

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2. When do open care initiatives outperform formal care institutions? A tentative taxonomy

This section is based on previous work done in the opencare consortium. Specifically:

1. Sanandaji and Lakomaa's [2016] analysis of how entrepreneurial incentives play out in the provision of care. The two key concepts introduced are *evasive entrepreneurship*, which in this context takes a hue of courage and positive disruption; and Ostrom's [1994] theory of managing commons.
2. Sanandaji and Lakomaa's [2017] reflection on the institutional challenges of reconciling an open approach with formal care institutions as we know them today.
3. Liebart and Manca's [2017] long-ranging history of the forms of governance and of the financing models of care provision.
4. Hassoun's [2017] ethnography of initiatives of open care, which draws on the same corpus we re-use here in its semantic social network form.

This research concluded what follows.

1. Though open care initiatives are not *stricto sensu* commons, they are similar enough that Ostrom's theory on managing commons applies.
2. Forms of "institutionalised Ostromian co-production"[2] can and do develop between grassroots innovators and formal care institutions. This tends to happen:
    - When governance capacity declines, for example during major crises (war, civil unrest).
    - When logistical issues put formal care institutions at a disadvantage (complex terrain, many poor households to serve in remote rural areas).
3. Some types of open care initiatives are a good fit for certain market failures commonly encountered in care provision. Specifically:
    - Online platforms supporting the exchange of experiences across patients. This provides useful information to individual patients, and doubles up as repository of data that can be re-used for medical research. Initiatives of this type solve the issue of aggregating patient data for providing better information, which is discouraged by regulatory barriers.[3]
    - Initiatives in which the participants themselves are the prime beneficiaries. This sidesteps the whole principal-agent problem paramount in care provision. In highly connected societies, these initiatives have more potential for scale and long-term sustainability.

[2] Defined as "the provision of public services through long term relationships between state agencies and organized groups of citizens." [Joshi and Moore 2004]

[3] Lakomaa [2017] also mentions "Multi-function health communication platforms. These platforms combine peer-to-peer "social" functionalities with top-down care management ones. They are meant as channels for formal care institutions to keep track of patients, plan treatments, crowdsource answering to requests for information etc.". These are typically commercial initiatives: normal cost-reduction process innovations, of the type found in many industries. While they must be applauded, they do not qualify as open care in the sense of our definition.

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4. Issues of mental health (trauma, depression, stress etc.) have attracted many open care initiatives. There seems to be a gradient from acute condition to chronic manageable condition, to lifestyle. This elicits an efficient division of labour, with care professionals treating acute cases and communities managing the chronic/lifestyle side of the condition (often deploying techniques like yoga, meditation and gardening).
5. Care issues arising in the context of migration and asylum seeking are also a good fit for open care. Here, open care seems to be superior to institutional care in giving migrants and refugees the ability to shape their own world, connect with other people, and do things for themselves.
6. Open care seems a superior way to deploying initiatives aiming to strengthen the cohesion and resilience of communities themselves (generally intended in the spatial sense of local community). A care initiative is seen as more trustworthy because it comes from the community itself. As a result, it elicits more cooperation and its chances of succeeding increase.
7. Finally, open source technology offers promise to enhance open care solutions, but social networks are key to the success of these solutions. This is because many of the barriers to creation and uptake are socio-political, not technological.

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3. Materials and method

The opencare project has collected information from, and even participated in, a substantial number of open care initiatives. In what follows we attempt to map this evidence onto the observations of the previous section.

Our evidence comes from two sources.

- A large-scale online conversation about open care spanning almost two years (March 2016-December 2017). This took place on the https://edgeryders.eu platform and was led mostly by Edgeryders, but with active participation of other consortium partners. At the time of writing, the forum consists of 657 discussion threads, normally started by a long-form post, with 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.
- Direct participation of consortium partners to implementing prototypes of open care solutions to disability issues. Two were directly realised by WeMake and the City of Milan (InPe' and Open Rampette); five more were proposed and built by the community, with WeMake's support. All these experiences were documented in the online conversation described above.

