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# Can Community Driven Care be integrated in the European Welfare System? Institutional Challenges and Historical Lessons

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## Introduction

Research in health economics shows that the health sector is characterized by high costs, a high degree of regulation, and a lack of entrepreneurship. There is also a limited dissemination of process innovations in the care sector (Cutler, 2011)<sup>1</sup>.

Despite the fact that digitalization has fundamentally affected industries and in many cases led to dramatically reduced costs, it has primarily led to better technical equipment in the field of care, not to reduced costs, or to new forms of organization.

Cutler discusses why innovation has not reduced inefficiency and waste in health care as in other sectors. Examples include the slowness to adopt efficiency savings and the fact that doctors waste time on routine administrative tasks that could be provided by less-trained personnel or by information technology (Gans, 2004).

Cutler (2011) further argues that improved production processes of the type that has been observed in such sectors as retail, logistics and manufacturing are far slower in spreading to health care due to the lack of organizational innovation:

“Medical care is complex, and it is natural that there will be inefficiencies in complex settings. Indeed, in any industry where human action is important, there are bound to be mistakes. The failure of medical care is not so much that mistakes are made, but rather that the system has not evolved mechanisms to minimize those mistakes. For many years, Toyota was famous for its attention to error reduction; Wal-Mart is equally known for its supply-chain management.”<sup>2</sup>

The explanations can be found in the current organization and financing model. Healthcare is almost always, and care of other kinds often, funded by third parties. This fact also means that the business must be controlled and audited. A public player will rarely be able to spend money on something that is beyond control. The same holds true for a listed company.

A privately held company or a foundation can act more freely. However, these are bound by the regulations that cover the healthcare sector in most countries. This binding gives a low level of experimentation, and in principle, new solutions must be approved before they can be used. At the same time, as the financing models imply that the businesses receive compensation for actual costs, there are limited incentives for innovation.

Different rules within different jurisdictions also make it less possible to scale. Although people are very similar between different countries, the organization of care is often national. This organization is due to, among other things, compliance and documentation constituting a significant part of the business. This fact may explain why we do not find global integrated care companies – those that exist are often conglomerates with separate national parts.

On the other hand, outside organized care, new solutions have arisen. We call these "open care". Open care involves care organized by groups outside formal health care institutions.<sup>3</sup>

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<sup>1</sup> In this context, care should be viewed in the broad sense and include child care, elder care, health care, assistance to persons with disabilities (mental and physical), and the treatment of addiction.

<sup>2</sup> Cutler (2011 p 2).

<sup>3</sup> Open care, as a concept, does not exist in previous research (other than as a synonym for "outpatient care").

Open care has similarities with open software development, as it is bottom-up and (generally) not for profit. One type of open care projects is that in which people are organized to offer care but do not do so within the framework of the public or private formal institutions available. Often, this occurs on a voluntary basis. Another type involves projects where patients themselves participate in care, exchange experiences and pool their knowledge. A good example of this is Alcoholics Anonymous in drug addiction. One can summarize open care as "community- and/or collective intelligence-based care projects".

It should be noted that, although it is easy to observe the connection to open source (as in open source software), open care is not necessarily IT based. IT might play a significant role in some open care projects (e.g., as a means of communication and to create critical mass), but open care does not need to have any connection to IT at all. Open care projects might have existed hundreds or thousands of years before the invention of the first computer. That said, most "open" projects will probably be driven by digitalization.

This paper will focus on open care projects, which in some way build on the potential of digitalization. I will use cases collected as part of an ongoing European research project on open care. At present, approximately 30 cases from European countries exist.<sup>4</sup> Cases include both ongoing and historically discontinued projects. In this paper, I will describe when open care arises and make an attempt to answer the question of when open care can help meet the challenges of care and the conditions under which open care emerges.

This paper is organized as follows: First, I review the theoretical background on the concept of the commons and the connection to open care, followed by a discussion of the reasons for the increasing costs of care. Then, there is an empirical part where some findings from existing open care projects are presented. Finally, this paper ends with a discussion on when open care projects are likely to emerge.

