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Integrating Community Driven Care Services in European Welfare States: Nonprofit Institutional Entrepreneurship as Driver for Expanding Access

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1. Introduction

Health care tends to be heavily regulated and produced by traditional public or private organizations. In addition to this, however, there is another often neglected organizational method in the form of voluntary health care production by self-organized communities. We review historic and current cases of this phenomenon, which we term *open care*. Examples include historic friendly societies that provided insurance and medical services to members, co-opts, unpaid community clinics, patient groups, self-help support networks, crowdsourcing and the IT-based aggregation of medical data. The definition of open care is based on the production of health by communities rather than profit motives, and therefore also includes for-profit firms that rely on voluntary input. This includes a growing number of e-health firms that aggregate collective intelligence on medical symptoms, rare diseases, doctor quality, drug and hospital prices and so on.

We attempt to analyze open care using the related literature on institutional economics in order to identify areas where community driven care projects are most likely to thrive, as well as to provide policy recommendations on how they could be integrated in the existing European health care system.

The unorthodox features of open care also make it a valuable case that provides new theoretical insights in institutional economics. The concept of evasive entrepreneurship has previously been restricted to for-profit firms that evade formal institutions. Reviewing open care however shows that the concept also fits for collective community projects, though in sometimes different ways. For-profit firms that evade institutions maximize profits, and often have incentives to corner evasion. By contrast non-profit evasive entrepreneurship that circumvents institutions to maximize quantity has incentive to expand the evasion to others or remove the barriers entirely. While prior analyses have focused on formal riles and policy, evasive entrepreneurship in open care is often about evading informal or non-coded institutions such as health care practices, discrimination, intellectual property and the *de facto* monopoly positions of dominant actors.

Open care tends to function when existing health system fails, when there are therapeutic advantages in co-producing health such as support and addiction care, or when knowledge is widespread, such as patient knowledge about medical rare symptoms. Advances in IT that allow pooling have significantly reduced the cost of pooling and accessing collective intelligence and facilitated a growth in internet-based open care, where patients share and collect data on their health in structured forms. The rapid growth of e-health, initially, in the United States and, recently, in Europe is currently the main frontier of Open Care.

It is found that open care is more likely to emerge and prosper when building on existing organizational structures, where the participants do not need to create new hierarchies or governance structures, and where they share common values. The paper may serve policy makers aiming to design institutions or regulations that may facilitate, or at least not impede, the emergence of community-based care.

These various types of alternative health care organization described in this paper can have different ownership forms including private, public, collective or mixed ownership. They are not defined by ownership form but rather by open input and community organization.

Open care is defined as health care that is coproduced by communities, rather than traditionally delivered through hierarchical organization by restricted producers. This definition of Open care includes both non-profit associations and for-profit firms that in turn organize users who contribute with coproduction or collective intelligence. We here define health care broadly, including medical services, addiction and mental health support, finance of health insurance, collection and dissemination of information as well as preventive health activities.

The central distinction is that health care is produced through what the seminal work of Elinor Ostrom defined as the third mode to organize production. This is aside from the two classical modes to organize health care services – privately owned firms, operating in the market using market prices, and regulated public sector activity. While the debate has focused on the relative merits of these two classical choices, there also exists a range of alternative organizational models. This includes self-organized community projects, collective intelligence knowledge creation, quasi-markets as well as evasive entrepreneurship that circumvents existing regulation. These various types of alternative health care organization can have different ownership forms including private, public, collective or mixed ownership. They are not defined by ownership form but rather by open input and community organization.

A wide range of organizational and institutional designs, with varying success and scalability, exist within the frame of open health care. Different methods of organization and ownership have different advantages and disadvantages, and are variously suited to different environments. Community-based health care and collective intelligence have several advantages, but also disadvantages, compared to market or public provision. This paper surveys case studies of open health care. The purpose is to provide input to European health policy design, by creating a theoretical framework for those circumstances when health care can be designed as open, and to analyze why self-organization takes place. The paper discusses how policy makers can encourage open health solutions, amongst others by funding research which identifies and encourages scaling of best practice in open care provision.

Health care provision in all member states of the European Union is characterized by mandatory or public financing, tight regulatory control, and public entities as the dominant or sole provider. The public approach ensures equity and can in some circumstances keep costs low, but also makes it difficult to rely on price mechanisms to disseminate information. Market systems incentivize service providers to innovate and focus their activities to areas where their efforts might be of the most use. In publicly dominated sectors, market forces may be distorted by regulation and public-sector provision which is used to achieve other goals, such as distributional concerns. While monetary profit motives are powerful incentives, the advantage of market systems in terms of bringing information to the surface, and as tools for collective intelligence, has been shown to work also using other types of incentive mechanisms. These include reputation, reciprocity, altruistic preferences and procedural utility from performing enjoyable tasks.

Collective intelligence can be utilized without relying entirely on direct monetary reward. The perhaps clearest example is scientific research in the academia, where the direct incentive in the form of publication and citations might lead to promotions and tenure. Similarly, many patents do not provide economic benefits for the patent holder, but might nonetheless incentivize innovation by granting the inventor an acknowledgement of innovative skill. One important reward mechanism in open source software development is recognition of authorship by peer. These and similar incentives can also be used in health provision, and supplement existing monetary rewards. Indeed, high-power monetary incentives might in some instances be less effective than low-power incentives, by excessively incentivizing certain elements of activity, by creating the tragedy of the commons, or by raising the temptation for opportunistic behavior. Limited forms of self-organization in health care, through patient groups and feedback being directed by groups of patients, can be found across Europe.

This paper aims focus at community care and collective intelligence projects in Europe which go beyond limited inputs from patients and patient organizations. We discuss the extent to which such projects are being used in the care sector in Europe by examining pertinent cases. The survey discusses the features of open health programs, and attempts to identify factors for success as well as the scalability of the project. While this literature is new, we attempt to provide a theoretical framework for the emergence of alternative organizational forms, and to use best practices from comparative case studies to inform European policy design, as well as suggest guidelines for both policy design and for communities that self-organize care projects.

Here health care is not only defined narrowly as hospitals, but includes broader provisions of activities that promote health. This includes psychosocial care, addict care, health efforts aimed at the elderly, nutrition and exercise. Also included are side activities dealing with improving treatment, such as advice on medication and symptom recognition. Another example of open care and collective intelligence is collecting genetic data from a large number of individuals in order to improve health research. Symptoms of illness, side effects of drugs, personal experience from dealing with addiction, and genetic data are all examples of intelligence that is widely dispersed, and where significant potential for collective intelligence approaches exist.

While collective intelligence and open community activity has many advantages, it also suffers from important disadvantages in many situations. Otherwise we would observe that most, if not all, activity would be carried out in this way. The seminal article “The Cathedral and the Bazaar” (Raymond 1999) discusses the tradeoffs in different settings from open and hierarchical methods in software programming, suing the open-source program Linux as a case. This includes contract theory, Elinor Ostrom’s work on self-organization and the recent work on the concept of evasive entrepreneurship.

Health care is a highly regulated sector, and many, though not all, self-organized community health care initiatives are examples of evasive entrepreneurship. This refers to circumventing regulation that restricts activities, and can be undertaken both by for-profit and non-profit actors. Due to the highly regulated and bureaucratic nature of health care in Europe, there are many examples of activities for which there is demand but that cannot be performed due to regulations. Evasive entrepreneurship generally does not refer to breaking laws, but using gray areas or using innovative methods to redefine the activity in order to get around prohibitions. Evasive entrepreneurship is more likely to be continued to be allowed when the rule being evaded is considered non-legitimate, or when the activity is worthwhile. This is often the case in health care, as denying care is morally viewed as taboo. Even those who support regulating the price of medicine might object to smuggled drugs for the sick to be disposed of.

Self-organization is far more likely when the group involved has common values and goals. Private firms and the public sector can rely on hierarchy to organize activities, and make decisions when there are agency problems and conflicts of interest. This is more difficult when a large number of people coordinate activities in open commons. Shared values reduce conflict of interest and increase costly penalty on opportunism, thereby mitigating agency costs. Shared values also reduce the risk of conflict or confusion that arise when different members of the groups come to different conclusions about the correct course of action, due to ambiguity and uncertainty. For these reasons, open activity and community projects often work in subcultures, but are difficult to replicate in broader settings. Examples include the hacking subculture, ideological movements such as communitarian socialism, and Amish communities. Projects that rely on subcultures are difficult to scale, but may nevertheless be important as innovative examples, or because the subculture is large.

