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Open Source Cancer. Brain Scans and the Rituality of Biodigital Data Sharing

In 2012, the Italian designer, open source activist and digital media artist Salvatore Iaconesi open sourced his cancer. Inspired by history of patient liberation and in an effort to de-medicalize his condition, he placed all medical data and information related to his brain tumor—from brain scans to medical reports—on a website called *La Cura* (the cure)¹ alongside an open and inclusive request for “cures.” In a Youtube video he explicitly addressed peers, physicians, activists, artists, designers and engineers, asking to engage with the data and use it to produce any cure they could imagine for his condition. He also promised to publish all the cures so that others could use them. Iaconesi subsequently received and shared hundreds of thousands of contributions in forms as diverse as medical advice, artwork, peer support and poetry. But what does it really mean to “open source” one’s cancer? Like other illnesses, cancer can be regarded as a metaphor for different political and social orders.² Bearing this in mind, this chapter looks at collective action mediated by digital technologies in order to analyze a public and participatory experience of cancer. The body is a battlefield where power relations are structured and negotiated. With the rise of pervasive interactive media, digital representations of bodies come to have force in the material world. Thus the act of becoming a patient, to put it in Foucauldian terms, is changing, and new ways to resist (or reinvent) this process seem to be emerging. In an effort to explore this evolving landscape we focus on the role of hacker cultures. Hacker is a polysemous term, one that encompasses several communities, practices and subcultures. Hackers draw upon different political backgrounds while sharing an interest for craftiness, cleverness and refusal of bureaucracies in favor of decentralized solutions and organizational forms. Regardless of its political orientation and technical nuances, hacking is often concerned with performing technological alternatives in the public sphere in order to convey their emancipatory potential.³ It is exactly by focusing on the symbolic significance of hacking biodigital data that we interpret the opening up of cancer’s “source code” as a biopolitical rite of healing, aimed at redefining concepts like “disease” and “cure.” Accessing and sharing the medical data that forms this source code are symbolic of the desire to re-appropriate the condition of being ill and foster a society which recognizes disease as a complex experience felt by social bodies as much as individual bodies: open source and crowdsourcing can be seen as dense biopolitical signifiers rather than

mere distributed technical solutions. We also discuss the role played by a participant public in fostering these emergent understandings, a public mediated by digital platforms and gathered around the biodigital data shared therein.

The chapter is organized as a narrative; the temporal unfolding of *La Cura* is supplemented by insights and reflections garnered from digital cultures studies, medical anthropology and feminist theory. We should highlight that Iaconesi is himself one of the authors of this chapter, thereby occupying a role as network-ethnographer embedded within the system being observed. Thus the material is culled from the direct experience of one of the authors, on repeated interactions and discussions with crucial individuals involved in the events, as well as on an analysis of the media products related to *La Cura* and a sample of the cures received. We would like to make the reader aware of two things: First, we have chosen to narrate in third person to reflect the chapter's formation through long collaboration and conversation. Second, we interpret this chapter as one of the cures advocated by *La Cura*. A bit of background will help explain what this means. Now in his mid-30s, Iaconesi is a well-known designer, artist, and open source advocate. He is a former TED Fellow, and alongside his partner Oriana Persico, he co-founded and runs the Art is Open Source collective.⁴ Through *La Cura*, his experience of illness also became a media intervention seeking to expand the domain of what it means to confront with cancer, moving beyond the state of medicalization and towards a scenario in which medical institutions are part of a broader system which includes one's social and affective worlds. The first step in this transformation was to convert his medical records from professional to common standards, making the data easily readable and shareable by laypersons. More abstractly, Iaconesi sought to construct an inclusive understanding of the word "cure," one which is not limited to a medical definition but extends to different practices and meanings. *La Cura* had several aspects and implications. Extensively discussed in the public sphere—both in digital networks and major international media outlets—it also altered Iaconesi's relation to the professional medical sphere. For example, Iaconesi met the surgeon who ultimately removed his tumor as a direct result of the suggestions provided through the website.

Here we focus on *La Cura's* public character as a collective media intervention. To this end, we turn to traditional ethnographic accounts of healing rites and use them as a theoretical framework to propose *La Cura* as an example of a "biodigital ritual of sharing." This ritual follows a protocol or script which derives from hacker practices and rhetoric, emphasizes public involvement and opens cancer to a plurality of meanings and understandings. According to this script one hacks into and expropriates data controlled by institutions; shares it in the open; and thus facilitates the construction of a community around its free and unpredictable use.⁵ Medical images are powerful signifiers of scientific authority,⁶ and while for medical institutions a piece of data such as a brain scan represents an instrumental, objective abstraction from an individuated body, its symbolic reinscription through *La Cura's* biodigital ritual seeks to salvage the social body that medical institutions tend to discard. The ill person is not the sole or primary