### **Theoretical background**

The theoretical foundation for developing this concept draws inspiration from research on the commons (Hess & Ostrom, 2005; Ostrom, 2007; Ostrom, Burger, Field, Norgaard, & Policansky, 1999; Poteete, Janssen, & Ostrom, 2010) and open source software development (Capiluppi & Michlmayr, 2007; Hippel & Krogh, 2003; Kogut & Metiu, 2001; Von Hippel, 2001). Institutional economics explains that community self-organization is a third method for organizing activities, apart from the traditional market and government division, and in many situations works well (Ostrom, 2007). Collective intelligence and open care in general are classic examples of such "commons". Self-organized communities in many cases work better than hierarchical systems but have their own challenges. This body of research also points to practical guides on how self-organized communities can better overcome collective action problems.

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<sup>4</sup> The cases collected include community-organized clinics in Greece, care for immigrants in France, parallel imports of pharmaceuticals in Romania and various online forums where patients can discuss their (sometimes rare) illnesses and, in some cases, provide feedback to care givers and researchers on, for example, the side effects of medications.

Self-organization and basic economic models predict that conflicts of interest cause voluntary collective action to fail, even when such cooperation is to everyone's mutual benefit. Mancur Olson concluded:

“Unless the number of individuals in a group is quite small, or unless there is coercion or some other special device to make individuals act in their common interest, rational, self-interested individuals will not act to achieve their common or group interests” (Olson, 1971).

This occurs when rational, self-interested individuals have a stronger incentive to free ride than to contribute to collective benefits. The collective action problem can be theoretically shown in n-player prisoner dilemma games, where cooperation fails despite mutual gains (R. Hardin, 1971; Lichbach, 1996).

The “zero contribution thesis” in public good production, however, is not the full story. While cooperation is challenging, we also empirically observe that many examples of successful voluntary organization are common. The work of Ostrom and her team showed that self-organized communities can solve collective action problems using cooperative norms. They examined real-life common pool resources such as fisheries and grazing land. They found that over time, communities organically developed collaborative institutions to overcome collective action problems (Gardner, Ostrom, & Walker, 1990; Ostrom, Stern, & Dietz, 2003). The rules for managing common pool resources could be monitored, and sanctions could be imposed by the community. The studies found that in a setting with repeated interaction and communication, social norms can replace an externally imposed set of rules, sometimes even outperforming them (Ostrom, 2014).

Ostrom focused on the commons, which is any resource to which members of some group share access. Individuals can extract resources from the common pool for private use but at the risk of degrading the commons through excess use – the “tragedy of the commons” (G. Hardin, 1968). One way to solve this collective action problem is privatizing the resource into parcels of private property, while another is assigning management to a central authority. Ostrom showed that groups could also cooperate and act as their own stewards, in practice transforming the resource into common property.

Successful cooperation is far from guaranteed and often fails. The potential for successful self-organization, however, is wider than the simple self-interested theory would predict. Individuals often follow norms of reciprocity and are willing to restrict their own use common resource as long as most others reciprocate.

In addition to trust and reciprocity, successful commons governance requires an active community and evolving rules that are well understood (Ostrom et al., 2003). The longer-term survival of these institutions also requires so-called design principles. These include boundary rules, restrictions on the use of resources, monitoring, graduated sanctions on offences, conflict resolution, and the ability of the participants to elect leaders and modify rules. Cooperation works because the participants monitor each other and can sanction or exclude cheaters. Over time, social norms often evolve such that the preference to follow the rules is internalized. This phenomenon allows for high levels of cooperation, without the need for close monitoring or costly sanctioning.

Organizational cooperation requires individuals to keep their promises to each other. Simple theoretical models often predict that credible commitment in negotiations is impossible without the coercive power of an external authority such as the state. Ostrom et al. (Ostrom, Walker, & Gardner, 1992) argued that other mechanisms could also effectively enable credible commitments:

“Empirical evidence suggests, however, that individuals facing social dilemmas in many cases develop credible ex ante commitments without relying on external authorities”.

This was possible through repeated interaction, communication and the ability to sanction those who acted opportunistically and broke their promises. In this setting, the threat of sanctions could create sufficient incentive to cooperate and often outperform other arrangements. The authors concluded that self-governance is possible and that

“[When] individuals are given an opportunity to restructure their own situation, they frequently – but not always – use this opportunity to make credible commitments and achieve higher joint outcomes without an external enforcer.”

Defining health care as a commons would stretch the definition too broadly, making it useless. There are, however, specific elements of health care provision that can be viewed as common pool resources. One important example is the provision of complex health care requiring the collaboration of different actors (Gochfeld, Burger, & Goldstein, 2001; McGinnis, 2013).