There are multiple theories about the role of the non-profit sector in society. One view is that this is a residual sector that provides public goods which other sectors do not or cannot provide – for example service gaps left unmet by market and public-sector failure (Horwitz 2007, Weisbrod 2009). Non-profits also have an advantage as they are more flexible than the public sector in terms of the rules they must follow. Another view is that non-profit have advantages due to ability of solving conflicts of interest and contract failures since they have less inventive to take advantage of consumers than for-profit firms.

2. Theoretical Framework

2.1 Structural Challenges in Health Care

The health care sector is one of the economy's largest and most valuable for human welfare (Chernew and Newhouse 2012). Health care in both the United States and Europe is at the same time been plagued by endemic problems of unequal access, inefficient production and high cost increases (Van Doorslaer, Wagstaff et al. 2000, Marmot, Friel et al. 2008).. Much of the debate has focused on the problems in the United States, but similar problems in varying degrees exist in European countries as well (Van Doorslaer, Masseria et al. 2006, d'Uva, Jones et al. 2009, Diderichsen, Andersen et al. 2012).

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

Health spending relative to the rest of the economy was fairly stable historically, but began to grow rapidly around the 1950s both in the United States and Western Europe (Getzen 2014). Between 1960 and 2010, health spending as a share of GDP grew from around 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 US and Western Europe, though 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 be mainly a temporary effect of the economic crisis.

The high cost increase in health care also affects equality by making health 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 which have universal health care (Cylus and Papanicolas 2015). High expenditures have put 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 et al. 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 et al. 2010, Skinner 2012).. The causes for 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 causes unique organization, which reduces incentives for process innovation and creates a bias towards high cost increase (Weisbrod 1991, Dranove and Satterthwaite 2000, Windrum and Koch 2008, Chernew and Newhouse 2012).

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.”

Health care fundamentally differs from most other services due to the strong moral arguments that it should be provided for those in need, regardless of ability to pay. Health care services are moreover often complex, difficult to evaluate for the patient, rarely used, but very expensive and literally vital when needed. Therefore, health care is generally financed by others than the patient. Health provision, consequently, involves three parties: the patient, the financer in the form of the state or insurance company, and the provider. The three parties tend to have conflicting interests in terms of cost reduction.

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 cost rather than lowering costs (Weisbrod 1991). Technological improvement can either focus on improving quality for given cost or decrease cost for given quality. In health care, there is a strong bias for the former, not for technological but for institutional reasons. Firms that invest in innovations know that a new treatment or drug that improves chance of survival is almost never denied by providers, regardless of cost. Focusing on drugs or treatments that lower costs may not be as profitable. Technology often decreases costs, but has instead had a tendency to make health costs increase (Cutler 1995, Cutler 1998, Berndt, Cutler et al. 2000). Higher cost of healthcare should not be confused with higher costs of health, which has indeed declined – for example measured by life expectancy.

Asymmetric information and moral hazard problems create other ineffectiveness in provision of health services (Dranove and Satterthwaite 2000). Patient and providers prefer higher spending, while the financer prefer lowering costs. Principal–agent problems and the information disadvantage may also make patients prefer providers who are not opportunistic and do not have strong incentives to maximize profit. Agency problems and the informational disadvantage of patients create a risk for profit-driven hospitals to act against the interest of the patient, which makes patients more trusting of non-profit private hospitals. This is likely one reason why for-profit hospitals are few compared to non-profit private hospitals in the United States. One way to deal with agency costs by financers such as the state is to control production in public hospitals. The organization structure of health care in either public or non-profit form, however, causes other problems such as bureaucracy, rationing and weak incentives to innovate.

Cutler (2011) discusses why innovation has not reduced inefficiency and waste in health care as in other sectors. Examples include slowness to adapt efficiency savings, and the fact that doctors waste time on routine administrative tasks that could be provided by less trained personnel or through IT (Gans 2004). Cutler (2011) argues that improved production processes of the type that has been seen in such sectors as retail, logistics and manufacturing are far slower to spread in 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."

Technological innovation tends to be expensive and characterized by high transaction costs, which makes creating incentives to fund R&D critical for technological development (Henrekson and Sanandaji 2016). Nevertheless, technology is not the most difficult innovation to incentivize without profit motives, since it can e.g. be directly funded by the state or universities. Another solution is using prizes to promote innovation where incentives are otherwise weak. One advantage is that prizes avoid the tradeoff inherent in granted monopolistic patents (Kremer and Williams 2010). In this case, the reduction of innovation through "tragedies of the anti-commons" will also be avoided (Heller 1998, Heller and Eisenberg 1998).

Improving processes that often spread by diffusion presents a greater challenge. Private firms with strong property rights and managerial structures, like Toyota and Wall-Mart, have obvious incentives to introduce process innovations. Once a procedural innovation is created in one part of the organization, it is actively copied by the rest of the firm. The best procedures are likely to spread in the industry, as the most effective firms take market shares while less effective competitors are forced to emulate or risk disappearing.

The organizational structure of health care, however, creates barriers for private market entrepreneurship that are not readily removed. This raises the question of other methods to introduce innovations. The profit motive is obviously not the only mechanism to introduce innovation. Windrum and Koch (2008) analyze innovation in the public sector, in particular health care. "Public sector entrepreneurs" tend to have weaker incentives to innovate, less risk-taking in public organization, and lower tolerance and higher sanctions for innovation failure. Innovation, however, takes place also in these organizations using other methods and incentives. Case studies in health care point to the key role played by the entrepreneurs, or "innovation champions", who drive forward the implementation and diffusion of innovation. Their success is in part dependent on willingness to experiment in the organization (Cunningham 2005).

Another organizational form that has shown strong ability to innovate without monetary incentives is the non-profit sector. Particularly impressive gains have been seen in self-organized open source systems, such as Wikipedia and Linux. Here incentives are different, including reputation, reciprocal altruism and a subculture of sharing. The work in new institutional economics, in the next section, has shown that these self-organized systems are more common and successful than predicted by simple theory.

2.2 Ostrom and the Theory of Self-Organization

While cooperation is challenging, we also empirically observe many examples of successful voluntary organization are common. The work of Elinor Ostrom and her team in particular 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 communities over time organically developed collaborative institutions to overcome collective actions problem (Gardner, Ostrom et al. 1990, Ostrom 2003, Ostrom, Stern et al. 2003, Ostrom 2007, Ostrom 2014). This was a revolutionary insight for which Elinor Ostrom awarded the Nobel Prize in economics as the first female laureate. Rules for managing common pool resources could be monitored and sanctioned by the community. The studies found that in setting with repeated interaction and communication, social norms can replace externally imposed set of rules, sometimes even outperforming them (Ostrom 2014).

Ostrom focused on 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 common through excess use, the "tragedy of the commons" (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 are however wider than the simple theory of 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, Stern et al. 2003). Longer-term survival of these institutions also requires so-called design principles. These include boundary rules, restrictions on use of resources, monitoring, graduated sanctions on offence, conflict resolution, and the ability of participants to elect leaders and modify rules. Cooperation works because participants monitor each other and are able to sanction or exclude cheaters. Over time, social norms often evolve where the preference to follow the rules is internalized. This allows for high levels of cooperation, without the need for close monitoring or costly sanctioning.

Organization 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 external authority such as the state.

Ostrom et al. (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. The threat of sanctions could in this setting 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.”

Self-organized collective action applies not only to fishing communities but many types of modern organization. Ostrom specifically discussed knowledge as a common pool resource whose production could be self-organized (Hess and Ostrom 2005). One challenge is that defining the community in terms of users and contributors is more difficult in digital information than e.g. fisheries. Schweik (2005) further discusses the institutions governing open source software.

Users are more likely to lack common understanding and to experience conflict of interests in large and complex resources. This makes the costs of sustaining large and complex resources higher than governing smaller, more homogeneous resources (Ostrom et al. 1999). The high degree of complexity and often large scale may be a problem for creating health care commons. The digital information commons have worked well despite high complexity and a large and dispersed community – perhaps in part due to the compensating effects of low costs of communication. Hess and Ostrom (2005) write “One of the surprising developments of global digital commons, such as the Open Source movement, is the high degree of cooperation and coordination that has been achieved by apparently disparate individuals, many of whom never have face-to-face contact”

Health care as such is not a common. Resources are generally privately or publically owned, and users can easily be restricted. Moreover, unlike a classic common such as grazing land, users of health care in the form of patients rarely participate in production. Defining health care as a common would stretch the definition too broadly so as to make 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 et al. 2001, McGinnis 2013).

