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Reparative Design: A Study of Collective Practices for Generating and Redistributing Care Online

Abstract: Online content produced by sick bodies, outside of clinical trials, is increasingly studied as real world evidence. US policy and biomedical companies are designing ways to make patient input legible and useful to their evidence-based medical system. My design study suggests an ethic of repair that might learn from the political agency of people with chronic autoimmune conditions. It brings feminist materialist studies into dialogue with two collective care groups who devise tools for reciprocal, collaborative *intra-action*. Their tools offer different ways to study illness online and negotiate boundaries (of bodies/expertise/ space). Together they articulate the values and risks in generating embodied knowledge and redistributing data through digital communities.

Keywords: Precarious collectives, care, informed refusal, digital patient labor, boundary negotiating tools.

Reparative Design: Eine Studie kollektiver Praktiken zur Generierung und (Um-)Verteilung von Care im Internet

Zusammenfassung: Die von erkrankten Körpern produzierten Web-Inhalte, die nicht Teil medizinischer Studien sind, werden zunehmend als Befunde der ‚realen Welt' betrachtet. US-Politik und -Unternehmen entwerfen Wege, um den Beitrag von Patient*innen lesbar und nützlich für ihr evidenzbasiertes medizinisches System zu machen. Das vorliegende Forschungsdesign schlägt eine ‚ethic of repair' vor, welche von der politischen Handlungs-kompetenz von Menschen mit Autoimmunerkrankung lernen kann. Es bringt Ansätze des Feminist Materialism in einen Dialog mit zwei kollektiven Care-Gruppen, die Instrumente für reziproke und kollaborative *intra-actions* entwickeln. Diese Instrumente bieten ver-schiedene Ansätze, sowohl Krankheit online zu betrachten als auch Grenzen (von Körpern/ Expertisen/Räumlichkeiten) zu verhandeln. Sie artikulieren Werte und Risiken im Gene-rieren von verkörpertem Wissen (*embodied knowledge*) und der Neuverteilung von Daten durch digitale Communities.

Schlagwörter: Prekäre Kollektive, Gesundheit, Verweigerung, digitale Patient*innenarbeit, Boundary-Negotiating-Tools.

Introduction

I have been studying an image, an infusion selfie taken in December 2016 by a 28 year old Californian receiving medical treatment in Mexico intended to halt the progression of multiple sclerosis. The treatment she's documenting is limited to exclusionary clinical trials in the US so, through the help of closed Facebook groups, she sought care elsewhere. I am struck by the selfie's formal

similarities to Lynn Randolph's painting "Cyborg" in constant dialogue with Donna Haraway's writing (2004: 111). The selfie shows a smiling girl with piercings who is hooked up to machines and tubes, receiving medicines likely tested on or harvested from other species. Snapchat's facial recognition program looks through her phone and places floppy ears on her bald head. The portrait articulates a kind of agency sick bodies experience online: negotiating boundaries of body, of technology, of place – while producing knowledge.

This study focuses on collective care groups – that mostly started in the US – who transgress the boundaries of the healthcare system. As a design researcher, I navigate healthcare data systems gathering material evidence that has cultural and political resonance.

The selfie comes from the subject's blog, journaling her experience for other sick people or caregivers interested in learning the kinds of information medical experts don't provide. This sort of photo is common and searchable online. But if her photo was a clinical record it could not be shared until 50 years after her death. Forms of regulation like 'de-identify data' policies[1] are meant to protect patients' privacy, but non-disclosure is not always an option for those seeking care. When people are performing and recording their sickness for each other online, privacy seems like a nostalgic value that historically has not protected marginalized people. The growing numbers communicating their felt experiences as patients and sick persons online has drawn the attention of the healthcare system that wants to enter their content into evidence. It's what the medical industry calls 'real world' data.