## **The increasing cost in health care**

Health expenditure has outgrown the overall economy in developed countries over recent decades, driven by factors such as ageing, higher incomes and the adoption of new technologies (Chernew & Newhouse, 2012).

Health spending relative to the rest of the economy was fairly stable historically but began to grow rapidly around the 1950s in both the United States and Western Europe (Getzen, 2014). Between 1960 and 2010, health spending as a share of GDP grew from approximately 5 to 17 percent in the United States and from 3 to 10 percent of GDP in Western Europe (Rebba, 2014). Interestingly, the rate of growth of health care expenditure is similar in the United States and Western Europe, albeit starting and therefore remaining at a lower level in Europe (Getzen, 2014). The increase in expenditure slowed sharply in recent years, though this is likely to mainly be a temporary effect of the economic crisis.

The high cost increase in health care also affects equality by making health care unaffordable for low-income individuals. Even in Europe, health care tends to have a significant component of private out-of-pocket spending. Lower-income groups are, therefore, more likely to perceive a lack of access to health services even in countries that have universal health care (Cylus & Papanicolas, 2015). High expenditures have placed great pressure on public finances and created an impetus for reform aimed at increasing productivity in health care in order to maintain the long-term viability of the welfare state (Pammolli, Riccaboni, & Magazzini, 2012). The costs of health care delivery vary significantly by provider and region beyond what can be explained by quality and input costs, which suggests that many providers produce at suboptimal levels of productivity (Cutler, 2002; Philipson, Seabury, Lockwood, Goldman, & Lakdawalla, 2010; Skinner, 2012).

The causes of the high cost and low effectiveness in health care have been intensely debated in recent years, but no definitive answers have been reached. While this issue is not fully understood, it is often argued that the unique characteristics of health care cause unique organization, which reduces the incentives for process innovation and creates a bias towards high cost increases (Chernew & Newhouse, 2012; Dranove & Satterthwaite, 2000; Weisbrod, 1991).

Weisbrod (1991) writes:

“To understand the markets in which health care is provided and financed, it is useful to consider ways in which health care differs from most other commodities. First, it sometimes involves the preservation of life, or, at least, major effects on the quality of life. Second, it is a technically complex commodity that abounds with informational asymmetries, adverse to consumers.”

One important explanation appears to be that the ethics of health care tends to incentivize technological change focused on increasing health quality and saving the patient, regardless of the cost, rather than on lowering costs (Weisbrod 1991). Technological improvement can either focus on improving the quality for a given cost or decrease the cost for a given quality. In health care, there is a strong bias towards the former, not for technological but for institutional reasons.

Firms that invest in innovations know that a new treatment or drug that improves the chances of survival is almost never denied by providers, regardless of the cost. Focusing on drugs or treatments that lower costs may not be as profitable. Technology often decreases costs but instead has had a tendency to make health costs increase (Cutler, 1995, 2002).

### **Open care and digitalization**

In this section, I will use cases collected as part of the European Open Care research project to outline what open care can be. In this study, the cases are limited to those using information technology.<sup>5</sup>

The first identified category of open care is online communities for patient interaction. Patient information sharing sites can play a key role as knowledge brokers in the health care sector. This fact is particularly true if patient organizations can be encouraged to participate in the platforms. As collectives with varied members and activities, patient organizations have a unique capability of easing the flow of information across networks (Nicholas & Broadbent, 2015). One such online platform is PatientsLikeMe, which was founded in the United States in 2004.<sup>6</sup> The social media platform, which has a global outreach, also engages many European patients and patient organizations. The health information sharing site encourages users to input data about their symptoms, environmental triggers, medication, etc. over time. The result is the creation of ongoing medical records. Users are encouraged to communicate with others who have a similar health status and exchange knowledge. Aggregated, de-identified data are also processed by PatientsLikeMe and form the basis of future health advancements. In addition to providing useful information to those who experience health issues, the mass data gathered at PatientsLikeMe are also useful for furthering the understanding of diseases. Numerous scientific publications rely on the data gathered by the patient communication platform.<sup>7</sup> The mass data gathered from this and similar platforms can in the long run play an important role in fostering collective intelligence in health care (Tempini, 2015).