The opencare partners encouraged participants to share experiences rather than opinions, and make the conversation evidence-rich rather than opinionated. This work resulted in a wealth of open care experiences and initiatives, as told by their protagonists. An "initiative of open care as told by its protagonists" is called a *story* in this essay.

The corpus was then rearranged in the form of a *semantic social network* [Cottica et. al., 2017]. This can be thought of as a graph database, which can be queried for ant ethnographic code to obtain the other entities in the graph related to that code.

In Section 4, we start with the taxonomy of conditions for success of open care initiatives (relative to formal care institutions) listed in Section 2. Next, we map each one onto a list of the codes that best match it. For example, the analytical category "decline in governance capacity" maps onto ethnographic codes like `resource strain`, `existing systems failure` and others (for visual clarity, ethnographic codes are represented with the Courier New typeface in the text). We also provide a count for each code.

We then briefly discuss one example of a story that is coded with one or more of those codes, and illustrates well the kind of reform problem implied by the conditions for success of open care initiatives at hand. Finally, we list all stories (by title) associated to those codes.

Since reality rarely fits neatly into conceptual models, stories and codes can be allocated to more than one condition for success.

We encourage the reader to take this report as a point of departure for exploring the data, and engaging with the voices of the people out there, trying to make open care happen. This

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can be done through an interactive visualisation that uses the Graphryder software, itself developed as part of opencare[4]. The visualisation is available at https://bit.ly/graphryder.

To learn more about a specific story:

1. Navigate to Graphryder, and go to the "Degree of Interest" tab.
2. Type or paste the title of a story from one of the lists provided in this report (for example: "Care by communities: Greece's shadow zero-cash health care system", without quote signs.), and click on the magnifying glass icon.
3. The graph now shows you the story. The initial post is represented in green. Replies are represented in yellow. Ethnographic codes are represented in red.
4. Click on the green node to open a window with the full text of the initial post. This window has a "comments" tab where you can read the comments in chronological order; alternatively, you can click on yellow nodes to read specific comments.

To learn more about a specific ethnographic code:

1. Navigate to Graphryder, and go to the "Code view full" tab.
2. Type or paste an ethnographic code (for example: `resource strain`) into the search string, and click on the magnifying glass icon.
3. A window opens with live links to all initial posts and all replies coded with that code.
4. You can also explore the interactive codes co-occurrence graph that appears in this tab. A codes co-occurrence graph is a mental map of the the corpus generated by the collective intelligence of the conversation [Cottica et. al., 2017].

[4] The code is available at https://github.com/opencarecc/graph-ryder-dashboard .

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4. Open care initiatives: empirical evidence

Applying the method described in section 3 resulted in attributing 11 to 42 stories to each of the conditions for relative success listed in section 2. The number of ethnographic codes that befit each condition varies from 3 to 10; the total number of code occurrences from 58 to 415. This is detailed in Table 1

Category	Stories	unique codes	codes occurrences
governance capacity declines	23	6	136
logistical issues	24	4	85
Online platforms supporting the exchange of experiences across patients	24	4	122
participants are the prime beneficiaries	11	3	109
Mental health	26	6	146
Migration and asylum seeking	36	10	415
Buliding resilient and cohesive communities	42	6	234
Open source technology	23	6	237

Table 1. Allocation of opencare stories and ethnographic codes across the conditions for relative success of open care initiatives.

Co-production between grassroots innovators and formal care institutions

Co-production between grassroots innovators and formal institutions exists when 1) governance capacity declines, like during major crises and 2) when logistical issues put formal care institutions at a disadvantage.

Many opencare stories fall into both sub-categories. An example of the first is the Helliniko Metropolitan Community Clinic, which is a volunteer organization that exists outside of existing institutional frameworks, yet provides the kind of healthcare typically provided by those institutions and utilises government resources despite not being formally affiliated with it. The clinic is a volunteer organization without legal or taxable status and does not make profit. Nor does it accept financial donations, only materials like medical equipment. Technically, the clinic is illegal, yet it operates out of a government building which belongs to the Municipality of Helliniko-Argyropoulis, and the municipality pays its electricity and phone bills.[5]

[5] https://edgeryders.eu/t/care-by-communities-greeces-shadow-zero-cash-health-care-system/4880

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In places like Greece where crises have crippled existing institutions, these kinds of interventions provide vital care to those in need.