I've been studying collective care groups with chronic autoimmune illnesses (AI) that disproportionally affect women, speaking with them about digital tools and labor that might undermine market logics by de-centering the expert and addressing what's missing or biased in the system. These groups connecting online metabolize the politics of sick bodies, a kind of agency in dependency,[2] where biological systems are said to malfunction and patients interface improperly (i.e. critically and politically) with corporate medical systems.[3] Their work speaks to my central question: Rather than designing patient interfaces that allow sickness to appear in a recognizable format to normative healthcare, how might design make systems more intelligible as 'made-up' and in that sense repairable in multiple ways? In what follows I will define patients as digital laborers, forming precarious collectives. Real world data grounds the analysis in clinical discourse. It provides an understanding of the political forces within the healthcare system, 'made-up' of boundaries between patients and care.

Within this landscape, boundary negotiating tools are examples of collective repair that stake ethics of repair for design. Feminist physicist Karen Barad wrote, "reality is sedimented out of the process of making the world intelligible" (2007: 105). Barad offers the term 'intra-action' to describe how concepts and objects, humans and artifacts are 'mutually constituted' through encounter. Agency occurs and transfers in encounters like the practice of measuring. Measuring is an intra-action which gives a sense of realness to the thing measured and the tool of measurement. Artificial Intelligence in medicine reading and measuring medical imaging is humanly unfathomable (Brouillette 2017). Black

boxed to medical experts – it does not try to pass for human intelligence. Thinking about digital data, "discreet units of analysis are not given but made" (Suchman 2006: 283), which suggests that healthcare data system design has social-material consequences that are untraceable even to experts. Lucy Suchman calls on critical practice to cut through bio political lines and open up interfaces to "redistribution across the human-machine boundary" (2006: 285).

Two case studies will illustrate kludgy and improper use of tools and systems: The Open Artificial Pancreas System group design tools of increasing self quantification, whereas the Canaries group of artists record themselves by improper use of digital tracking.

This research offers an interpretation of their artifacts, diffracted by observation and tools of measurement. Diffracted in Karen Barad's terms of taking a transdisciplinary approach that might rework disciplinary boundaries through interference and diffracted in the sense that Donna Haraway wrote about observing and looking for interference patterns on our lives and bodies. My design research is towards a feminist materialism. The work of queer theorists and feminist science and technology studies that responded to the near-simultaneous emergence of AIDS and the internet is woven into my thinking about systems design as co-constituting structures (as the study of immune systems mingled with theories of information networks). Today's emergent works of groups addressing autoimmune conditions are descendants of their struggles and assemblages.

Haraway lauded the efforts of 1990s AIDS activists, ACT UP, for replacing clinical discourse with more 'generative grammars' to produce knowledge among many unlike actors. Writing about the experimental design of research at the time she said, "unable to police the same boundaries separating insiders and outsiders, the world of biomedical research will never be the same again" (Haraway 2004: 105). Boundaries between industry and patients, and between digital and organic matter are "rendered intelligible and made real" via material-discursive apparatus (Hayles 2016: 284). They are constructed in research practices with lived consequences. ACT UP and other groups who are identified through illness, have challenged these boundaries to claim other ways of knowing and living in the world. When Haraway writes, "boundaries take provisional, never-finished shape in articulatory practices", (2004: 89) she suggests that negotiating boundaries can define new collective agents. When biomedical boundaries were blurred in AIDS research, patients experienced social activism and the biomedical industry started searching for ways to capitalize the knowledge. Years later, in an unrelated study, the term 'boundary negotiating artifacts' was introduced as an analytical framework by Computer Supported Cooperative Work (CSCW) researcher, Charlotte Lee, to distinguish the material evidence of collaborators' provisional boundaries (Lee 2007: 307). They establish/destabilize protocols; transmit info across boundaries; divide labor; are messy and contested; and transform with use. Following Lee's work, CSCW research of patient-provider data (Chung et al. 2016) adopted her framework to a context suitable for my study. Artifacts studied include Skype conversation transcripts, tweeted images of medical devices, Instagram metadata, GitHub chats, and more. In what fol-

lows two case groups' artifacts will be analyzed for the ways they diverge from the measurements and discourse of care providers and experts and forge collaboration with other patients.