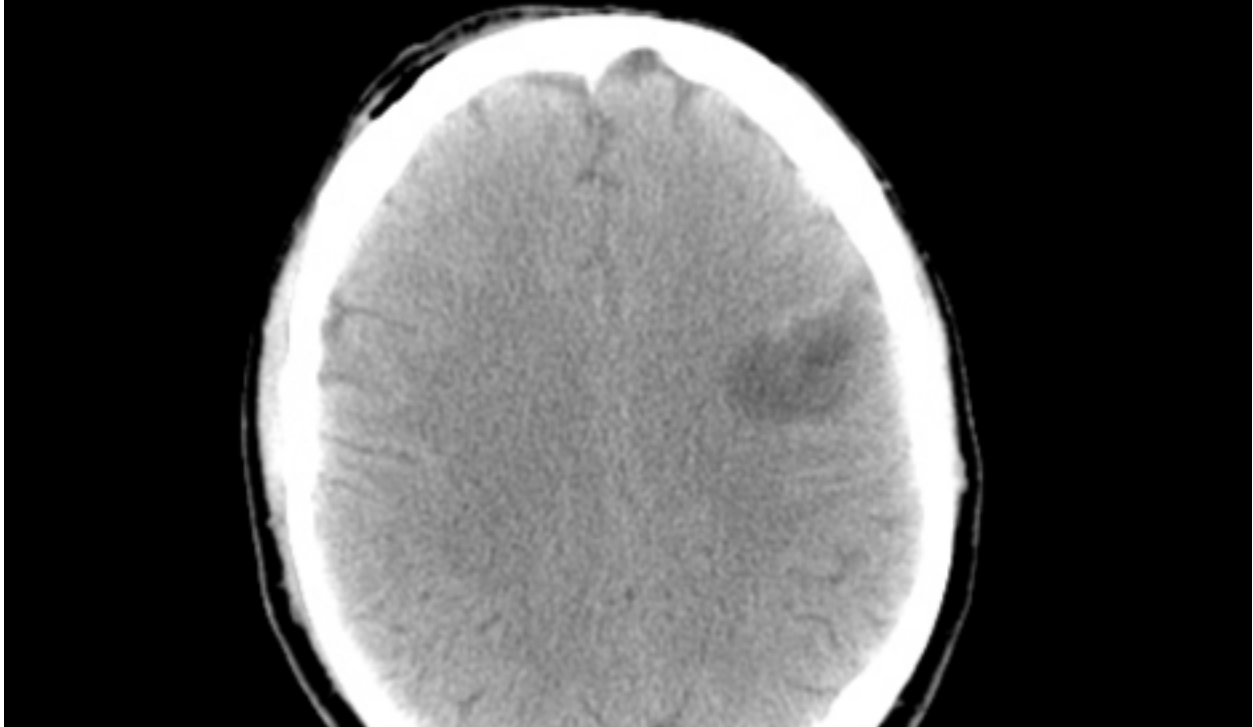
object of the rite. Instead, the ritual focuses on a broader target: attempting to fix social and political imbalances that affect the entire collective. From this perspective, we lend our efforts to an attempt at defining the significance of openness in relation to scientific and medical knowledge. Scholarly literature on biohacking, citizen science and do-it-yourself biology each insist on the role of openness, in terms of open access to data and tools, as a prerequisite for public participation in the “domestication” of biomedicine.⁷ Although we acknowledge the importance of access to information, we add to the picture a consideration of the ritualistic and symbolic aspects of openness: *La Cura* framed access as a necessary but insufficient first step. It also sought to confront the symbolic apparatus represented by medical institutions and their processes, in order to imagine the possibility of plural degrees of freedom, diversity, and sociality. Still, the free circulation of digital artefacts is a prerequisite for the ritual because it allows the creation of a public that shares a common knowledge upon which a sense of participation could be encouraged and built.

While this specific case study is related to hacker cultures, we believe it offers broader insights into the biopolitics of health and illness as performed in the digital sphere and allows us to supplement understandings of contemporary biomedicine with other aspects of today's information environment. Institutions act as enablers and facilitators of digital participatory practices, yet at the same time they can be challenged by practices that happen outside of their control. As institutions typically attempt to incorporate and transform these practices, institutional and technical protocols need at times to be circumvented or cracked open. In doing so, constraints, intentions, and conflicts can be revealed and confronted. Following feminist theory, we also suggest that, in the face of illness and disability, digital cultures often imagine and perform technologies as social and relational, rather than bodily, prostheses.⁸ The prosthetic role of technologies can, in fact, be focused on enhancing one's social capabilities as well as intervening in the materiality of his/her body. Finally, in the conclusion we suggest that this example is part of an emergent culture of *digital solidarity*, wherein the building of common, open and autonomous spaces is advocated as an alternative to institutional crises of legitimation.⁹ By simultaneously acknowledging the risks of such endeavours, we suggest they could pave the way for new forms of medicalization, surveillance and healthcare privatization.

From scars to scans: open source as a symbol

When you have cancer you disappear, only to be replaced by something else: a patient. This is a strange being, on the one hand, entirely made of data: blood exams, images of body parts, lab values, diagnoses—the list goes on. But, on the other hand, this data is not simply *you*: it barely approximates the full complexity of selfhood. As a patient you are suspended from the world around you. This is a major transformation, in which all daily activities and routines tend to cease as the patient enters into a crisis. You don't eat the same anymore, you don't work at the