Illustrative of structural difficulties of plugging in or reforming current institutions, opencare initiatives often subscribe to the making of alternative economies. They operate through bottom up solidarity, crowdfunding, and ad-hoc support raising, which makes opportunities to co-opt government bodies less clearcut.

In our semantic social network, the following codes are a reasonably good fit for a situation of decline in governance capacity.

resource strain (33), `crisis` (18), `working with policy-makers` (12), `government's inefficiency` (16), `working with existing institutions` (13), `existing system failure` (44)

The following stories and related interactions are associated with them:

Living Streets, Open Insulin, Mercato Lorenteggio (Milan) an intersection of care practices, What is the role of the Government in this Bottom-Up Care Project, Designing Communities of Care- Belgium Design Council's Story, Wir Bauen Zukunft: Learning from a Community with 3 kinds of showers, Woodbine Health Autonomy Group (x5), From Eco-Activism to Food Sovereignty and beyond, FairCoop-Spreading the seed of cooperation to replace competition, OpenCare Legal Evasion Guide: mortal issues for humans helping out, Huis VDH, Community Care and Care Structures for Community Activists (Prinzessinnengarten), Welcome to the Jungle, The Slow Revolution: Community Acupuncture and Social Medicine, Backpacks for Refugees, COSMUS (diy), Trauma Tour, Breathing Games, OpenRampette, WeHandU, Street Nurses, "Creating conditions for open care" means creating culture, influencing policy, learning from collectives' work, How can transitional communities take care of their host neighborhood?

The second sub-category of co-production, logistical issues, is exemplified by Trauma Tour, a trauma therapists' attempt to help those who cannot be served by formal care institutions due to their lack of stable living place. While psychotherapy typically takes place in a therapist's office, with the patient coming to the therapist's fixed location, this kind of relationship is impossible to sustain when the patient is moving. Many displaced people, for example, are unable to regularly access formal institutions to receive medical care. Trauma Tour flips the approach: it is the therapist who is on the move, bringing care to people wherever they are[6].

In our semantic network, the following codes are a reasonably good fit for situations where institutions are incapacitated by logistical issues.

volunteer labour (18), **resource allocation (17)**, **accessibility (17)**, `outside existing systems` (33)

The following stories and related interactions are associated with them:

volunteer labour (18): Welcome to 'The Jungle' - We've got fun and games, DIY Science Network - advocating for community access to research funding, Organizing the open science behind open insulin, Backpacks for the Refugees-The Day After, Care on the

[6] https://edgeryders.eu/t/a-bus-tour-for-a-trauma-informed-world/762/

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camp - A Calais story, COSMUS (diy) - One to One: Donating backpacks full of care, Care by communities: Greece's shadow zero-cash health care system

resource allocation (17): Organizing the Open Science behind Open Insulin, Connecting common questions, Health Autonomy at the End of the World, After #NowConf | How can mayors, funders and activists collaborate to #unfail the "refugee crisis"?, Ethiocracy: Love, land and peace

accessibility (17): HandYwiN: Map to let them go further, Opening the dimensions of access by openrampette, ARTS for Differently Able and Other Initiatives, Openrampette makes questions about co-designing, OPENandChange Workshop Berlin, Open&Change: Workshop Brussels – A symposium, Cycling for people with paralysis: how do we researchers and citizens contribute to more testing and usability of technologies like FES?, After Occupy: How we are developing structures to empower community health, access to resources, and preventative medicine, Bringing quality biology education to every child equally, Woodbine Health Autonomy Center, Notes from community call on emotional health and possibly inappropropriate conversation,

Stepping in for Market Failures

People can step in for market and institutional failures through the use of online platforms which support exchange across patients. This approach is exemplified in opencare by the Cytostatics network, which seeks to distribute medicine across borders when access to affordable medication is limited. The network originated in Romania, where despite being able to diagnose diseases, doctors were unable to obtain the required medicines to heal patients at a reasonable price point (and sometimes not at all). Doctors could not administer drugs to patients, but could tell them what they needed to obtain and advise them to take whatever measures they were able to in order to get the medicines.