> I was counting T-cells on the shores of cyberspace and feeling some despair… I have miscegenated and mutated, tolerated and assimilated and yet I remain the same in the eyes of those who would fear and despise me. I stand at the threshold of cyberspace and wonder, is it possible that I am unwelcome here, too? Will I be allowed to construct a virtual reality that empowers me? Can invisible men see their own reflections? I'm carrying trauma into cyberspace – violent gestures, a fractured soul, short fuses, dreams of revenge… My primary public characteristics continue to be defined by dreads of me, myths about me and plain old homegrown contempt. All of this confusion is accompanying me into cyberspace; every indignity and humiliation, every anger and suspicion. (Hemphill 1995)

Precarious Collectives + Patients as Digital Laborers

Donna Haraway observed that AIDS activists like ACT UP not only challenged expert knowledge, but insisted on its rapid improvement and equitable dissemination (2004). The refusal of terms to accessing care is the impetus for reconstituting boundaries. Since patients with autoimmune conditions are understudied and often experience misrecognition, they seek online those with similar experiences to their own for emotional support and knowledge sharing. How legible a group is to evidence based medicine is inversely proportional to their excludedness and their level of precarity.

The experience of chronic sickness in the US is often isolating. Autoimmune conditions (described as a malfunctioning system) can take years to be diagnosed. Those with 'invisible' symptoms feel compelled to repeatedly prove or act sick in order to qualify for services or strive to be able-passing in order to retain employment, relationships, etc. Any time sick people find each other it is a break from the neoliberal condition of individual survivalism and accountability. Patients' collective labor can produce community. Peers value and utilize evidence that clinical practice deems anecdotal and has no room to accommodate. They validate embodied experience. Symptoms and side effects that were never accounted for in a clinical trial are observed and measured in collective care groups. The production of this knowledge and the administrative tasks necessary to maintain their digital platforms is gendered, uncompensated and, in addition to producing content for social media platforms and behavior tracking algorithms, might concurrently be part of clinical and commercial observation.

T.L. Cowan and Jasmine Rault's paper on the "labour of being studied" (2014) considers this kind of collectivizing digital work (what they call a "labour of love") especially prone to capitalist exploitation of affective and domestic labor. Patients that might be denied employment or are unable to work can be exploited by the same internet tools that allow them to build solidarity.

Volunteer patient labor is a source of precarity. For people with limited energy and income, the choice of where and how to spend their time is of acute consequence. Making do with existing technologies and interfaces exposes their work to market forces and surveillance, but allows patients to focus their efforts on articulation and mending broken connections. In an effort to provide the missing infrastructure for each other's precarious existence, patients assemble existing social media platforms, open source software, and digital sensing devices to transmit embodied knowledge. They bear inconsistencies. This distinguishes them from interfaces designed in anticipation of patient use and requiring some measure of compliance. Inconsistent, overabundant, and anecdotal data frustrates industry attempts to reincorporate extraneous forms of real world data back into evidence-based medicine. The objects queer the system of care. They are deviations from accountability. Small groups are not meant to be comprehensible to everybody. The meaning attached to group material diminishes in legibility as it moves away from its community's orbit. The groups are perceived as not consistent or rigorous in their methods and so their information can be misinterpreted or invalidated by researchers. As sharing economies, they are self-exploiting and prone to oversharing.

The feminist scholar Sara Ahmed wrote, "Capitalism is a health system: a drastically unequal distribution of bodily vulnerabilities" (2014). When patients actively engage as subjects of study while understanding their own exploitation, questions of value are further complicated. The same data accrues different values and agencies depending on context and position of the actor. Free patient labor may produce monetary or speculative value for biomedical scientists, engineers, or corporations. Peripheral clinical surveys and patient advisory roles, even though they aren't subject to non-coercion laws, are often underpaid or unpaid. This free giving by patients produces knowledge and evidence for academic research like mine, which garners a degree, legitimacy, and an avenue for my future work. The value I extract from the subjects of my research exceeds the "magical symbolic currency that might be called 'the cache' of being studied" (Cowan/Rault 2014: 473). The harm might be reduced with research methods that materially protect collective care work and compensate sick femmes for their administrative tasks and embodied knowledge.