same pace, you don't spend your time in the same ways or with the same people. New routines, schedules, bureaucracies, administrative tasks, and people appear and surround you. All these new things in your life relate to the disease. Almost everything else is erased. These processes are bolstered by the fact that you are also objectified through a set of data. Your body, personality, social connections disappear, and are replaced by data and images. Everyone around you begins speaking in terms of these data and images. Your prior self vanishes as you are taken over by the disease, on one side, and by the data and images, on the other. Language changes: different words, pauses, timings, embarrassments, taboos, phrasings, different ways of saying, or not saying, things. People cease to simply talk with you; rather, they speak about you, and only discuss the patient which you have become. In August, 2012, in Rome, after episodes of epilepsy, Iaconesi was diagnosed with a brain tumor. One day, in the hospital following several brain scans, including CT (computerized tomography) and MRI (magnetic resonance imaging), he asked for a digital image of his cancer. He wanted to look at it, to see this thing that was growing inside him. But his request was denied. Everything got in the way, from administrative red tape to privacy and legal issues, and barriers imposed for insurance reasons: everything about the medical system made it impossible for Iaconesi to access his own cancer. He had the distinct feeling that this situation was not about him, but about a medicalized version of himself, a self reduced in complexity. This situation triggered his first response: after several attempts at consultations with doctors and surgeons Iaconesi left the hospital against their advice. At that time, nobody knew his tumor was a benign and removable glioma, and the spectre of death was still implicit in the diagnosis. In leaving the hospital he signed an agreement lifting all responsibilities from the hospital and requested his medical records, including brain scans, in digital format on a DVD. Only by assuming full responsibility for his condition was he able to put in motion the bureaucratic machinery that would provide him with the images. He finally had the files but, to his chagrin, upon arriving home he discovered that while the files were in a format that is technically open (DICOM), they were not suited for access and use by non-professionals.¹⁰ One needs specialized software to open these files, and even if one can open them, they are not really meant for a layperson to use: the language, terminology and nature of the icons are completely abstracted from the layperson's experience. The images of Iaconesi's cancer were only meant for technicians and physicians. Iaconesi felt it impossible to easily translate such data into his complex social world, which includes global digital relationship built through his activity with the Art is Open Source collective.



[Figure 1]

Modern processes of medicalization tend to extract and isolate the ill person from her social, cultural, and perceptive contexts. In the medicalized sphere, disease is no longer perceived as a social matter or object of shared, societal action and instead becomes a specialized object reserved for treatment by professionals and institutions. In a biomedical model of illness, ill health is in fact a “deviation from [...] the normal range of measurable biological variables”.¹¹ Imaging technologies such as x-rays or PET are just one vector along which the medical gaze objectifies their use privileging images and data over individual experiences and, crucially, even the body itself.¹² The increasingly pervasive digitization of life (for example in genetics) has taken this phenomenon further still, pushing towards a reconceptualization of the body as pure information. This dematerialization accounted for a *disappearance* of the individual and his/her complexity.¹³ Digital images were restricted to professional settings and were thus central in defining the strict boundaries of Iaconesi’s role within the hospital. He felt that within medical institutions his affective and social relationships were being rendered invisible, as if his body was being separated from his social world. This had multiple manifestations starting with the experience of time and space in the hospital: the strict wake up calls; the fixed routines for doctor’s visits, assumption of drugs, meals, visits from relatives and friends; and constraints to movement within and outside the hospital. However, the loss that he felt most deeply was the progressive disappearance of those activities and relationships that enrich one’s life: music, art, culture, hobbies, preferred food, up to the negation of friends and relatives participation in activities such as cooking or moving together. For medicalized individuals, this “pathway from

person to patient”¹⁴ is a common experience that coincides with a heightened vulnerability to biopower. This was clearly the case also for Iaconesi, but the reaction which led to *La Cura* was triggered by recognition of the way biodigital information was produced, inscribed in digital supports and shared. Foucault insisted that technologies of governance are composed by practices and objects through which biopower is exerted and resistance emerges.¹⁵ Iaconesi’s brain scans quickly assumed this double-faced role and became a symbol of different social orders: first signifying medicalization before subsequently facilitating processes of individual *reappearance* and collective reappropriation.

As soon as he found out about the file format, Iaconesi worked to convert the files into more ordinary, shareable formats like .jpeg, .doc and .html. To do so, he had to write his own software code. It was in this moment, sitting intently at his computer—having left the hospital and returned home, determined to share his medical records—that those around him again recognized him as the Iaconesi they had known: he reappeared. He ceased being a patient and became a human being again. Hacking and sharing his medical record was the most natural thing he could do to reconnect with his broader social and affective world. Only days after he received his diagnosis, according to his partner Oriana, hacking the data allowed them to retake control over the dispossession experienced at the hospital. While the DICOM standard embodied the biopower experienced in the hospital, reinforcing the disappearance of the person in favour of the patient, by reinscribing the data through an open source approach Iaconesi effectively reappropriated the medicalized experience of cancer. Biodigital data assumed the “polarization of meaning” Turner describes as inherent to the symbols used in rituals, associable simultaneously with a physiological fact (cancer) and a social fact (resistance to objectification).¹⁶ Iaconesi set up a website with his medical data available for download by anyone; brain scans, blood tests, medical reports and diagnoses, all in easy-to-share formats. Through data sharing, he resisted his reduction to a mere cancer body—constituted only as an aggregate set of medical data.