Hundreds of people joined the network through the website, coordinating voluntarily to import small quantities at once and using their own Facebook networks to get the word out. It involved a mix of Romanian immigrants abroad, transportation workers in the country and other network brokers finding ways to distribute it to the patients who were waiting: "doing a simple thing, an easy gesture, meant helping someone's health and fighting a system that seemed not to care about the people". Perhaps equally telling, no financial compensation was involved for network members contributing to solve a system level problem.[7]

In our semantic network, the following codes are a reasonably good fit for online platforms as solutions to market failures:

`international collaboration (25), existing system failure (44), sharing knowledge (32), care networks (21)`

The following stories and related interactions are associated with them: Living Streets, Open Insulin, Mercato Lorenteggio (Milan) an intersection of care practices, What is the role of the Government in this Bottom-Up Care Project, Designing Communities of Care- Belgium Design Council's Story, Wir Bauen Zukunft: Learning from a Community with 3 kinds of

[7] https://edgeryders.eu/t/how-i-got-involved-in-the-cytostatics-network/665

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showers, Woodbine Health Autonomy Group (x5), From Eco-Activism to Food Sovereignty and beyond, FairCoop-Spreading the seed of cooperation to replace competition, OpenCare Legal Evasion Guide: mortal issues for humans helping out, Huis VDH, Community Care and Care Structures for Community Activists (Prinzessinnengarten), Welcome to the Jungle, The Slow Revolution: Community Acupuncture and Social Medicine, Backpacks for Refugees, COSMUS (diy), Trauma Tour, Breathing Games, OpenRampette, WeHandU, Street Nurses, "Creating conditions for open care" means creating culture, influencing policy, learning from collectives' work, How can transitional communities take care of their host neighborhood?, How sharing economy platforms could power a new collaborative economy,

- Initiatives in which the participants themselves are the prime beneficiaries. This sidesteps the whole principal-agent problem paramount in care provision. In highly connected societies, these initiatives have more potential for scale and long-term sustainability.

A second category of initiatives that step in for market failures are those in which participants themselves are the prime beneficiaries, removing the distinction between provider and recipient. Self-organized support groups are a prime example of this type of care. In opencare, MAZI Greece exemplifies this type. 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". They 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."

MAZI is a non-profit organization founded by patients and relatives of those with mood disorders. The organization runs 3 groups in Athens, 1 in Thessaloniki, and seeks to create and support a nationwide network of support for those with mood disorders. Peer support and self-help motivate the group, and it exists outside of existing formal institutions, filling a gap by providing peer-to-peer care for those with mood disorders.[8]

In our semantic network, the following codes are a reasonably good fit for participants as prime beneficiaries of solutions to market failures:

peer-to-peer (23), story sharing (38), participatory design/collaboration (48)

The following stories and related interactions are associated with them: DIY Science Network - advocating for community access to research funding, [MIR application] WeHandU - Kickoff Event, How sharing economy platforms could power a new collaborative economy, Cosain Community Wellness, Care on the camp - A Calais story, FairCoop - Spreading the seed of cooperation to replace competition, Rethinking Healthcare Professions Curricula in a Open Knowledge frame, Using the University that is Rethinking Higher Education to Rethink

[8] https://edgeryders.eu/t/people-fighting-depression-together/718

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Mental Health Gradients and Divisions of Labour

Issues of mental health (trauma, depression, stress etc.) have attracted many open care initiatives. There seems to be a gradient from acute condition to chronic manageable condition, to lifestyle. This elicits an efficient division of labour, with care professionals treating acute cases and communities managing the chronic/lifestyle side of the condition (often deploying techniques like yoga, meditation and gardening).