Due in part to technical complexity, modern health care is a fragmented field where many different professionals and organizations often cooperate in devising new treatments and providing care (McGinnis 2013). Specialized knowledge is often spread in different actors that must work together in innovation and the provision of complex care. It is common for complex health programs to require the coordinated efforts of participants with diverse skills rather than being fully under one actor. Stakeholders can include different physicians, technicians, hospital administrators, regulators, research organizations, professional associations, private pharmaceutical and medical device manufacturers, community service organizations and patients.

McGinnis (2013) writes: “Although most do not realize it, participants in these programs are learning how to manage common property, that is, resources which are made jointly available to a specific group of individuals, each of whom has only limited rights to the use of that resource, since many consumption and allocation decisions must be made by the group as a whole."

Because several participants collaborate and have a joint stake in the outcome, complex health care programs have elements of common property and can, therefore, be seen as micro-commons. Like other commons, improved stewardship of collaborative health programs benefit all involved actors but require rules and non-hierarchical cooperation.

Health care systems in total are, however, not commons but rather public or privately owned, with clear boundaries of control and property rights (McGinnis 2013). One example can be a health care program where hospitals, research universities, public agencies and private medical companies work together in provision and innovation of a particular treatment. The individual actors are not commons but either public or private organizations. The joint elements of the program, though, are in part a common pool resource.

However, there are even more pure examples of health care commons. In unusual circumstances, health care providers and other parts of the community have self-organized to provide health care outside of public or private property in surprisingly large scale.

Open Source development is a common feature of rapidly developing industries (Von Krogh and Von Hippel 2006, Dahlander and Gann 2010). In the late 19th and early 20th century open source development was common in the then cutting edge heavier than air aircraft community. New innovations were readily shared – under the assumption that it was better for each individual inventor or developer to be able to use the advanced made by others. Most inventions was patented, but patents was not enforced by the patent holders (Meyer 2014). The same phenomenon is not present in the software industry where proprietary software companies are challenged by open source software (e.g. Linu, Apache, Mozilla, MySQL) that are developed collaboratively (Raymond 1999). The research on open source have primarily focused on how these project come about and how to improve the efficiently of such development projects (Feller and Fitzgerald 2002, Hippel and Krogh 2003, Von Krogh, Spaeth et al. 2003, Capiluppi and Michlmayr 2007). A subset of this literature explores the motivations behind participation in open source development, results that there can be applied to wider fields than software (Hars and Ou 2001, Kogut and Metiu 2001, Von Hippel 2001, Lerner and Tirole 2002, Hippel and Krogh 2003).

2.3 Institutional and Evasive Entrepreneurship

Institutional entrepreneurship refers to how entrepreneurs are influenced by and influence institutions (Henrekson and Sanandaji 2011). Entrepreneurship typically refers to business activity. More fundamentally, however, it includes all innovative activities aimed at change, not only firms. Other categories include “social entrepreneurs” who create non-profit organizations(Boettke and Coyne 2009), “political entrepreneurs” who recombine resources in the policy arena to bring about reform, and “community entrepreneurs” who organize to provide local public goods (Schneider, Teske et al. 2011).

According to Schumpeter (1934), the defining characteristic of entrepreneurship is not earning profits but disrupting the current equilibrium inherited from the past. Business entrepreneurs who change the market equilibrium with new technologies, products or organizations are one important group, but the term can be applied to other actions which bring about dynamic change. The Swiss businessman Henry Dunant is not famous for his private investments but for founding of the Red Cross, for which he received the first Nobel Peace Prize in 1901. Another example of non-profit entrepreneurs includes Jimmy Wales and Larry Sanger, who in 2001 created Wikipedia. Like for-profit entrepreneurship, The Red Cross and Wikipedia were innovative initiatives that required novel ideas, alertness to opportunities, risk taking and organizational effort.

Entrepreneurs act within the rules of society often referred to as institutions. Formal written institutions include laws, property rights and regulations, whereas informal unwritten institutions include as traditions, cultural practices and norms (Acemoglu et al. 2005). The concept of institutions is not perfectly defined, but the most common definition in institutional theory is that defined by North (1990) “Institutions are the rules of the game in a society or, more formally, are the humanly devised constraints that shape human interaction”. This is close to the definition in Ostrom et al (1990): “Formal and informal rules that are understood and used by a community.” Institutions such as property rights, rules, market structure, the political system and social norms largely regulate society and influence the extent to which entrepreneurial talent is directed toward productive or unproductive activity (Baumol 1996).

Entrepreneurs can in turn work to abide, evade or alter institutions (Henrekson and Sanandaji 2011). The abider might adjust the organization to minimize cost of both compliance and of doing business.

An alternative is to try to change the restrictive regulation. The most common way is by means of lobbying. Lobbying however comes with coordination problems. For each individual company the best strategy might be to let someone else organize and pay for the lobbying activities – as they therefore could reap the benefits without paying the prize. Lobbying is therefore often conducted by trade organizations which are able to overcome the coordination problems (Olson 1971). The flipside is that lobbying will be seldom used if the regulation only affects a small number of companies or persons.

An alternative to lobbying could be to evade the regulation. In this case it might even be better for the (successful) evader if the regulation stays in place as he then might capture the economic rents created by the regulation.[1] Border shops belong to this category. They thrive on the difference in prices (and taxes) between countries – by offering low taxed goods to the residents of the high tax country – and would be out of business if the high tax country cut taxes.

Here, however is a difference between for profit and nonprofit. A nonprofit organization will not usually be interested in capturing rents but to provide a service. In this case the entrepreneur would welcome others to do the same – and would prefer that limiting regulations are abolished.

If the regulations are appropriate and effective, both lobbying and evasive entrepreneurship can make “wrong” regulations disappear. If the regulations are ineffective or have been corrupted, at the same time evasive entrepreneurship can lead to them remaining, but some may circumvent them. Here, society as a whole had served to lobbies instead of changing the regulations. If some organizations manage to evade the regulations it might contribute to the continuing existence of these inefficient regulations.

However, evade could also be a lobbying strategy. A company might exit a market in order to incentivize the politicians to change the regulations, one example is to refuel its vessels (e.g. ships and planes) in another country where the fuel taxes are lower. Here, the evasive activity might be costly to the entrepreneur as the tax difference might be less than the cost of the detour, however, as the high tax country loses revenue it might be incentivized to adjust taxes to get the revenue back. This could be called weak evasive entrepreneurship.

Another difference between lobbying and evasive entrepreneurship is that lobbying generally is a costlier strategy for the lobbying organization since it requires capital expenditure up front but the benefits (if any) will be reaped only in the future (when the regulation is abolished – or even later as the lobbying organization also need to adapt to the new environment). Evasive entrepreneurship on the other hand, if successful, will provide benefits to the entrepreneur right

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[1] Uber spends significant resources on lobbying, not primarily to deregulate taxi services but to prevent the taxi regulations to cover their operations.

from the beginning. This might explain why lobbying primarily is the strategy of incumbents while startups or challengers will probably prefer to evade regulations.

3. Cases of Open Care

The empirical foundation for this paper is a large number of historical and contemporary cased of open care. The method used is the multiple case study (Eisenhardt 1989, Eisenhardt and Graebner 2007). The cases have been collected using a variant of chain referral sampling, also known as snowballing (Salganik and Heckathorn 2004).

Open care, as a concept, does not exist in previous research (other than as a synonym for “outpatient care”) and therefore it is difficult to collect project information using just one search method. We have used a number of methods in order to find projects – and also used them iteratively. Cases are collected from previous literature (albeit the term “open care” is not used we have found useful previous studies on the field in medicine (Aring 1974), institutional economics (Gurses and Ozcan 2015) organization studies (Segal and Lehrer 2012) legal history (Glennon 2011), public administration (Van Slyke 2006), history (Beito 1999) and sociology (Borzaga, Fazzi et al. 2016)), an online survey[2], an online forum (“Edgeryders”), blogg posts on well-read blogs with calls to provide examples as well as projects collected by other participants of the Open Care consortium. We believe one important reason is that at this stage of development, the concept remains undefined and overly abstract for most people. Once the concept is better explained and understood, many may find it easier to point to activities that are in fact open care health.