Real World Data

Foucault's critique (1969) on systems-design and poststructuralist lineage have made possible a critical feminist materialism that considers what digital tactics are privileged or ignored in (non-)clinical studies. Foucault's study (1963) of the clinical relation between doctor and patient producing 'individual facts' suggests that the clinical gaze and discourse makes the reality of sickness legible through the clear delineation of roles: the expert and the patient. Today the healthcare industry (structured around clinical trials) is adjusting to a new knowledge paradigm: the atmosphere of real world data surrounding it. In the 'real world'

patients are asked to track their self-observations. An accumulation of quantifiable evidence, produced by bodies, enters into equations of risk.

Studies find that 'predictable lives', or people represented by large data sets, receive 'greater' care and protection from the healthcare industry than those unaccounted for in available statistics and therefore 'unpredictable statistical lives' (Lipsitch/Evans/Cotton-Barratt 2016). Such differentials in care have no ethical basis but seem rooted in economic incentive and historic violence against marginalized populations. Medical science forms the basis of how rights are determined and medical evidence reigns supreme within the legal system. With the high stakes of legibility and predictability impacting healthcare access and outcomes, patients are burdened to produce legible data to improve chances of survival.

In "Black Data", Shaka McGlotten suggests the current data climate redeploys racist technologies in determinations of both digital recognition and representation as well as allocation of care and information (2016: 263). Technologies that determine access to care are often based upon an archetype that perpetrates the denial of personhood via slavery, pioneering, and other acts of domination. Within healthcare technologies designed for the ongoing ableist colonial project, sick bodies are misrecognized and our experiences are gendered, classed, etc.

Big data is an ambiguous realm where laws and policies tend to play a game of catch up with industry moves such as genetic risk assessments and wearable sensory devices. These so-called advances bear the same bias and threats as earlier technologies but with less regulatory oversight or human comprehension. The first step toward value is devaluation, or in order for one thing to have value, something else must not. In an evidence-based health system sickness is a devaluing condition, producing unproductive bodies and debt. Real world data bears an enormous market potential for extracting monetizable information from sick bodies, if made compliant.

With 500,000+ members and over 35 million data points, PatientsLikeMe (PLM) is one of the largest players in the industry (PatientsLikeMe 2018). The self-described 'not just for profit' recently raised $100 million to "merge genetic, biological and patient-generated data with sequencing and artificial intelligence" (Bartlett 2017). Investor Jun Wang, said, "PatientsLikeMe will be at the core of this ecosystem as we digitize, analyse and share insights and knowledge that can improve lives" (ibid. 2017). PLM ideology requires one quantified identity per user.[4] Real world data, however, offers messy pluralities within systems of care. Artist and writer Manuel Arturo Abreu notes that as patients use digital technologies to impact that reality,

> a medical label becomes a coping mechanism becomes a community becomes a politics becomes a metaphysics. The institutions scramble to keep up. (2016)

This opens up the possibility that if real world data continues to interfere with the system in non-compliant, non-normative ways it could transform values and redirect power. Rather than bigger data sets they could be smaller and divergent.

Real world data studies call reality into question, to consider the frames of perception applied to agents. 'Realness' passes as true within a normative culture. All it requires is to perform for the observer as expected. Practices within trans and drag communities might be useful in thinking through cultural expectations of normalcy and 'passing' for sick bodies. Judith Butler wrote an essay in response to the documentary film "Paris is Burning", which depicts drag, vogue, and 'real' as categories in competitive, queer, black ballroom culture. She builds upon the film's definition of 'passing', which trans communities lifted directly from racializing dialectics where people of color 'pass' as white. Butler describes 'passing' as the embodiment and reiteration of norms, to the extent that they "compel belief" (1993: 129). The ballroom brings awareness to conditions of life only called to the fore when we 'fail' to comply or we are unbelievable.

Sick bodies do not perform properly. In "The Body in Pain", Elaine Scarry talks of injured and vulnerable bodies in relation to objects. She recognizes objects and systems as existing in

> a state of 'realness' rather than 'madeness,' until the need for repair calls attention to the fact that they are 'made-real,' and may even remind us that before they were 'made-real' they were 'made-up'. (Scarry 1985: 313)

Malfunctions and repairs which patients make to systems have a power in exposing healthcare as a system that is 'made-real' and can be made otherwise.