In typical community provided care, many of the projects in opencare take as point of departure the needs and aspirations of sufferers, subscribed to the need for empowerment ("to be shown compassion, empathy, a voice, to be listened to, to be believed in"[9]). Reportedly, in mental health care this emerges from at least two points of failure in the medical model: firstly, the inability to offer attention to the individual's unique needs in the treatment process leads to a sense of feeling dehumanized; secondly, the inability to support her full recovery and regaining of autonomy, following treatment, makes it much harder to adjust and resume life outside the clinical process. Healing, across its entire spectrum of solutions, has to do with being embedded in communities of support ("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"[10]).

The most promising initiatives tackling mental health and care are those where groups took it upon themselves to complement the former. Their approach is based on ground evidence: leaders of initiatives are current or former patients themselves, understanding the workings of the medical system inside out. Lining up different stakeholders at the design table is a task normally reserved for system actors, yet non-professional experts do it in their regular community practice. They make systematic and coherent design choices as to which groups have a say in improvement reforms, which aspects of the medical system need be included in or left out from a new model. While some projects are entirely independent from the system, others are constituted from the beginning through interactions with system actors and formalized partnerships. Most recognise that their activities are not intended to supplement clinical treatment.

At the core of solutions is the idea of wellness for all, as something accessible and attainable through vehicles of mutual care and support ("mutual support is amongst the most therapeutic of acts"). Depending on the specifics of each project, wellness is pursued through:

1. flipping the narrative of care, in scenarios where patients become caregivers and vice versa. The overarching benefit here is that healing others becomes a tool for healing oneself.
2. a focus on activities for health promotion. Community organisations can become reliant partners through helping people in recovery to build skills and engaging them in learning and productive activities (Gal Gael). Particularly when dealing with trauma,

[9] https://edgeryders.eu/t/cosain-community-wellness/724

[10] https://edgeryders.eu/t/kindness-and-connection-can-sustain-us-through-tough-times/777

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members report finding solace in lifestyle choices: healing through gardening, art, food sharing activities, or intergenerational connections.

3. opening up to creative outlets. This expands the locus of healing from medical settings to more "normalized", everyday spaces for regular interactions i.e in Ireland, groups were hosting activities in an Arts Museum; other groups are democratising the mental health conversation space by taking to twitter.

The above mechanics are those which communities perform best, sometimes in early forms of institutional co-production. It however remains to be seen how the dynamics between community and professional health providers play out in the longer term, and how partnerships can be sustained to formalize changes at the system level. We are seeing both some types of projects which grow organically through many volunteer hours (Cosain), and others which start out through government funding (MAZI[11]).

One illustrative initiative is GalGael, a charity in Glasgow which provides wood/stone/metalworking lessons, programs, and activities for those who have battled worklessness, depression, addiction, and other mental health issues. People craft furniture, process timber, work at events and cook. For over 20 years, GalGael has focused on helping people build skills and engaging them in activities, building community and more abstract coping skills 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, and regain their sense of belonging to a community[12].

In our semantic network, the following codes are a reasonably good fit for issues of mental health and solutions:

mental health(69), trauma (20), stress(19), therapy (13), suicide (13), depression (12)

The following stories and related interactions are associated with them:

Woodbine and ZAD of Notre-Dame-des-Landes, Fellowship Post #1 - weird conversations and early insights, Health Autonomy at the End of the World, Who you will meet at OPENVILLAGE and how we're doing open programming!, Meet the Edgeryders | Gehan Macleod - woodmaking, community, activism, marginalization, policy, wellbeing, therapy, mental health, Handling Stress and Avoiding Burnout, Kindness and Connection Can Sustain Us Through Tough Times, Dutch Nursing Combats Social Isolation And Depression Among The Elderly, Losing Hope & Gaining Hope, Vital Networks: the work of transforming experience into understanding, Building tweeting communities for mental health nursing with @WeMHNurses, Baby Crying Sound Reducer, A holistic, integral, evolutionary, self-directed and self-integrated community, Cosain Community Wellness, People fighting depression TOGETHER, Care on the camp - A Calais story, Trauma Tour, Using the University that is Rethinking Higher Education to Rethink Mental Health Care for Students, Woodbine Health Autonomy Center, The Shit Show - A Mental Health Awareness Campaign, Notes from community call on emotional health and possibly inappropropriate conversation, Under