The cases are analyzed using historical cognizant methods (Muzio, Kirkpatrick et al. 2011, Kipping, Wadhwani et al. 2014). There are thousands of organizations that engage in open care today and historically, in tens of distinct areas. The intention with the case collection is therefore not to evaluate all open care projects but to obtain a sufficient number in order to find the key characteristics for institutional and policy analyses.

The historic cases show that what we refer to as open care is not a new phenomenon but was a viable method to provide care in many countries prior to or parallel with the emergence of the modern health care system. There are of course many contemporary cases of open care, with great variation in organization and health domains. We here go through some cases to illustrate the wide range of activity that open care includes and to inform the theoretical and policy

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[2] This method only had moderate success and produced a handful of cases, with many readers pointing to the same case. We believe one important reason is that at this stage of development, the concept remains undefined and overly abstract for most people. Once the concept is better explained and understood, many may find it easier to point to activities that are in fact open care health.

analysis. We give more examples of contemporary cases than historic cases, and therefore shorter descriptions for each.

3.1 The Voluntary Hospital Movement

Community organization of healthcare has long historical roots. Throughout much of European history, the state had limited role in the provision of health care. Instead, local communities organized health care. Nordic regional medieval legislation indicates that health care provision rested with the extended family before the arrival of Christianity. During the late Middle Ages a more sophisticated form of self-organized health care evolved through the craft guilds. The guilds created mutual assistance associations in which members collectively funded a form of health insurance, and were in return provided health services when in need. The first recorded guild funds date back to the 14th century (Saltman and Dubois 2004).

During the early industrial revolution, a new form of health provision developed in Britain through a large number of private voluntary hospitals. The English voluntary hospitals have been referred to as the “flagship of the voluntary movement” (Cherry 1997). They relied on philanthropic gifts had unpaid labor of both medical staff and management committees recruited from the local elite (Waddington 2003, Gorsky and Sheard 2006).

Hospitals provided superior health care services but were expensive. The growth of this modern form of medicine was the manifestation of an organizational or institutional innovation in the form of associated charity, where a large number of agents contributed funding and effort without centralized direction (Borsay 1991, Gorsky and Sheard 2006). Prior to the development of associated charity hospital were only possible through the rare donations of single wealthy benefactors. Voluntary hospitals broadened their appeal through the model of subscriber democracy, where the supporters of the organization received a voice in how money was spent (Morris 1983, Waddington 2003). This prevented fraud and mismanagement and could also ensure that communities such as the working classes were not excluded from resources by elites.

The voluntary hospital movement relied on high social capital and a genuine communitarian involvement, through representation, fundraising and a sense of ownership by the local population (Shapely 2016). The hospitals enjoyed broad support and often pride in the community across. The hospitals were initially an institution developed and funded by the elite and middle classes, but gradually also broadened them appear to working classes. The English working class had their strong traditions of charity and self-help (Waddington 2003). While working class supporters of hospitals could not afford the sums donated by wealthier funders, they provided large sums through donations from regular collections and local appears where large numbers each gave a little. A strong motivation was to acquire access to hospital treatment for their communities.

Voluntary hospitals combined traditional philanthropy with elements of open care. Though the link was not direct, donating fund or labor to private hospitals led to a better chance of being admitted as patients should the donor or their dependents require treatment, making donations a quasi-insurance. Shapely (2016) writes that voluntary hospitals “created the unusual situation where workers were only but also producers of hospital services”. Patients who were capable would often also provide simple labor in day to day operations of voluntary hospitals such as nursing other patients, sewing, cooking and cleaning (Horwitz 2007)

The voluntary hospitals were eventually replaced by the public National Health Service in the 20th century. The need to finance activity through donations limited their ability to expand as medical services increased in complexity and cost, and gifts gradually declined as a share of revenue. While eventually supplemented, for voluntary hospitals contributed with important innovations in modern medicine and service organization. The movement emerged without central planning due and left a lasting influence on the public hospitals which in many ways followed in its footstep.

3.2 Friendly Societies in England

One of the countries with the strongest and earliest developments of modern civic society and mutual aid associations was England (Shapely 2016). The poor and working classes in premodern England had to rely on the state or charity for social services. The development of mutual aid networks which pooled resources provided a third option. Charities funded by higher social classes treated the poor as clients in a one directional relationship and were associated with a stigma. By contrast mutual aid had an egalitarian structure and conferred active involvement and democratic rights. Workers club received contributions from the members, which gave them the right to have expectations for welfare without the need to feel as paupers.

Aside from trade unions, the perhaps most important type of mutual aid was so called friendly societies. These were self-governing mutual associations that provided an early form of sickness insurance. Unlike most other types of civil society, friendly societies had roots in a much older association, namely medieval guilds (Gorsky 1998). Late medieval craft guilds in both England and the Netherlands had developed the practice of pooling alms to a common locked chest as a type of insurance. The guilds provided mutual support by visiting the sick, attending funerals and providing financial support. The associations upheld cohesion through regular gatherings, ritualistic ceremonies and annual festivals. This fellowship and social ties created in the clubs allowed moral hazard to be held in check.

As the economy changed and guilds declined in importance, friendly societies emerged which copied several practices from guilds and filled the gap, but which were not restricted to a particular craft and could be founded freely for any “odd fellows” (Gorsky 1998). The clubs often centered in ale-house clubs and involved regular drinking and engaging in ceremonial acts. They were democratic organizations which pooled membership monthly fees used to provide sickness benefits and funeral expense, where bembers were both consumers and mutual guarding of joint resources. The great British economist William Beveridge known for his pioneering work on the welfare state referred to sickness insurance as “the invention of friendly societies” (cited in Gorsky and Shepard 2006). Similar to guilds, members also provided other types of solidaristic practices such as visiting the sick and attended funerals. Peer visits also had the benefit of ensuring that those who received sickness insurance were indeed ill.

The clubs had supported in parliament who wanted to encourage mutual aid as a complement to poor law reforms. The first Friendly Societies Act in 1793 granted friendly societies various privileges in return for registration. Following this legislation, many occupational clubs registered as friendly societies, continuing the evolution of guilds into clubs. The difficulty in obtaining health services through the Poor Laws encourage mutual sickness insurance as an alternative (Gorsky and Shepard 2006). The strong demand led to the rapid expansion of friendly societies and the creation of new ones, which were regional but not limited to any specific occupation. Estimates of membership are unprecise and vary, but one approximation is that in 1803, a quarter of English male adults belonged to societies (Gorsky 1998). There were an estimated 27,000 friendly societies operating in the United Kingdom alone (Bennett et al. 2004).

While the most prominent case, England is far from the only country where this type of mutual aid developed, and similar mutual health insurance associations existed in other countries. In France and Belgium, friendly societies were referred to as *sociétés de secours mutuels*. German mutual insurance was part of the widespread *Gemeinwirtschaft* cooperative movement and termed *freie Hilfskassen*. Friendly societies of the English model were widespread in Ireland, Australia, New Zeeland, the Caribbean and other parts of the anglosphere (Buckley 1987, Bode and Evers 2004, Downing 2012). Also in Japan, community insurance scheme referred to as *Jyorei* was created in 1835 in one village to ensure the presence of community-based doctors in their villages through contributions mainly in the form of rice, a successful scheme copied elsewhere (Ogawa, Hasegawa et al. 2003).

At first, friendly societies in England provided cash insurance to the sick and employed doctors to assess claims. The medical attendant was also the arbitrary of actuarial risk, checked the health of new club applicants and confirmed lying-in claims of sick members. Later in the early 19th century the practiced develop to employing doctors to provide medical care to members, often in the home of the patients. One reason clubs employed own doctors in addition to paying out cash was that they had bargaining power over doctors. It became more common that friendly societies provided both sickness insurance and medical services through employed physicians. In the initial phases of the expansion of the welfare state, parts of the British welfare state were administered through friendly societies, where membership was compulsory for many workers. The Germany public health insurance system developed by Bismarck similarly absorbed the character of the German mutual insurance associations (Bode and Evers 2004). The mutual insurance systems were important precursors of the universal health insurance program also in Japan and several other countries.