Repair as Design Ethic

Design criticism is often speculative and predictive. Methods of risk prevention touted as design innovation are also looking toward the future; solving anticipated problems. Today the amalgamation of health records, AI, and other species we are co-creating threaten to overwhelm the future of bodies and identities. Critical discourse exposing the biases in an algorithm or a healthcare system is an important stage that might be taken further. Instead of the future, repair as a design ethic prioritizes the present: ongoing maintenance, destruction, and mending as labors which continually alter the shape and meaning of the materials we have. Informed by a feminist ethic of care, some technology studies claim

> worlds of maintenance and repair and the instances of breakdown that occasion them are not separate or alternative to innovation, but sites for some of its most interesting and consequential operations. (Jackson 2004: 227)

Reading data for realness or truth is, in Eve Kosofsky Sedgwick's terms, paranoid. In "Paranoid vs. Reparative Reading", she observed how often critical discourse during the early AIDS crisis, which sought to expose a conspiracy, fed paranoid fears and produced negative affect (Kosofsky Sedgwick 2003). The act of exposing prejudices doesn't immediately topple their power and so we must

acknowledge how confirming worst fears as truth offers scant support to sick bodies in urgent need of care. Kosofsky Sedgwick asks us to go beyond seeking truth and making predictions. Repair as design ethic digests data for sustenance now.

To take the position of repair calls into question evidence-based value systems and their methods of care – reconfiguring digital space to support pluralities in ways of knowing all kind of vulnerabilities and bodies. In lieu of paranoia, Kosofsky Sedgwick suggests a reparative knowing that reconfigures how we assemble bodies in digital space. Without rejecting predatory online platforms wholesale nor reforming healthcare attempts at patient interfaces, how do sick people and caregivers stay with the *trouble*[5] and mutate the digital objects at hand?

> What we can best learn from such practices are, perhaps, the many ways selves and communities succeed in extracting sustenance from the objects of a culture – even a culture whose avowed desire has often been not to sustain them. (Kosofsky Sedgwick 2003: 150)

Care communities are developing by assembling and reconstituting bits of digital culture that divert meaning and power away from the system's design intention. Suchman critically rethinks "the relations between practices of professional design and the conditions and possibilities of information systems in use" (2006: 278). The study of collective forms of computer use acknowledges design as an ongoing, social process. Not exclusive to professional designers, CSCW recognizes creative 'design-in-use'. Learning from collaborative design-in-use, repair as a design ethic resists normative interaction with material culture. Rather than forcing users into compliance, allowing for repair offers options to resist. In contrast to how I'm distinguishing repair here, participatory design practices employed by corporations seek to implicate users in policy agendas. Collective repair favors a healing "amalgam of powerful part-objects" (Kosofsky Sedgwick 2003: 150). Studying digital objects as they distribute and articulate embodied experiences of sickness offers new ways of knowing that require collective effort. The internet, as one of the primary cognitive assemblages discussed by Katherine Hayles in her work on the materiality of information,

> invites ethical inquiries that recognize the importance of technical mediations, adopting systemic and relational perspectives rather than emphasizing individual responsibility (2016: 34).

Mindful designs of repair offer the possibility to reject neoliberal regimes that individuate patients' human capital and saddle patients with debt while leaving corporations and states unaccountable for bodily harms inflicted by their extractive tech practices.

Sick Body Measures + Values

> Rate your pain on a scale of 1 to 10? I try to answer, but the correct answer is always 'a-numerical.' Sensation is the enemy of quantification. (Boyer 2015)