But what does “hacking” mean in this context? Among the many facets of hacking, here we focus on its communicative and performative side.¹⁷ The media interventions constituted through data hacking and sharing were aimed at the “transformation of suffering into communicative signs,” as described by Tamar Tembeck in the context of visual autopathographic practices. Hacking subverted the standard cultural meaning of what being a “good patient” means, including the acceptance of an objectified role in the machineries of medicalization.¹⁸ In converting his medical data to more widely accessible digital formats, Iaconesi circumvented two codes. The first code was plainly visible: the digital code which underwrote the brain scans themselves, encoded in such a way that only medical professionals could access and utilize the information. The second one was rendered visible by the hack: it was the institutional code that maintained the specific social order found in modern health systems, inscribed into the DICOM format with the effect of preventing Iaconesi from using the scans in a way not envisioned by medical institutions. These codes were easily representable as the legacy of calcified bureaucratic

systems that needed the infusion of new practices and values. In contemporary societies openness is more than just an organizational principle. Free access to information can symbolize concurrent values, like the desire to resist privatization or democratize the political sphere.¹⁹ Performances related to transparency and openness have been used in countercultural activist approaches to cancer since the 1990s. For example, by publicly displaying one's body after a mastectomy, some women famously reclaimed the scar as an "object of political significance".²⁰ While Iaconesi didn't have a scar (yet), his brain scans alone became objects of political significance in their exposure. Yet this was not related to the need to overcome the social stigma associated with cancer. In *La Cura*, openness was used to contrast the ways in which a person is transformed into a patient in the medical system. It symbolized the possibility of reverse-engineering the transformation by re-appropriating data and inserting it into a wider process which included one's social, political, relational, economic, affective and creative life, as well as the willingness to engage other members of society in the process. In this performance of hacking, open source data exposed Iaconesi's fight against a form of medicalization exacerbated by digital technologies. This was a performance in more than one sense. First, hacking the data allowed Iaconesi to construct and reclaim his identity that was not limited to simply that of the patient; the act of writing oneself into being, as suggested by Jenny Sundén,²¹ in an explicitation of self-reflexivity. On a subsequent level, open sourcing the data allowed for the creation of a public that performed and participated in the biodigital ritual hinted at above and discussed further in the next section. *La Cura* became a platform for performance through shared and recombinant reproduction, re-appropriation and reinterpretation. The result of the initial action was the production of a performative space across a variety of media, and the inaccessibility of Iaconesi's data set the scene for the translation of hacker rites into the world of cancer.

La Cura: participation in the ritual

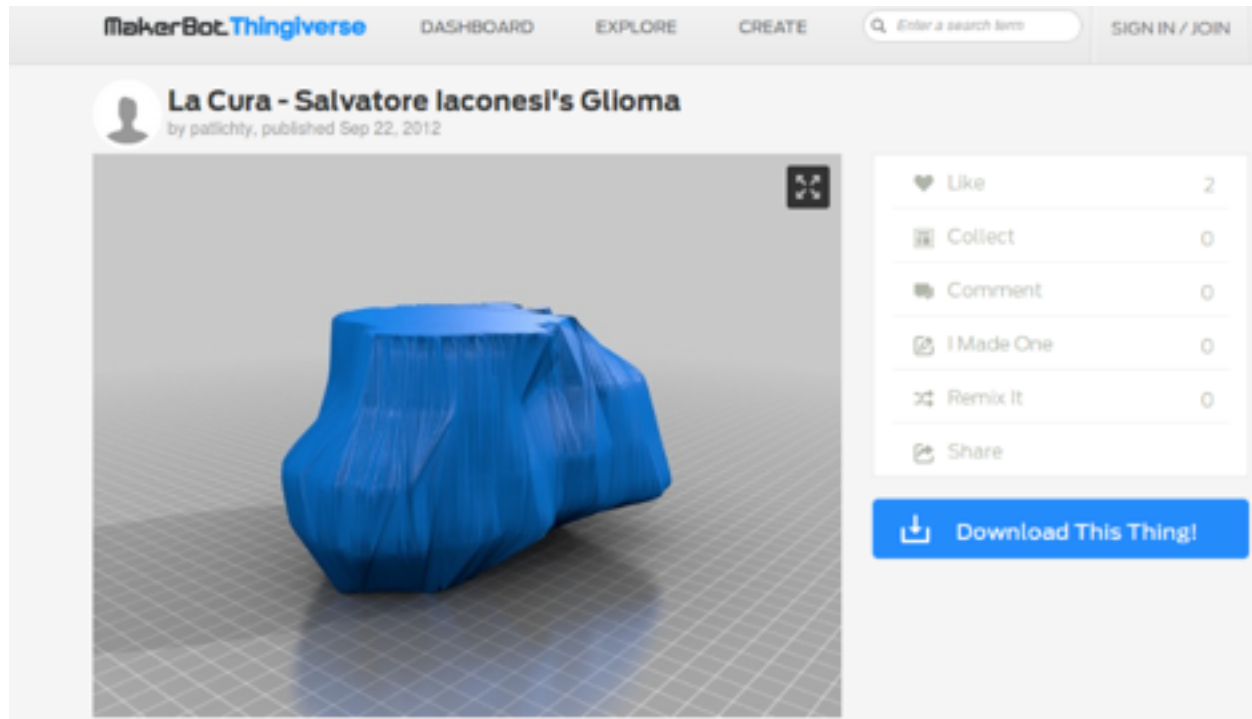
On September 10, 2012 Iaconesi posted two videos on Youtube, one in Italian and one in English. The video, entitled "My Open Source Cure," begins with a simple declaration: "I have brain cancer." Iaconesi continues:

"This is a cure. This is my open source cure [...] In different cultures the word cure means several different things. There are cures for the body, cures for the soul, there are cures for communication, for socialization. So what I ask you is to give me a cure. [...] Use the data and information in open format that I published to produce something... to produce a video, a graphic, an artwork, a game, or maybe even study the information to find a cure for me [...] I will publish all the cures that you send me so that everyone will be able to benefit from them"²²

The video sought to enlarge the scope of what a cure is or can be. Iaconesi invited everyone to join him in his disease, turning it into “a matter of engagement for the whole society.” He was interested in finding out how a person could participate in his cure: what could an artist do with the data? Which cures could be envisioned by a designer, an academic or a hacker? The video went viral. Italian and international news outlets published the news that Iaconesi was asking people to help him find a solution to his brain cancer, and he was frequently interviewed.²³ Over the following months, he continued to post every medical record related to his condition: post-surgery reports, brain scans, blood exams and histological results, in addition to other messages.

In the beginning, Iaconesi mobilized a network of artists and designers who had been previously familiar with his work, but it wasn't long before *La Cura* swelled outside of this network. Then the cures started pouring in: he began receiving and exchanging myriads of messages, of all sorts and from multiple sources; from online and offline; through emails and social networks; from people in the streets and those on their phones; through live, physical visits from friends and strangers; and across continents using Skype and Google Hangouts. One medium would lead into another, as Iaconesi would respond to an email by meeting its sender in person. The cures were as diverse as one can imagine. People contributed stories, artworks, medical advice, consultations, traditional healing, magic, spirituality, dietary advice, and offers of financial support. Cancer patients asked their own doctors for suggestions about Iaconesi's condition. Contributions were generated across the globe, with epicenters emerging in Italy, Spain, Slovenia, Croatia, Greece and the United States complementing numerous cures from Northern Europe, Chile and Brazil. Most countries of the world were represented. In fact, it would be impossible to analyze the cures without using automated tools: ultimately they comprised about one million texts (as of June 2014)—a number which does not include Facebook and Youtube comments, tweets, emails and face-to-face interactions still accumulating as we write this chapter.²⁴ Here we can only hint at some of the radically different cures received through the website. One of Iaconesi's old companions, who he had not heard from since the friend had moved to Argentina several years prior, advised him to visit Argentina, relax, eat natural food and breathe clean air. A Communication Science professor suggested, in a beautiful, poetic way, a meeting with one surgeon in particular—the one, in fact, who would eventually perform Iaconesi's operation: through social network interactions, emails and phone calls she described her own experience with the surgeon as she was diagnosed with a meningioma, interweaving descriptions of his techniques, scientific evidence, considerations on the doctor's Mediterranean approach and warmth, as well as on her feelings and emotions. Someone suggested a method invented by a Brazilian monk: a mix of aloe vera, honey and whiskey. A person commenting on the initial *La Cura* video suggested that Iaconesi could give up his quest for a cure and instead kill himself, a decision which could supposedly grant enormous amounts of insurance money to his friends and relatives, so that they could live a happy life afterwards. An artist created a performance which ritualized the magnetic aspect of MRI scans.²⁵ Another artist offered one of Iaconesi's favourite cures—using the brain scans he constructed a 3D design of the tumor and

offered it as a design on Thingiverse, a website for digital design file sharing, so that anyone could print it out using a 3D printer: a pocket sized physical realization of Iaconesi's tumor.²⁶ Now anybody could have his tumor.



[Figure 2]

Yet as media outlets became interested in *La Cura*, this wealth, and thus the radically inclusive character of the platform, struggled to emerge. No matter how Iaconesi and Persico struggled to convey different images, the dominant narrative seized upon by the mainstream media remained focused on the technicalities of the open source, crowdsourced process.²⁷ This narrative performs the technological determinist view that digital distributed creativity is a technical solution: in this view, Iaconesi's open file sharing was presented as narrowly concerned with facilitating a collective intelligence towards the discovery of a faster and more efficient technical solution to cancer. But, in our view, *La Cura* was more a biopolitical performance that exposed underlying power structures crystallized into the medical system, rather than a positivist platform for narrow conceptions of medical, technical progress. *La Cura* presented opportunities to re-appropriate health and illness from inside of the narrow, biomedical model of what being a patient means. As Arthur Frank notes, illness can provide justification for new desires:²⁸ for Iaconesi, the key role of desire was the role it played in facilitating unexpected ways to crack the codes at work in the medical world, such as the implicit negation of data usage by patients and the asymmetric relation between experts and non-experts, thus revealing and exploiting the frictions and tensions therein.