The friendly societies and other mutual aid clubs eventually declined in 20th century as the welfare state nationalized health care and health insurance. The decline of mutual-aid organizations after the emergence state substitutes points to limits of this type of organization. Members were paying consumers and involved in order to receive individual benefits and lost interest when the organization was no longer useful to themselves, they did not go along with mutual-aid for the sake of it (Shapely 2016). Mutual aid associations in health were often innovative and ahead of public sector in identifying needs and developing solutions, and left an important legacy by influencing the growth of the welfare state. They introduced innovations that were adopted by the British National Health Insurance, such as the system of panel practice by which doctors were contracted (Gorsky and Sheard 2006).

3.3 Black Fraternity Hospitals during Segregation

One of the most impressive historic cases of self-organized community health was achieved in the poorest parts of the American south, the rural Mississippi Delta (Beito 1999). Until the mid-1960s, African Americans in this region were excluded from regular health care white hospitals by segregation and racism. Many hospitals simply banned African Americans and refused to admit them under any circumstances. Other hospitals admitted black patients but gave them inferior second-class treatment under humiliating conditions. African Americans could not enter the front door and were forced to enter the hospital in side entranced marked “colored”, and often placed in the basement of the hospital near coal furnaces. White segregated hospitals often required blacks to bring their own eating utensils, sheet and toothbrush so as not to mix with that of white patients and pay extra for black nurses. In addition, the black population in rural parts of the Deep South was one of poorest groups in the United States and could often not afford private hospitals, while the state and local public were hostile to funding black health care.

The response to this treatment in Mississippi as well as other parts of the south was a surprisingly successful and largescale movement to create black fraternity hospitals, relying on traditions of mutual aid and self-help in the black community (Whaples and Buffum 1991, Angell 1994, Beito 1997, Beito 1999). This was achieved by the fraternal orders, an association type involving clubs and lodges, regular social activity and a strong element of symbolism such as secret passwords, parades and ritual. Well known examples remain today as university fraternities or the type of "Loyal Order of Moose" and the notoriously secretive Free Masoners. In historic United States this type of club was highly vibrant, and the late 19th century and early 20th century has been referred to as Golden age of fraternalism, with a high percentage of the adult male population belonging to at least one order. The element of ritualistic behavior, hierarchy and the overall depth of involvement in lodge practice were higher than European friendly societies, and not mainly focused on providing health insurance and health care. However, many fraternal orders provided health care services, not the least among minority groups. This was done through mutual insurance and contracting doctors to and in some cases creating hospitals. (The fraternal orders in addition upheld strong norms of education and temperance which could have been indirectly linked to health.)

African Americans as well as immigrants such as the Cuban community in Florida created a large number of cooperative medicine programs and mutual health organizations in this period (Long 1965, Mormino and Pozzetta 1985, Beito 1999)

The Taborian Hospital and the related Friendship Clinic in Mississippi is a prominent case of this widescale historic phenomenon, and were funded by "The Knights and Daughters of Tabor" in the 1940s. The initiative and organization were provided for by middle class blacks, but the rank and file were mostly poor farmers and workers who each donated small amount. Despite these challenges, the Taborian Hospital was successfully operated for over two decades, as described in detail in Beito (1999). Many donations to the hospital were in kind, such as washcloths and soap. Professional medical staff including black doctors received a low salary, and much of the labor was provided for by internal training local residents without medical certification. The hospital used for the time modern equipment and conventional medical technology, but was resource-strapped and often overlooked work and building regulation such as storage and bed space and rules against excessive reliance of uncertified personal. This allowed the cost of providing hospital care to be reduced to accommodate the poor target group, while medical outcomes seemed to have been comparable to other rural American hospitals (Beito 1999).

Interestingly, this was possible since white politicians in Mississippi intentionally overlooked the circumvention of regulation by self-organized black hospitals in order to avoid having to pay medical services for black patients. The light-hand of regulation from the state was paradoxically a tacit understanding between African Americans and their supporters in the white community and segregationist politicians who wanted to avoid spending taxes on blacks or having them attend white hospitals. Beito (1999) writes:

> One of the factors that contributed to the success of the hospitals was a lack of state regulation. This environment had been fostered by Mississippi's history of rigid hospital segregation and low welfare spending. Many white leaders feared that, if the hospitals ceased operation, white taxpayers, doctors, and planters would have to pay the medical bills of poor blacks. Therefore, regulation was virtually non-existent. Officials of the Mississippi Hospital Commission rarely, if ever, bothered to inspect the facilities.

The fraternal hospitals were locally popular, but eventually declined due to institutional and technological development. The rising costs of health care and medical technology made it more difficult to operate on a low budget and forced more patients to purchase health insurance. A related and important factor for the decline of Taborian Hospital as well as many other fraternal hospitals in the United States was that higher cost of healthcare was followed by the growth of third-party payer method of finance, either by employer provided health insurance or the state. Beito (1999) writes: "Since World War II there has also been a slow demise of fraternal hospitals and hospital plans that did not serve blacks, such as the Security Benefit Hospital, the Latino hospitals in Tampa, and the hospitalization services of the Woman's Benefit Association and the Independent Order of Foresters. While the reasons varied greatly, all suffered to some degree from the rise of third-party insurance and the opposition of organized medicine to contract practice."

The decline of minority fraternal hospitals was also due to positive social change which eventually allowed patients more options, such as driving to city hospitals, the abolishment of segregation and that the federal government in the 1960s started to pay greater interest to providing healthcare to neglected communities in the south. For the period when they were needed, the hospitals were greatly appreciated and a source of pride of the ability for self-help in the community. The black fraternity hospitals also represent a highly interesting historic case for analyzing evasive entrepreneurship and the institutional factors that enable and limit open care.

3.4 Community Psychiatric Care in Geel

The Belgian town of Geel of about 40.000 inhabitants is known for its unique tradition of foster family care for the mentally ill (Aring 1974, Goldstein and Godemont 2003, Feldman 2012). The fascinating background can be tracing back to the middle ages. In this region a legend long existed about the 7th century Saint Dymphna credited with miraculous healings of the mentally ill and viewed as their patron saint. With the dissemination of her legend, Geel became a site of pilgrimage and renowned as a center for the treatment of the mentally ill hoping for a cure. Since many miracles of cures by the mentally stricken was reported, the catholic church canonized Saint Dymphna in 1247 AD. The influx of the ill continued, and in 1480 the church built small infirmary in the Geel cathedral. This infirmary was inadequate to deal with the ever-increasing number of patients, and as it overflowed the townfolk started to house the patients. During the Renaissance, Geel became famous as a place of sanctuary for the mad, and the populace became accustomed to the mentally ill who they absorbed as an act of piety in return for menial labor in farms.

This system of borders for the mentally ill has persisted as a two-layered system with family care supported by a medical safety net. A relatively low incidence of violence is reported, and adherence is high (Feldman 2012). Each family has a psychiatric nurse assigned to them, and has access to hospitalization if necessary. Goldstein 2003 writes: “The history, evolution, and current status of this system demonstrate that those with serious mental illness (SMI) can be successfully integrated into community life. Furthermore, it suggests that acceptance by the community itself may be one of the most important variables contributing to such success.”

Boarders are integrated in the family and neighborhoods, given the opportunity to do meaningful work and welcomed in pubs, stores and other establishments. The exposure to and experience with mental illness enables a high tolerance and acceptance of deviant behavior by the mentally rather than unease.

A key to this model is the lack of stigma attached to mental illness and effort by the population to be protect rather than fear the patients. The Geel model of Community Psychiatry is often cited, but difficult to replicate outside the town (Feldman 2012). This is likely due to the fact that it based on a rare local culture that evolved over centuries and is bolstered by local pride over Geels distinct historic traditions.

3.5 Community-Based Insurance in Low-Income Countries

Community-based insurance is often used often in rural areas in developing countries to provide financial protection from the costs of health-care, relying on prepayment, voluntary membership and community control (Mladovsky and Mossialos 2008).It is interesting that poor, underdeveloped parts of the world rely on an association form with many similarities to historic in 18th and 19th century mutual insurance Europe and Japan.

Community-based insurance schemes generally involve prepayment, links to a local hospital and an ethos of solidarity mutual aid. There are hundreds of these programs across Africa, India and other parts of the third world. Payments are regular and typically cash, but sometimes in kind, such as agricultural products. Not surprisingly, the success of Community-based insurance is linked to high levels of social capital (Donfouet and Mahieu 2012).