[11] https://edgeryders.eu/t/people-fighting-depression-together/718

[12] https://edgeryders.eu/t/fellowship-post-2-some-reflections/6626

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Pressure: On the relationship between creativity and emotional/mental health, JUS: Design for vulnerability, JUS: Sharing is Scary, Care in the Community, On being a self-entrepreneur

Migration and Asylum Seeking: Open Trumps Institutional

Care issues arising in the context of migration and asylum seeking are also a good fit for open care. Here, open care seems to be superior to institutional care in giving migrants and refugees the ability to shape their own world, connect with other people, and do things for themselves.

This category of projects focused largely on skill building in order to discover and fulfill migrants' aspirations: building furniture (Berlin); language courses (Milan); learning to code (Berlin). The reasoning at their core has to do with putting a service on offer that people are able to choose themselves, and judge for themselves if it meets their expectations. The potential for new productive economies with these skills at the core is recognised:"In the informal PIKPA camp in Lesvos for example, refugees create beautiful, colourful bags from discarded, life-jacket materials and are also planning to distribute them abroad"[13].

In opencare, a hard consensus emerged around the inability of key institutional actors to cope and resolve the so called "refugee crisis": national governments, local authorities, international donors (i.e. UNHCR), local volunteer groups. This has been reported by community members from Thessaloniki, Athens, Calais, Berlin, and Brussels, all of whom were directly involved in informal care provision for migrants.

"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."[14]

In addition to this, there is a high lack of coordination between traditional service providers and a lack of core infrastructure to make care delivery a coherent, effective process. While some material support is being provided by the usual suspects, the services are bulked, depersonalizing recipients, similar to mental health treatments described above ("It's not possible to speak about refugees in general when trying to be of real help"[15]). There is no interrogation or consultation of refugees themselves as to what kind of support they need. The case is made that effective interventions are those where material resources covering basic needs need to be supplemented by social spaces and interactions where people can regain their autonomy. The main failure point to which community initiatives offer a solution is providing newcomers with psychological support and access to non-material resources.

[13] https://edgeryders.eu/t/r2r-call-center-a-cooperative-developed-from-refugees-to-refugees/759

[14] https://edgeryders.eu/t/backpacks-for-the-refugees-the-day-after/517

[15] https://edgeryders.eu/t/italianostranieri-why-learning-and-teaching-a-foreign-language-for-refugees-is-a-form-of-care/482

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Pervasive feelings of uselessness spanned stories on the refugee crisis. One illustrative story, "Fostering Productive Potential in Refugee Camps" exemplifies this need for autonomy and purpose.

The story's author, Tomma, finds through her work in camps in Berlin 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. It makes those who are displaced feel they are doing something useful for themselves and their community.

Since refugees are not allowed a proper work permit for the first three months of their time in Germany, there can be long periods of worklessness. The story illustrates the creative ways for refugees to improve their living spaces in the Internationales Congress Centrum in Berlin, showing that collaborative engagement with volunteers as well as the ability to transform one's own living space is effective in improving situations in the camps.[16]

In our semantic network, the following codes are a reasonably good fit for care issues in the context of migration and asylum seeking:

migration (94), autonomy (50), self-organization (19), building relationships (19), skill sharing (29), story sharing (38), education (67), cultural difference (34), resource strain (33), sharing knowledge (32)