Patients and their families turn to the Internet in order to retrieve information, discuss pathologies and treatments, provide peer support, share their stories or medical experiences with other patients, and mobilize.²⁹ Yet debates regarding patient inclusion and participation must be updated by including new forms of affective and social relationships that are changing the participatory landscape.³⁰ Digital networks can be seen as new “opportunity structures”³¹ that offer individuals new possibilities to fulfill their desire to participate in health management, while also potentially constraining and shaping their ability to act in other venues. In fact, diffused visions of the “revolutionary” characteristics of digital media often overlook power dynamics, hierarchies and failures that are integral to the web. Rather than change power distribution patterns, spaces of digital media can reinforce and reproduce them—and even introduce new ones³². Authors such as Kate O’Riordan or Marina Levina, to name only two, describe the emergence of, respectively, *biodigital publics* and *digital networked subjectivities* as new forms of biopower based upon the circulation of biological information through digital artefacts. For them, the free circulation of biodigital artefacts enables collective public action towards re-elaborations and reappropriations of health practices, but is also underwriting new forms of governance and capital accumulation.³³

Building upon these arguments, our concept of a *biodigital ritual of sharing* allows us to account for other aspects of biodigital publics, and chart the historical influence of hacker cultures in current practices of data sharing. Also, the concept acknowledges the rituality of processes of digital community formation. Finally, instead of focusing on practices of sharing organized by commercial entities, like companies that provide direct-to-consumer genetic testing and themselves benefit from the digital labor provided by participant consumers, in this chapter we consider a public organized around an independent, digital commons. We believe that the reduction of biodigital sharing to a form of labor precludes a complete understanding of the complex entanglement of health and digital cultures. Public rituals are crucial symbolic and communicative acts that restate and renew basic social values and maintain community cohesion. Rituals can have a strong creative power, as they continuously recreate both the categories through which societies are perceived and constructed, and their underlying moral and relational orders. Rituals are standardized and divided into specific parts: they are scripts or protocols.³⁴ Furthermore, rituals related to healing, health and illness are important parts of our experience and contribute to our social identities. In exploring the symbolic and ritualistic side of open source, we supplement traditional anthropological accounts of the social aspects of illness and healing in indigenous societies with emergent, technologically-mediated experiences. Processes of healing are intimately linked with the social structure in which the healing takes place. For example, according to V. W. Turner the “rites of affliction” performed by the Ndembu people of Zambia symbolized that which “poisons” group life, demonstrating how rites of healing can perform a social regulatory function.³⁵ Indeed, rituals are meant to domesticate illnesses and resolve social conflicts, and are flexible enough to encompass new needs and adapt to change. In the case of *La Cura* such flexibility is enabled by its public and participatory characteristics,

which we regard as key to the emergence and stabilization of *La Cura*'s digital public. Recursively, the formation of a participant public is key to the success of the ritual.³⁶

By using digital technologies, participants to *La Cura* were able to ritualize their experience into a collective performance that builds community. Indeed, drawing upon the notion of ritual, we suggest that desire was able to assert itself through a rite which aimed at re-manifesting the social self which the medical institution had negated. Via public rituals, symbols attain status as objects that allow the reproduction and maintenance of social order, functioning as “restatements” of the terms of social life and human interaction.³⁷ A ritual includes specific objects and gestures that compose its choreography, or its script. In *La Cura*, the ritual borrowed such choreography from hacker cultures. The public ritual of sharing performed when hackers “liberate” information follows a script that we can (over)simplify as follows: data are hidden by bureaucracies using passwords, security, closed formats and secrecy; somebody hacks into the data and shares it freely on the internet; and an open community makes unpredictable use of it.³⁸ Over the last few years, this script has become a crucial, and common, narrative within information societies—one need only consider the protest hackers Anonymous, the leaking organization WikiLeaks or the ex-NSA contractor turned mega leaker Edward Snowden to ascertain its significance. In the case of *La Cura*, data were hidden by the hospital, and access to it was denied to anyone who did not belong to the bureaucracy which deemed itself responsible for its management: the hospital denied Iaconesi access to his medical record, and when he finally received the files, they came in a format that did not allow him to use them. Iaconesi could not simply share the files: he had to hack into them and convert them into shareable formats. Finally, through *La Cura* he staged a media intervention that rendered the data visible, and aggregated a public that could interact with and use it in ways that were not controlled or normalized by medical institutions.

La Cura is part of broader countercultural approaches to health and illness. A direct inspiration for it was the history of patient liberation in 1970s Italian asylums. Psychiatrist Franco Basaglia, influenced by Foucault and the uprising of post-1968 social movements, set up open communication platforms (especially in the form of political assemblies) in which secluded mental health patients, physicians and nurses shared desires, needs and approaches to suffering. They reclaimed the will to understand, subvert and eventually tear down the various kinds of walls that formed the fictional territory of hospitals, separating psychiatric institutions from the rest of society. Basaglia wanted to open up the physical, political and knowledge-based power architecture of the institution. Besides changing how cures were performed, he imagined more open, inclusive and permeable spaces and communities in which collective responsibilities were shared among all components.³⁹ In her book on self-help feminist movements in 1970s California, Michelle Murphy describes what she calls “protocol feminism”.⁴⁰ These groups would construct a procedural script that allowed the spreading and maintenance of practices they wished to encourage, such as collective self-examination outside of medical institutions.