International aid agencies often support Community-based insurance, both as a short-term solution and in the hopes that mutual insurance is transitional mechanism that will evolve into universal public coverage, as it did in Europe and Japan .(Criel and Van Dormael 1999). The sustainability of Community-based insurance schemes has however been questioned, and it is interesting to note that most of the programs are top-down interventions led by aid agencies or the state rather than bottom up initiative by farmers, workers and employers as in Europe and Japan (Mladovsky and Mossialos 2008).

3.6 Greek Metropolitan Community Clinic

Greece in modern times was generally a country with a relatively weak civic society and low citizen engagement, but the pressure of the deep financial crisis led to astonishing increase in the volunteer sector. In a short time, Greece developed an unusually active of social solidarity groups that in part supplemented the failed welfare state, not the least in the health care sector (Sotiropoulos and Bourikos 2014).

Health care provision in Greece faces major difficulty following the financial crisis, which brought the public to the brink of bankruptcy and, in addition, led to many Greeks losing their jobs. In Greece, the national health service is tied to employment. High unemployment led to many unemployed Greeks losing their insurance, virtually lacking access to public health care and no money to pay for private clinics. One response to institutional failure was Metropolitan Community Clinic, a self-organized initiative evading existing institutions to provide health care to those lacking health care. Cottica (2015) writes:

> This is a very strange animal as health care providers go. It has no legal existence. Its literature proudly proclaims: “MCCH is a volunteer organization without Legal or Taxable status and it is not a ‘Non-Profit-Making-Organisation’.” Maria: “We are technically illegal.” It does not accept donations in money. It does accept donations in kind: medicines, equipment, blood sample analyses. It operates from a building that belongs to the Municipality of Helliniko-Argyropoulis. Though none of its employees works in the building, the Municipality still pays the electricity and phone bills that the MCCH generates.

The municipality accepted this arrangement by counting to pay phone and electric bills. The perhaps most noteworthy feature of this Open Care case the sheer size of the Metropolitan Community Clinic, with tens of clinics. Traditional economic theory would have concluded that this arrangement is impossible, and the example serves as an illustration of Ostrom’s Law that “A resource arrangement that works in practice can work in theory” (Fennell 2011)

3.7 Japanese Health Co-Operatives and Self-Monitoring

Japan has a long history of co-operative movements in health, and one of the largest and most active associations for open care. An estimated three million Japanese are members of health co-operative and neighborhood mutual help groups. The co-operatives operate a large number of hospitals and clinics. Most interesting is the cooperative mass movement in self-monitoring, health knowledge and preventive measures (Kurimoto and Director 2011). The neighborhood “Han” well-being groups with teach each other to monitor their own blood pressure, measuring salt content in bodily fluids, and even checking their teeth, with the initial help of nurses. Members with signs of health problems in self-monitored tests are encouraged to see doctors at the health coop. Member inform each other about conditions such as diabetes, stroke, dementia and risk factors such as stress, diet, drinking and smoking. The member of these small groups aims for various healthy habits and measures indicators, and some engage in activities such as exercise. Mutual peer-to-peer support is complemented by that of health professionals (The Being Well Project (2017).

Members are encouraged to attend courses and become cooperative “health advisors” who then lead voluntary activities within Han groups. The aim is to reduce health care costs and prolong healthy life by preventive measures, by increasing consciousness about health, improving diet and thought early detection and treatment of illness.

From time to time, member volunteers conduct “open air health checks” for the general public in front of supermarkets or in community facilities as part of a coop campaign for health promotion. This Japanese open care case is interesting since it uses simple and effective methods to prevent health care costs through prevention, rather than costly medical intervention after health problems occur.

3.8 Self-Organization of Health Care for Refugees

The migrant camp in Calais has been referred to as “the jungle”, where thousands of migrants were residing aiming to make the crossing to the United Kingdom between 2015 and 2016. Before actions by authorities to clear it out, The Jungle was Europe’s largest informal refugee camp. Health conditions were described by many organizations extremely poor (Sandri 2017). That of the camp lacked regular services which led to an impressive range of self-organized actions during a short time, with churches, mosques, schools, a library and a theater being created by the refugees. The migrants are in many cases undocumented and lack access to regular health care, a gap which was filled through volunteer groups and community organized care. British medical students traveled to Calais to provide aid, stretching regulations that restricted requirement for formal credentials.

A self-organized clinic run by Doctors Without Borders also operated in the camp, using both doctors and staff without formal medical certification. The clinic operated in harsh conditions, both being outside formal law, exposed to security risks and lacking running water and electricity. While initially located on the outskirts of the camp, as the number of tents grew, so the clinic became geographically enclaved in the camp, restricting the possibility of rapid evacuation of patients. The clinic operated during daytime. At night and during weekends, the equipment was removed from the clinic for security reasons.

A French taskforce recommended the French government to provide funds for development of the self-organized clinic in the massive refugee camp, an eventually the camp was cleared out in response to the poor conditions. The Calais refugee and others makeshift refugee clinics like it are examples of evasive entrepreneurship open care in response to gaps in regular healthcare.

Similar self-organized health activities have been directed to migrants residing in refugee camps in Greece, again as a reaction to the lack of publicly funded health care (Sotiropoulos and

Bourikos 2014, Sandri 2017). 1While these measures are undoubtedly a second-best emergency solution, it emerged quickly to respond to undoing disaster in the shadows, and thereby pointed the state to the unfulfilled medical needs on the ground.

3.9 Patient Organizations Groups

One of the most important current association forms for open care is patient organizations. These often involve both patients, their family, engaged volunteers and medical professions with specialization in their health problems. The associations act as knowledge brokers from both patients themselves about symptoms, drugs, side effects, psychological issues of dealing with the illness as well as specialized medical expertise. In many cases, the health advocacy groups also inform the public sector and represent a link to hospitals, drug companies and other stakeholder. This type of open care has grown in importance following the development of digital technology which allows more patients across different countries to be linked and lowers barriers to communication. Patient organizations have played an important role by bridging advanced information to patients in a credible way.

The role of specialized health advocacy group has also grown as the store of medical knowledge grows while new advances in in molecular diagnostics identify more rare diseases and stratify common ones. The increased amount of information and added complexity of decisions and involved in healthcare makes it important to have skilled organizations trusted by patients who contribute to the medical system (Nicholas and Broadbent 2015).

The opportunities allowed after spread of the internet has been exploited by a range of entrepreneurial individuals in various, in many cases ahead of the medical establishment. A European developed example of a social patient communication platform HealthUnlocked, is a peer-to-peer support network through which individuals with health issues can communicate safely online, with guidance from credible organizations. The platform 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.

A review by Nicholas and Broadben 2015 shows to the entrepreneurial role played by patient organizations groups in utilizing new technology in e-health and collective intelligence. Due to their knowledge base and passionate members patient organizations are one of the foremost modern types of open care with potential both to scale, grow in numbers as well as and increase their partnership with the public sector.

3.10 Open Rampette

Open rampette is an initiative in the municipality of Milan to improve accessibility to stores for those in wheelchairs who need ramps and other aid to cross obstacles, including maps of accessible stores and smartphone “bells” which notify shops to request assistance from participating shops.

Interestingly, this health-access project is not conducted by profit firms but by the WeMake community, a technology workshop which provides a lab and advanced equipment for inventors who engage in co-design projects. This community creates open-source technology and relies on volunteers to develop prototypes and tech solutions. WeMake and similar initiatives rely on the ideals of open source, sharing of ideas and intellectual property and collaboration with a broader set of stakeholders such as citizen.

Unlike for example Wikipedia, this creation mode is extended to physical invention and tool making using 3D-printers and laser printing machines to develop porotypes in addition to the input of information. The participants are motivated by philanthropic goals, private enjoyment and the skill accumulation of engaging in developing modern new technology. As the health sector is knowledge intensive, extending the open source model into physical invention and development of broader health infrastructure can potentially offer large gains. This type of open source is however more challenging to uphold than data entry since it requires large costs of running the lab and offering equipment in addition to motivating high-skill inventors to donate their time.

3.11 Open E-Care and Digital Platforms for Health Information Sharing

A growing 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 and Broadbent 2015). One such online platform is PatientsLikeMe, which was founded in the United States in 2004.

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 massdata 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. 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). A French equivalent to PatientsLikeMe, Carenity, is now established in several European countries. Castejón et al. (2013) report that also data from this patient communication platform can be useful in scientific studies.