The second category is multi-function health communication platforms. There are several multi-function health communication platforms that may be considered open care. The Hungarian PraxisPlatform is a platform that, in addition to facilitating communication between patients, serves as a way for health care professionals to communicate with patients.<sup>8</sup> The latter role is filled through sending therapy-related information to patients to increase their adherence to/compliance with medicinal therapy and medical device use. Through the online platform, pharmacy care services to large patient populations can also be carried out. PraxisPlatform is an example of how a single platform can fill two different roles: first, e-healthcare, through which the traditional health care system can efficiently reach out to patients at typically low costs, and, second, as a social patient communication platform. The combination of facilitating patient-to-patient communication as well as health care sector-to-patient communication (as well as patient-to-health care sector feedback) might create synergistic effects for patients as well as health care professionals. These might occur,

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<sup>5</sup> For a thorough discussion on the project and the concept of open care, see (Sanandaji & Lakomaa, 2016).

<sup>6</sup> There are similar sites in other countries, e.g., Carecity, which is now established in several European countries (Castejón, Chekroun, García, Gay, & Rebollo, 2013).

<sup>7</sup> An example is the paper by Naujoks et al. (Naujoks et al., 2016), in which patient-reported data from the PatientsLikeMe community are used to explore how migraines impact the day-to-day life of patients.

<sup>8</sup> PraxisPlatform website, <https://www.praxisplatform.hu/>.

for example, since through the same platform patients can receive complementing forms of information and since the burden on health professionals to reach out with online information can be reduced if patients can receive part of the information that they seek from other patients. Through forums, patients can also help each other better understand the information given by health professionals.

Another example of a social patient communication platform developed in Europe is HealthUnlocked, which aims to become the social network for health. HealthUnlocked is a peer-to-peer support network through which individuals with health issues can communicate safely online, with guidance from credible institutions and organizations. The platform, which was founded in 2009, is multifunctional since it also encourages patient advocacy organizations to become engaged. Through HealthUnlocked, these organizations can communicate with their members about health-related matters, as well as allow members to foster patient-to-patient health sharing.

Communication platforms are also increasingly encouraging and simplifying open communication between care providers. Hospitals and health clinics tend to be organized in a hierarchical manner, in which communication between different units and even between different doctors in the same hospital is often limited. Information sharing to patients is even more limited within the traditional hierarchy of health care provision. Information sharing applications during recent years have disrupted this system by encouraging more open communication. An example is Klara, a communication platform developed by the entrepreneur Simon Bolz and the physician Simon Lorenz. The communication platform simplifies information sharing from doctors to patients and was launched in 2014. The cloud-based web and mobile apps offered by Klara have since spread to hundreds of health systems across the United States, including solo providers and large medical groups. Gradually, Klara has moved towards simplifying communication between health care workers and health care systems. Klara is currently attracting capital to finance future improvements. The aim is to allow patients to exercise greater influence over the healthcare provided to them, as well as allow operational efficiency in health provision by simplifying information sharing. The example of Klara shows that open information sharing among patients, between patients and health providers and among health providers can occur through the same basic platforms.<sup>9</sup>

A similar platform in Europe is ENJECT. ENJECT is a 4-year coordination project funded by COST – a European funding organization for research and innovation networks.<sup>10</sup> ENJECT focuses on promoting new models of healthcare delivery incorporating wireless, digital and mobile technologies. The stakeholders in the process of health delivery are connected in information sharing networks. The aim is to promote the concept of “connected health”, in which the patient can gather, link to and interpret information from different sources. Providers, patients and researchers can also use aggregate data in order to improve decision making. This information sharing from providers to patients is relevant in the scope of open care, since the information can be fed into social patient communication platforms and peer-to-peer support networks.

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<sup>9</sup> PR Newswire (2016). "Healthcare Messaging Platform Klara raises \$3 Million from Lerer Hippeau and Project A to become the Central Nervous System of Healthcare", 2016-09-14.]

<sup>10</sup> ENJECT website, <http://enject.eu/about/>.



A third category is that in which digitalization realizes “long tail effects” (Anderson, 2006). RareConnect is an international platform for rare disease communities. The platform, which has been developed by Eurordis and NORD, acts in cooperation with patient organizations. The organizations contact the site managers to gain permission to set up community pages. These pages have learning resources in the form of moderated forums and spaces for patients to share their stories with one another. Individual patients can also connect with health professionals in the forums. Another platform is HealthTalk, developed in partnership between the charity DIPEX and the Health Experiences Research Group at Oxford University. The platform collects text and video narratives from patients who communicate their experience of having a certain disease. The experiences of individual patients are presented on a timeline through the early stages, diagnosis and treatment; hence, they reflect the entire patient experience. The patients included for each disease are chosen to represent a range of disease stages, ages, genders, socioeconomic status, etc. (Nicholas & Broadbent, 2015).