According to Murphy, these highly politicized scripts depended on cheap and accessible communication technologies and infrastructures—i.e. photocopiers and highways—for dispersion. Feminist protocols of self-help were designed to reproduce and maintain a specific order of collective care and counterpower (what was once called *consciousness*). These practices were aimed at “seizing the means of reproduction,” as Murphy puts it. In a fashion similar to the protocols described by Murphy, based on opening up one’s own body to one’s sisters’ gaze, we suggest that biodigital rituals of medical data sharing can align participants in relation to each other, maintaining a social order which is currently imbalanced by a formalized, institutional dominance. By collapsing the symbolic power of biodigital data and the choreography of hacking into one practice, *La Cura* created a social body⁴¹ that made the ritual possible, and expressed the need for individuals to re-appropriate experiences of cancer from medicalization. The public visibility achieved through social and mass media was key in the building of a participant public. According to Levi-Strauss, a participant group functions as a “gravitational field” for the ritual: it is key to its success and enables it to assume a significance that exceeds the role of the individual subject of the rite by expanding its relevance to the whole participant community.⁴² The ill person is not the real object of the rite: in fact, Iaconesi’s name was never mentioned in *La Cura*, and the website provided little personal information about him. At the center of the rite is a public concerned with social, collective imbalances. Utilizing biodigital rituals, a participant public can form when people identify with digital artefacts allowed to circulate freely in the mediated public sphere; they can contribute to or ignore them and choose not to participate; and they can build a sense of bodily participation. The digital artefacts ultimately allow for the constitution of a mediated participation that expresses the need to overcome societal frictions, obstacles or hierarchies.⁴³

Conclusions

In the wake of *La Cura*, Iaconesi feels, in many ways, that he has been successfully cured. The rituals of medicalization that articulate life in the hospital were shaken but the institution also acknowledged the changes triggered by the circulation of data in new spaces and Iaconesi’s re-positioning as a different kind of node within the information flux. The international visibility and support he received from an ample community, previously non-existent, transformed his relation with the medical system, as well as with his family and friends. His surgeons and his Chinese traditional healer contributed equally to aspects of the therapy he followed within health institutions. In the hospital, staff started referring to him as “Salvatore and Oriana,” recognizing the significance of importing his affective world into the care they provided. Eventually his glioma was removed, and both the choice of surgeon and choice of surgical technique stemmed directly from *La Cura* and the relations which were established in the course of the process. For example, while two surgical techniques were initially identified as equally effective, Iaconesi was able to incorporate in his choice a plurality of views that go beyond usual technical

considerations and include social, philosophical and political considerations not commonly offered to patients. The method used involves the implantation of brain sensors that allow the surgeon to perform functional tests. The final surgery is preceded by a critical conversation between the doctor and the patient, based on the results of the tests. Iaconesi was thus able to consciously take part in the decisional processes connected to the surgery and its potential risks and effects.

La Cura thus enabled discussions of several important stakes. And more discussions seem poised on the horizon. This case could, for example, be used to interrogate issues such as the role of digital media for patient empowerment, emerging forms of surveillance and resistance to them, the changing nature of medical expertise and knowledge, the construction of the body-self through digital data, and the role of the market in recuperating and managing such practices. The latter is particularly important in *La Cura*. As the website became internationally visible, also thanks to Iaconesi's appointment as a TED Fellow, web companies interested in developing commercial applications for medical data sharing approached Iaconesi for advice. What kind of participation and governance might stem from corporate services that organize patient biodigital information through open source approaches? The change towards a more participatory, self-responsible and proactive citizenship fostered by the digital sphere is related to similar transformations at the biopolitical level, where discourses of empowerment, participation and collaboration constitute an emerging form of biopolitical governmentality. However, even as digitalization changes public views and practices, medical institutions can be ill-equipped to respond to requests for radical inclusion and often need to renew by incorporating external practices. For example, pharmaceutical companies can emulate websites used by patient associations in order to establish a "sense of community"⁴⁴ and present web services as seemingly neutral and democratic.⁴⁵ Indeed, hackers are entwined in cycles of incorporation and recuperation and often try to resist the way institutions adopt grassroots innovations for adaptation to their needs.⁴⁶ Biodigital rituals of sharing in the context of interactive technologies might themselves become part of such a trend. Governmental medical power might easily extend to these emergent digital spheres, mixing self-control, responsibility, and radical transparency into a pervasive medical gaze.

While patient reclamation of the medicalized body is becoming a more common subject of discussion, by proposing the concept of the ritual we have here focused on the cultural significance of biodigital data: once liberated through hacking from their objectifying role in the context of medical institution, open source data provides a commons upon which new forms of digital solidarity can emerge.⁴⁷ In doing so they can trigger public responses which enable collective reappropriations of the experience of cancer and other illnesses. Against techno-determinist ideologies, we also suggest that, by performing such rituals, members of digital countercultures—such as hackers—can turn to digital technologies, rather than only their bodies, as a battleground for the reconfiguration of social and political possibilities. In fact, hackers'

technological and communicative skills can be used to construct spaces in which power is collectively called into question. A broader analysis of these rituals will need to explore the different cultural, technological and political variables that shape forms of digital participation⁴⁸ (or non-participation⁴⁹), as well as the way different pathologies can originate both different forms of online organization and different patterns of digital solidarity. Ultimately, *La Cura* signals the presence of a social imbalance which may be corrected through rituals which provide rallying symbols and facilitate collective interaction. This leaves us with the task of imagining other public rituals based on biodigital data sharing that might fix social and political imbalances without exacerbating the present asymmetry of (bio)power, or accidentally introducing new asymmetries of their own.

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Notes

¹ Accessed July 20, 2014. www.opensourcecureforcancer.com.

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⁴ Accessed July 20, 2014. www.artisopensource.net.