A number of social patient communication platforms are currently being developed. An example is Hungarian PraxisPlatform. Besides facilitating communication between patients, the platform also serves as a way for health care professionals to communicate with patients. The latter role is filled through sending therapy-related information to patients to increase their adherence/compliance in medicinal therapy and medical device use. Through the online platform pharmacy care services to large patient populations can additionally be carried out. PraxisPlatform is an example of how a single platform can fill two different roles: firstly e-healthcare, through which the traditional health care system can reach out efficiently to patients at typically low costs and secondly 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 synergy effects for patients as well as health care professionals. This might for example occur since patients can through the same platform receive complementing forms of information, and also since the burden of health professionals to reach out with online information can be reduced if patients can receive part of the information they seek from other patients. Patients can through forums also help each other better understand the information given by health professionals.

These might occur, 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.

Needless to say, it is important to develop mechanisms to verify the credibility of patient medical information. A study of reviews written on amazon.com about cholesterol reduction and weight loss products by de Barra (2017) showed that patients with good treatment outcomes were more inclined to share information about their treatment, distorts the information available to others. Barra concludes that electronic and verbal word-of-mouth of health products given a biased and overly positive impression of the curative value of that treatment compared to results reported in clinical trials. This study is not of interactive open care, but points to the risk of unfiltered user generated medical data.

3.12 Communication Platforms Linking Health Care Providers and Patients

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. Klarahas 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.

A similar platform in Europe is ENJECT, a European project focusing on promoting new models of healthcare delivery incorporating digital and mobile technologies. 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.

3.13 Rare Disease Communities

Another 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 and Broadbent 2015).

3.14 Peer-Based Mental and Addiction Support

Similar to patient communication platforms, Peer health education is a form of crowdsourcing for knowledge transfer in health care. Examples include communication towards young people regarding sexually transmitted diseases. Peer-to-peer education and support has also been used by other types of patient organizations and associations for support and knowledge-sharing, such as Alcoholics Anonymous (AA) who rely on peer-to-peer support where members utilizing their experience of substance abuse to assist each other. The concept is based on individuals of similar age or status participating in sharing health information, which increases credibility and persuasiveness of the message for the target group. Another is that talking to an individual with similar background, interests, and use of language makes it easier to discuss sensitive personal information.

An example of peer-based mental support in Europe is “First Person”, a regional federation in Spain for people with mental health problems. The organization is focused on fostering self-managed associations made up of people with mental health problems in different provinces of

Andalucia. The main areas of the federation activities are the following: peer support and recovery through workshops, training activities and meetings, development of guidelines, actions of support, supervision and advice. The website is used as a platform for a virtual network of mutual support, and in addition training activities and meetings aim to combat stigma and social discrimination. As the use of internet grows, online forums are increasingly used for mutual support groups such as these.

3.15 Digital Platforms for Mass Data Analysis

A recent trend is the interest to incorporate genomic information in platforms built upon detailed patient information. Organizations such as 23andMe have made it possible for large groups of people to carry out genetic tests at a relatively low cost. Geneix is based on analyzing the raw data from personal tests, and merges this with information about the patient's reaction to drugs. This allows for the creation of drug-gene profiles, so that when doctors prescribe a new medicine they may be alerted of possible pharmacogenomics interactions. This type of platform can rely on pharmacogenomics interactions available from research literature, as well as the information made available by individuals who share tests about their genomics and drug reactions. The more individuals that analyze and share their genomic information and experience with various drugs, the more information will be available for pharmacogenomics interaction analysis platforms. Similarly, Reg4All is a platform for patient organizations to manage registries and biobanks of members and collect data using surveys about health information, allowing patient organizations to design condition-specific questionnaires. Although patient information sharing is a part of the platform, the main objective for the data-gathering is to facilitate research activities and clinical trials (Nicholas and Broadbent 2015).

A major current challenge in health care is that drug response and disease progression may vary significantly from one patient to another. The rapid development of biotechnology has allowed for the identification of potential biomarkers that may aid in the understanding of why patients respond differently to diseases and treatments. However, knowledge gaps remain in puzzling together the data from biomarkers to that of patient outcomes. Pharmacogenomics interaction analysis, based on mass data, can allow for the pieces of this puzzle to be matched much more rapidly than what would otherwise have been possible to achieve (Chambliss and Chan 2016). The information gathered and analyzed in various platforms coupled to biomarkers are highly valuable for health care research since they significantly reduce cost and time needed to gather data.

4. Analysis

4.1 A Taxonomy of Open Care

We have classified the cases found into four general groups. Open care projects are often complex and may have elements which fit several categories at once in overlapping ways, and the projects could be categorized in more than four categories using more refined definitions. This broad categorization is nevertheless useful for policy analyses.

The first category of projects consists of collective intelligence and other forms of aggregation of knowledge. These projects provide large advantages when information is widely dispersed, for example sites where patients can compare symptoms or side effect of medication. Another example is projects where individuals can voluntarily share genetic and health information for research, which is dependent on large samples that are otherwise rare or costly, and where ethical concerns prohibits mandatory collection of data. There are also successful open projects that provide value by allowing patients to rate doctors and health care professionals. Open care projects of this type are scalable and work well regardless of how efficient the conventional health system works. As expected, IT plays a central role in facilitating this type of open collective intelligence care. Effective IT solutions lower the cost of participation and made geographic factors unimportant. This can, for instance, create sufficient critical mass for patients with rare disease or on rare medication to compile symptoms or share experience with patients in other cities or countries.

A second type of open care solution is locally organized medical services. This type of activity is common when the conventional system fails but is otherwise rare. When the conventional health system functions well, community organized health is not needed. Successful collaborative projects in community provision of health care often require a strong subculture or ideology that motivate participants, and are less scalable. Nevertheless, there are many subcultures and situations where this type of health can work. There are also emergency situations where there are benefits from self-organizing care, such as examples from refugee camps where there are many idle health professionals that can be put to work. This type of project is scalable, since there are many similar situations when the conventional system does not work well, as long as there is sufficient cohesion to self-organize care – in particular with external support.

These projects often emerge when formal institutions fail and are consequently rare when other health organizations function well. They may also emerge when the formal health institutions work well, but some individuals are excluded from their services (Beito 1999). To this category can also the aforementioned Geel community be counted; persons with mental illnesses was historically (and still is) not the most prioritized group in society. It was due to the specific religious and historical circumstances that the community in Geel came to organize the long-lasting care project for people with mental illnesses (Goldstein and Godemont 2003). Geel is not unique, although rare; other open care projects for patients with mental illnesses or disabilities organized by religious communities also exist (Van Walsum 2004). This type or projects often requires – such as in Geel – a common ideology or subculture. Faith has historically often been this common culture, but project based on political ideologies exist as well (Cottica 2015).

A third class of community care is where participation in production itself gives health benefits. This is usually the case for mental health therapy and addiction programs. There are several highly successful such models in Europe where participants with health problems, such as disability, help in providing health with therapeutic benefits for themselves. Addiction programs where participants both receive help and give support to others with similar experience and problems is a clear example. This type of health also tends to require strong subcultures, but works even when the conventional health system functions well. The reason is that the therapeutic effect of participation is not replicated by the conventional hospital system regardless of how efficient it is. Another conclusion is that there more examples of community-driven open care if health is defined more broadly than hospital style health care and includes health prevention, athletic programs, diet and mental care. These types of activity are less specialized and more suited to self-organized communities.

The fourth type of open care programs is not directly about health but use open solutions for the infrastructure of health care. Examples include open-source computer programs for the use of health providers that have been developed in order to reduce the often very high costs of intellectual property. This for example allows small clinics to provide cheaper health care to patients. There are a wide and growing number of such programs, which can be promoted or scaled up with ease.

4.2 Limiting Free Riding and Reducing Costs in Open Care

Several of the historical cases we found were organized within the framework of religious organizations – even though the activities as such do not necessarily have religious motives or elements. Many others are within organizations that are not religious as such but are motivated by other strong ideals. There are several plausible explanations for this. One is that these organizations can offer a complete organizational form. This reduces the barrier for those who want to start a project. The existing organization already has established decision-making processes and hierarchies that can be used directly. Those who want to offer care to, for example, migrants can do so without putting effort on developing bylaws on how the organization is to be organized.