### **When does open care emerge?**

Open care projects are unlikely to emerge where the traditional care institutions work well but, rather, where they are inadequate. This phenomenon may apply either where care systems failed because of an economic crisis or in areas where no such systems have been established, e.g., care for recent immigrants or for minorities or people in remote geographic areas. They may also emerge where there are scale effects but the number of patients in a specific jurisdiction is too small to cater to the demands of the users or patients. The ability of a patient with a rare disease to share knowledge with others might be of little value if the number of patients in a country is three and the knowledge exchange is organized within the national health care system, but the value is enormous if the patient is able to interact globally with tens of thousands of other patients.

Several of the projects that have been able to scale successfully are those in which the users themselves are the prime beneficiaries. The abovementioned PatientsLikeMe and other social media platforms are devoted to the acquisition of knowledge. This fact also applies to non-digital open care projects such as Alcoholics Anonymous, where their own participation is both important for the alcoholic participant and for the other participants in the gathering. Projects based on self-help and exploiting economies of scale and the lack of regulatory border obstacles can therefore be expected to have greater potential than other projects.

Projects based on the acquisition of big data can also be expected to be successful even if they are likely to rely on external incentives for participation, insofar as data collection does not give immediate benefits to the participants. However, the interest in creating such incentives may be great, as alternative opportunities for obtaining these data are often missing for traditional health services.

To help solve the health care cost crisis, open care projects must be able to scale. The insights from Ostrom offer some help in hypothesizing when this is likely. Most open care projects are organized as non-profits. As they do not have a bottom line, the efficiency of the projects is difficult to evaluate, allowing room for opportunism. A strong common culture might be a remedy. Historically, many projects that can be defined as open care have been organized by religious organizations where a common set of values already exist – a person who is involved knows what a good outcome is. This phenomenon also increases the costs

for opportunistic behaviour from outsiders. The cost for a person to follow religious rules and rituals is low if the person is a believer in the faith, but it is costly for an outsider. Religious organizations may also provide an organizational structure, alleviating the need to create one for a new project.

A common understanding of what a good outcome is also exists in other communities. In the open software culture, what constitutes superior performance (e.g., the writing of structured and commented code) is generally agreed upon. Different functions are also more or less likely to be developed in the absence of financial incentives (Von Krogh, Spaeth, & Lakhani, 2003). Research on software development could therefore be used to also understand open care projects.

## **Conclusions**

In a world where the increasing costs of (health) care, and, in some cases, limited access to care are a growing problem, open care is a novel concept that can be useful in understanding the formation of care projects outside formal (health) care institutions. In this paper, I have given some examples of how IT-based open care projects – both in the collective intelligence and the community provision type – may help solve some health care challenges.

Open care projects are often, but as historical examples show, not always facilitated by digitalization. Using the cases and the previous literature on the commons and evasive entrepreneurship, it is possible to hypothesize where open care projects may emerge. Open care can be expected to emerge mainly where the traditional health care system (public or private) is inadequate (or has failed). This phenomenon applies to both public and private systems.

It may also be conjectured that open care is easier to organize if the participants have shared values because they can more easily agree on what is a good result (Capiluppi & Michlmayr, 2007). This phenomenon has been identified, for instance, in open source software development, where a consensus on what is good code and what the rewards are, exists. The same can be observed within collective intelligence projects such as Wikipedia, where the internal incentive and reward systems are based on a common culture.

It may also be argued that open care, in the sense of community-based care, has a low cost of experimentation; however, in public health systems, which are risk-averse, there might be many failures, but due to the low cost of failure, these failures are outweighed by the value of a few successes.

Thus, open care may relieve the pressure on the formal health care system in two ways. First, it may do so by facilitating entrepreneurship and the dissemination of process innovations. If some “open” solutions are able to scale, then they might lower the cost for specific treatments or types of care. This fact is especially true when similar projects – due to, for example, high monitoring costs if organized within formal care institutions – have a limited potential to scale. Through the structuring of incentives, many of the projects described in this chapter will avoid the problems described in the “commons” literature.

Second, even when they lack the potential to scale, open care projects can help by providing benefits to groups that have limited access to formal care institutions or where the participation of the patients in itself is therapeutic.



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