The following stories and related interactions are associated with them: Welcome to 'The Jungle' - We've got fun and games, Emergency mutual aid, MIR application - ResQ, Mobile independent clinic, Who you will meet at OPENVILLAGE and how we're doing open programming!, PHD's in Europe for asylum seekers from Iraq, Language, culture and cinema for an alternative imagery of immigration and integration, From eco-activism to Food Sovereignty and beyond..., Backpacks for the Refugees-The Day After, R2R call center: a cooperative developed from refugees to refugees, RefugeesWork: programming skills for a new generation of freelancers to change the ecosystem and how we work together, The story of the Migrants social center in Thessaloniki, Care on the camp - A Calais story, Trauma Tour, COSMUS (diy) - One to One: Donating backpacks full of care, Italianostranieri: why learning and teaching a foreign language for refugees is a form of CARE, Fostering Productive Potential in Refugee Camps, Newcomer - an app that connects people in a playful way, Food security includes the opportunity to cook, What are the expectations about the use of public spaces when it comes to cooking on the street?, "A Taste of Home" or the use of public spaces, Home, sweet Home, re:Publica | Care by Communities: non zero-sum provision of health and social care, A new chapter in Other People's Story Books, Day 1 Reflexions, Helping Refugees in Denmark is Now a Crime, How to resolve the fear of the unkown?, You and me and everyone we know: The many faces of care, Living Social In Brussels: co-living as a lifestyle for grown-ups, Suicide prevention, dementia, refugee health: Please validate the cases for Op3nCare, OpenCare Outreach Events | Meeting with migrant community, 17 March 2016, Milan - 7.30 pm #LocalActivity, Op3n Hangout #2: How do we navigate the tension between asking for permission and asking for forgiveness?, Dutch Volunteer Turns

[16] https://edgeryders.eu/t/fostering-productive-potential-in-refugee-camps/670

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Refugee Boats and Life Jackets Into Backpacks, BBC Frontline Documentary on Two UK Doctors Helping Refugees, After #NowConf | How can mayors, funders and activists collaborate to #unfail the "refugee crisis"?.

Building Resilient and Cohesive Communities

Open care seems a superior way to deploying initiatives aiming to strengthen the cohesion and resilience of communities themselves (generally intended in the spatial sense of local community). A care initiative is seen as more trustworthy because it comes from the community itself. As a result, it elicits more cooperation and its chances of succeeding increase.

In Greece, the vehicle groups put forward repeatedly is the solidarity networks underpinning the country's own new and informal economic crisis grassroots support which had been growing in the last years. The networks offer support across different needs: from access to information (refugees-to-refugees call center), to real hospitality ("teams of lawyers, doctors, translators and networks of families offering hospitality in their homes, are offering voluntary support and practical solutions, whenever needed"[17]). Similarly, opencare community members reported acts of collaboration between each other, illustrating the practice of solidarity. For example, one group used their network to help deliver backpacks which had been assembled and sent by another[18]. The social aspect of interventions is not to be minimized - sharing food in particular was reported as a low hanging fruit for basic socialization between newcomers and permanent residents in a place. In France, Belgium, Sweden, Germany and Greece, such new social enterprises (constituted or not as such) are potentially the farthest on the way to regularity and incrementality of what constitutes effective interventions.

In the opencare global network, 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. 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.[19]

In our semantic network, the following codes are a reasonably good fit for community resilience and cohesiveness:

community-based care (69), **resilience (34)**, autonomy (50), sustainability (34), place-based (24), building diverse communities (23)

The following stories and related interactions are associated with them:

[17] https://edgeryders.eu/t/r2r-call-center-a-cooperative-developed-from-refugees-to-refugees/759

[18] https://edgeryders.eu/t/the-story-of-the-migrants-social-center-in-thessaloniki/715/6

[19] https://edgeryders.eu/t/woodbine-health-autonomy-center/488

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community-based care: Wir Bauen Zukunft: Learning from a Community with 3 kinds of showers, Nuka? Anyone have connections with the Nuka System of Care Alaska?, Rapid livelihoods rebuilding via agriculture & health based livelihoods initiatives, Who you will meet at OPENVILLAGE and how we're doing open programming!, Liberties Local Health Project, How can transitional communities take care of their host neighborhood?, How to share care in a living community, Mobile Medic - mobile phones for health care in the developing world, Kindness and Connection Can Sustain Us Through Tough Times, Backpacks for the Refugees-The Day After, After Occupy: How we are developing structures to empower community health, access to resources, and preventative medicine, FairCoop - Spreading the seed of cooperation to replace competition, #OPENandChange Thessaloniki: Greeks imagine the future of care, Using the University that is Rethinking Higher Education to Rethink Mental Health Care for Students, Woodbine Health Autonomy Center, The Cytostatics Network seen through the eyes of a member, Community Care and Care Structures for Community Activists, "Coeur d'Or": collaborative efforts for promotional and preventive cardiovascular care in West-Africa, Community Acupuncture - an ongoing mutation, Questionmark, Care = Community, Intro, Suicide prevention, dementia, refugee health: Please validate the cases for Op3nCare, Documentation | Narratives of Care Storytelling workshop, Masters of Network 4: Networks of Care, Care by communities: Greece's shadow zero-cash health care system.