Moreover, religious organizations offer a way to prevent opportunistic behavior without extensive pre-screening of participants. For those who are, for example, Catholic, it is not a big expense to visit the mass as part of the care service. Most non-Catholics on the other hand should see this as a cost. The same phenomenon can explain why activities historically were often conducted within the framework of fraternal orders. The rituals make opportunistic behavior more difficult and reduce the need for formal monitoring of participants. The reduced need for monitoring also will provide, ceteris paribus, more resources for care.

In addition, the participants may also be intrinsically motivated (Wasserman 2006). Researchers have emphasized that participants in projects of this type might be driven by a desire for ”growth, achievement, affiliation, self-actualization” (Davis & al 1997, p 28) but also autonomy (Davis, Schoorman et al. 1997) or trust (Hernandez 2008).

Open care organizations may also increase the attractiveness to some people and have easier to find the right people (Donaldson and Davis 1991, Van Slyke 2006). Segal and Lehrer (2012) write:” Indeed, the socio-political landscape of most organizations is permeated with bureaucratic controls, such as audits and surveillance, that signal a suspicion that corruption may erupt if employees are not monitored”. If the members share the same values it may also be easier to delegate.

Since many open care projects are about activities where those in need of care participate, the need for monitoring is reduced. Those who attends an AA meeting do not need to monitor other for shirking they receive benefits by participating. The same applies to those who work on a forum for people for people with for example rare diseases. Those who do not participate automatically do not share the benefits, which makes the rules self-enforcing and incentive compatible (Leeson 2007).

Healthcare is an area that requires extensive oversight and where open care can reduce the need for monitoring. This can lead to open care activities in areas and geographical locations where formal care institutions due to monitoring and auditing costs are not viable. Since care is generally paid by third parties, monitoring and audition will be particularly extensive in this sector. Few taxpayers and shareholders approve of spending of resources without control.

Choosing to evade can also happen when the rule as such is acceptable but where it creates a minimum viable size that is too large for a particular activity to be practiced. It may be an activity if it is aimed at groups that are too small to be able to bear complicity costs. Examples of such activities include care in geographically remote areas or those who are looking at persons with rare diseases. There, the critical mass cannot be found for activities conducted within a country but can be reached if you include people from a larger number of countries. Because healthcare regulations are often national, it will be very burdensome to meet the requirements.

5. Policy Conclusions

5.1 Insights from Institutional Theory

Evasive entrepreneurship can be assumed to be most attractive as an option in regulated sectors, where there are high entry barriers and where there are strong incumbents with monopoly rents maintaining the status of quo. In these cases, innovation is expected to come from challengers whereas the level of innovation of incumbents tends to be lower. This is in line with observations from the healthcare sector (Cutler 2011). Here the example of eye laser surgery can be used as contrast to other types of health care. Eye laser surgery is less regulated than other care practices and has experienced rapid declines in cost (Grupp 2000).

Even though the care sector fulfills the criteria above there is a mitigating factor. Support for regulation health care practices is wide spread, in part due to the difficulty for the consumer to evaluate the quality of the service before it is performed. This limits the public support for at least some types of evasive entrepreneurship. However, some small scale evasive projects might gain support albeit the regulation they evade also has support. It could e.g. be possible for a person to support small scale parallel import of cancer drugs which might help patients that otherwise would not have had access to hem and at the same time support regulations of pharmaceuticals. In formal terms the choice between lobbying and evasive entrepreneurship can be formulated as follows:

Proposition 1: An entrepreneur facing a limiting institution have the choice between abiding, lobbying or evading.

Proposition 2a: Lobbying is requiring financial resources, to lobby or to finance the operations before the rules are changed, as effects of lobbying is not immediate.

Proposition 2b: Lobbying benefits competitors equally – outlays may not be recovered.

Proposition 2c: Lobbying is therefore rarely an alternative for nonprofits or for startups.

Proposition 2d: It is easier to lobby for status quo, which makes lobbying the choice of established firms, not challengers. An established firm has also, by definition, adopted to the existing institutions.

Proposition 3: Evasive entrepreneurship is easier when the limiting factor is a formal institution rather than an informal one, as formals institution might be seen as illegitimate.

Proposition 4a: Evasive entrepreneurs face a risk of being closed down. Therefore, evasive entrepreneurship would likely be the strategy of a challenger.

Proposition 4b: Evasive entrepreneurship is more likely when the number of owners is small or when they share the same values and therefore have high cohesion.

5.2 Concluding Discussion and Policy Recommendations

We have found that open care is not a new form of care, though the concept has not been previously defined and analyzed. Projects that should be considered "open care" existed already in the 12th century, possibly earlier. This mode of producing health identified and resolved health care needs that for one reason or another had been provided. In many cases, the public sector followed and coopted the innovations created by open care self-organization of healthcare. Later, parallel to the expansion of the care provision under the auspices of the welfare states, open care has continued to increase access to care – especially in situations where the participation itself is therapeutic – as in some forms of drug addiction treatment, co-operatives or patient groups.

Digitalization has been a facilitator of open care. The Internet enables people to organize in new ways and to create critical mass for projects to can exchange experiences of symptom, treatments and side effects. Also the higher degree of experimentation, aided by the lower minimum viable size and the higher risk tolerance, among open care projects might boost innovation in the sector (Lakomaa 2018).

In addition, many of the more practical oriented open care projects, for example "makers" of assistive technologies for e.g. persons with disabilities, and providers of care have been helped by digitalization; both as an organization and fundraising tool.

Many open care projects fail, and it is difficult to predict which will success. A general advantage is the low cost of experimentation, where failure only affects a few voluntary participants. Public health systems have lower tendency to experiment with novel solutions since they are heavily regulated and since public employees tend to averse to take risks. In small scale community open care, failed experiments do not cause large costs of society, and a few successes that can be emulated or scaled up can outweigh the costs of failed or stagnant experiments. In terms of experimentation, different European countries can benefit from the evasive entrepreneurship in other countries.

Private evasive entrepreneurship that circumvents regulation sometimes has stronger incentives than community programs, since the entrepreneur benefits from profits if successful. In cases when these experiments work, the success can sometimes be copied by other countries without the need for evasive entrepreneurship, or identify potentially harmful regulation. Since the successful projects are hard to identify in advance – programs to support open care must primarily focus on providing infrastructure or incentives.

We have based on previous research and empirical findings from analyzing cases identified seven policy recommendations that might help integrate open care in the European heath care system.

It is important to be aware of the potentially role the third sector already plays in health care. In some cases, the third sector is filled gaps that the public and private sector have not filled, and in many other cases the third sector supplements the existing health care structures. Regulators should keep this in mind when designing policy so that it is not unnecessarily difficult or expensive for the third sector to provide care. The large number of existing examples of third sector care also suggests that this mode is viable and can be potentially expanded given the right circumstances, preferably by creating a favorable environment and letting projects organically develop bottom-up where the community identifies needs and community capability to attend to those needs.

Cooperate – do not co-opt. Healthcare practitioners should not try to incorporate working open care projects into the formal systems. Many of the projects are based on participation and community that will be lost in a formal organization. There is therefore a risk that commitment will disappear, and volunteers would have to be replaced by paid staff if forced into a formal structure.

Create easy-to-use organizational structures and regulations. Historically, many open care projects have been founded in existing organizations – often churches. This is the case when you could take over existing organizational and decision-making methods. However, there may be room for offering the equivalent of not having a connection to an existing organization. By developing thoughtful and easy-to-use bylaws procedural rules for meetings, etc. you can help those who want to formalize nonprofit projects.

Introduce tax deduction for private contributions to NGOs in healthcare. We have found that avoiding the requirements for monitoring and auditing that comes with third party financing, is one of the drivers for lowering the minimum viable size of projects.

Create business labs and incubators for nonprofits. Just as it exists business labs or incubators to find and help grow new businesses similar entities might help find and grow open care projects. It can be assumed that the participants in open care projects are more interested in, and more knowledgeable about providing care – so help might be beneficial when it comes to organizational or technical issues.

In several European countries, healthcare professionals' liability insurance applies only during work. The nurse who contributes as a volunteer project therefore risks being uncovered. Probably the cost of extending these to apply even in voluntary work is small in relation to the benefits that would involve getting trained healthcare staff to take part in in open care projects.

Create specialized bachelor and master's programs in mutual health as well as and e-health programs in universities where there is student interest. In practice, degrees and formal programs play an important role for enabling the career of students that aim to be health care professionals and are interested in working in e-health or community health projects. There are great opportunities for open care in the field of digitization – areas have not developed much in the formal care industry in Europe.

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