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⁷ Morgan Meyer, "Domesticating and Democratizing Science: a Geography of Do-It-Yourself Biology," *Journal of Material Culture* 18.2 (2013); Barbara Prainsack, "Understanding Participation: the 'Citizen Science' of Genetics," in *Genetics as Social Practice*, ed. Barbara Prainsack et al. (Farnham: Ashgate, 2014).

- ⁸ Donna Haraway, *Modest_Witness@Second_Millennium* (New York: Routledge, 1997) and Michelle Murphy, *Seizing the Means of Reproduction. Entanglements of Feminism, Health, and Technoscience* (Durham: Duke University Press, 2012).
- ⁹ Felix Stalder, *Digital Solidarity* (Lüneburg: PML Books, 2013).
- ¹⁰ Digital Imaging and Communications in Medicine, see <http://en.wikipedia.org/wiki/DICOM>. Accessed July 20, 2014.
- ¹¹ Mildred Blaxter, *Health* (London: Polity Press, 2010), 13.
- ¹² Lisa Cartwright, *Screening the Body: Tracing Medicine's Visual Culture* (Minneapolis: University of Minnesota Press, 1995); Joseph Dumit, *Picturing Personhood: Brain Scans and Biomedical Identity*.
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- ¹⁶ Victor Witter Turner, "Symbols in African Ritual," *Science*, 179.4978 (1973).
- ¹⁷ Coleman, *Coding Freedom*.
- ¹⁸ Tamar Tembeck, "Exposed Wounds: The Photographic Autopathographies of Hannah Wilke and Jo Spence," *RACAR: Revue d'Art Canadienne/Canadian Art Review*, 33.1-2 (2008), 90. See also pages 94-96.
- ¹⁹ For an example of such symbolic role see Endre Dányi, "Xerox Project: Photocopy Machines as a Metaphor for an "Open Society"," *The Information Society* 22.2 (2006).
- ²⁰ Lisa Cartwright, "Community and the Public Body in Breast Cancer Media Activism," *Cultural Studies* 12.2 (1998); see also Jean Dykstra, "Putting Herself in the Picture: Autobiographical Images of Illness and the Body," *Afterimage* 23.2 (1995).
- ²¹ Jenny Sundén, *Material Virtualities* (New York: Peter Lang Publishing, 2003). See also David Gauntlett, *Media, Gender and Identity: An Introduction* (London and New York: Routledge, 2002).
- ²² Salvatore Iaconesi, "My Open Source Cure," accessed July 20, 2014, <http://youtu.be/5ESWiBYdiN0>.
- ²³ La Cura was featured in media outlets such as *BBC*, *CNN*, *La Repubblica* and *Le Monde*.
- ²⁴ See www.opensourcecureforcancer.com for an initial analysis of the content, connections and origin of the cures
- ²⁵ Francesca Fini, "Healing," accessed July 20, 2014, <http://www.francescafini.com/#!/video2/cabw>
- ²⁶ Patrick Lichty, "La Cura - Salvatore Iaconesi's Glioma," accessed July 20, 2014, <http://www.thingiverse.com/thing:30987>).

²⁷ See for example Jane Wakefield, "Crowd-sourcing a Cure for Cancer Through the Internet," *BBC News*, October 15, 2012, accessed July 20, 2014, <http://www.bbc.co.uk/news/technology-19899469>, or Alison George, "Crowdsourcing a Cure for my Brain Cancer," *New Scientist*, October 31, 2012, accessed July 20, 2014, <http://www.newscientist.com/article/mg21628880.300-crowdsourcing-a-cure-for-my-brain-cancer.html>, in which a full hour of phone conversation has been cut to the few and sparse answers which dealt with the crowdsourcing process, systematically discarding all other issues

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²⁹ See, among others, Jacqueline Bender, Maria-Carolina Jimenez-Marroquin and Alejandro Jadad, "Seeking support on Facebook: A Content Analysis of Breast Cancer Groups," *Journal of Medical Internet Research* 13:1 (2011), Joe Dumit, "Illnesses you Have to Fight to Get: Facts as Forces in Uncertain, Emergent Illnesses". *Social Science & Medicine* 62.3 (2006), Gunther Eysenbach, "Medicine 2.0: Social Networking, Collaboration, Participation, Apomediation, and Openness". *Journal of Medical Internet Research* 10.3 (2008), and Hugh Stephens, (2014) "Social Media and Engaging with Health Providers," in *Rare Diseases in the Age of Health 2.0*, ed. Rajeev Bali et al (Berlin: Springer-Verlag, 2014).

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³⁴ Michelle Murphy, *Seizing the Means of Reproduction*.

³⁵ Victor Witter Turner, *The Drums of Affliction. A Study of Religious Processes Among the Ndembu of Zambia* (Oxford: Clarendon Press, 1968).

³⁶ Claude Levi-Strauss, "The Sorcerer and his Magic" *Structural Anthropology* 1 (1963).

³⁷ Turner, *The Drums of Affliction* and "Symbols in African Ritual".

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⁴² Levi-Strauss, “The Sorcerer and his Magic” *Structural Anthropology* 1 (1963).

⁴³ See also the dimensions of participation, Kelty and Panofsky, “Disentangling Public Participation In Science and Biomedicine”.

⁴⁴ Carlos Novas, “Genetic Advocacy Groups, Science and Biovalue: Creating Political Economies of Hope”.

⁴⁵ Tarleton Gillespie, “The Politics of ‘Platforms’,” *New Media & Society* 12.3 (2010).

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