resilience: Circles of openness, Mobile independent clinic, Bagmati River Art Project, Kathmandu, Nepal - Using art to access complicated social and environmental issues, Freeflow Creativity, Mercato Lorenteggio (Milan), an intersection of care practices, Teachín (Small House), How cultural differences can make us understand our flaws in the care sector better, People fighting depression TOGETHER, MakeStorming 2017, Huis VDH: how can we build vacant spaces into home-like structures to build up resilience, Italianostranieri: why learning and teaching a foreign language for refugees is a form of CARE, Greece as a hot-spot of transformative future (conversation with Pavlos Georgiadis, part 2), JUS: Design for vulnerability, Care in the Community, On being a self-entrepreneur.

Open Source Technology

Finally, open source technology offers promise to enhance open care solutions, but social networks are key to the success of these solutions. This is because many of the barriers to creation and uptake are socio-political, not technological.

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.

The Open Insulin project is a prime example of open source in open care. Open Insulin is a collaboration between biohackers at Counter Culture Labs in Oakland and the DIYbio space ReaGent in Ghent. Both groups are trying to create open source insulin toward three

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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, they 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, they 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."

As one of the Open Insulin biohackers puts it:

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.[20]

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.

Social collaboration seems to be at the center of how fast the groups advance and branch out. Over the course of a year, the initial group in Oakland has partnered up with others in Ghent, Sidney, and Cameroon.

In our semantic network, the following codes are a reasonably good fit for open source technology and its solutions:

open source (36), design intervention (78), participatory design/collaboration (48), hands-on/DIY (30), biohacking (28), openness (17)

The following stories and related interactions are associated with them: Open Insulin: Getting Started, Community Conversations -reHub, How sharing economy platforms could power a new collaborative economy, Call for Applications: OpenCare Maker in Residence (call closed), Mobile Medic - mobile phones for health care in the developing world, The story of Hubotics -- A DIY physiotherapy kit, How Open Insulin works to open-source science and medicine, OPENandChange Workshop Berlin, Open&Change: Workshop Brussels – A symposium, Mobile ECG, Caring for Life - a dream of fixing the care home crisis in the UK, SENSORICA and health care, echOpen - Open Source handheld Echo-stéthoscope, OPENandchange: SC!FY aplies and offers scientific knowledge for free, WeHandU - maker space for developing

[20] https://edgeryders.eu/t/how-open-insulin-works-to-open-source-science-and-medicine/519

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solutions for cases of motor impairment, Open Insulin, Faircap, Related care research -- first case, Maestro!, Gifteconomy, Hello, introducing myself :), #LocalActivity: PRENDERSI CURA CON STRUMENTI OPEN SOURCE WORKSHOP @ 5° Forum delle politiche sociali, Shenzhen Assembly - Know thyself and our world in the digital era, Hacking diabetes.

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5. Conclusions

The list of conditions for relative success of open care initiatives presented in Section 2 turns out to be a relatively good fit for the evidence collected in the course of the opencare project. Conversely, the opencare conversation, viewed through the lense of the semantic social network it was encoded in, provides a rich palette of experiences of trying to build open care initiatives in practice: roadblocks and breakthroughs, single points of failure and unexpected allies. This is likely to be extremely valuable evidence for reformers of care provision.

The concept of semantic social network analysis, developed in the course of opencare, shows promise as a tool for aggregating large, messy corpora of ethnographic evidence, while still maintaining direct access to the raw data – "war stories" from the frontlines of social change, which in our case is the development of bottom-up care services.

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