Sick people are affect processors who externalize and materialize sensation as well as feelings through digital interfaces. Of the quantifying variety, Open Artificial Pancreas System (OpenAPS) is an open source platform with 340+ members hacking digital tracking devices and making data accessible for people with type 1 diabetes. Type 1 diabetes is an auto immune condition that requires constant monitoring of blood sugar levels and treatment with insulin. Many patients are provided with an implanted sensor to alert them when the numbers are off, and another device is used to instruct their pump to release the right insulin dosage. Patient and designer Dana M. Lewis and a band of DIY pancreas makers have figured out how to access the code from the sensor to communicate to the pump so the whole system is automated: a closed loop organ (Lewis: 2016). Both devices' codes and data are designed to be available only to the manufacturer. Once the patients had access to the codes and data they were able to learn how the devices work and then design a third device that links the two. It's a basic computer made up of parts that cost about $150 (Fisher-Gunn 2017). The device can fit inside a tic-tac container, a popular storage solution [Fig. 1], but an unlikely vessel for internal organ communications.
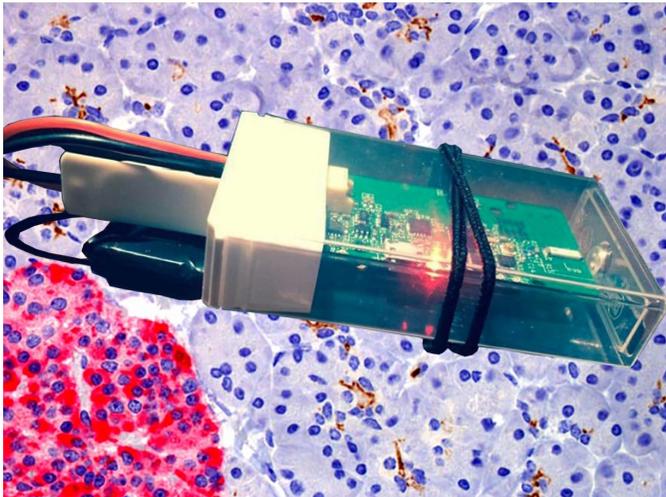

Fig. 1 (Karisa Senavitis, 2017)

Although there are various designs, transparency is a common characteristic observed in the group's devices [Fig. 2]. Transparency allows the visible hardware to match the ethic of the visible and readable code the OpenAPS community values. The materiality of information is not obscure or obtuse. OpenAPS runs on open source code and cloud-based software that the group collectively maintains.

OpenAPS was started in 2015 and continues to iterate and grow. Products that can be hacked by patients are seen as a manufacturer's liability (Weiss 2016). But as long as everybody in OpenAPS makes their own pancreas, by only sharing free information, the FDA has no jurisdiction (OpenHumans 2018). In Kosofsky Sedgwicks' sense of the reparative, the group is taking and reconfiguring the materials from the dominant industry to offer more sustenance to their community. The artificial pancreas's multiple, ambiguous presentations and constructions, through an unstable constellation of nodes, is non-normative even when it aspires to pass as the dominant cultural model. The OpenAPS pancreas is open to multiple ways of being and knowing a pancreas.

Fig. 2 (Karisa Senavitis, 2017)

For most healthcare consumers, a pieced-together medical device reads as less reliable than mass-produced industrial products. Parts that don't 'match', like Intel chips and tic-tacs, imply a tenuous, temporary connection. Joseph, a person with diabetes unconnected to OpenAPS, wrote,

> I have always been happy knowing that my meter is one of the most accurate on the market. I have been uninterested in how the meter determines my glucose level. The output is the event. I accept what my meter tells me. (Cevetello 2007: 64)

Something that looks mass-produced and therefore beyond an individual's capability can earn trust without understanding. But even Joseph admits when he's surprised by a reading: "my first reaction is to doubt the meter rather than myself […]. I am unwilling to place absolute trust in my meter" (ibid.: 66). His doubt suggests an opening towards trusting OpenAPS. While the object might look kludgy, the code can be read and understood. OpenAPS designers trust in what they have intimate knowledge of in collectively making and constantly maintaining. They demand the value of the object be measured not by

the market but its capacity for repair and reciprocal knowledge sharing. As in 2017, OpenAPS has begun to work with academics via Open Human to see if the FDA might review their open source algorithm. "They would never approve something full of hacks so they will never ever ever approve the whole OpenAPS system", Lewis told me over skype in 2017, "but could we just get approval on the algorithm or some design element?" Keen to accelerate and validate innovations brought forward by hacker and maker communities, Dana went on to tell me, "for the real world work we're doing there would have to be a different model and a firewall from the open source community." If the FDA regulatory process adapted to such a model, it would theoretically make OpenAPS-type technology more widely accessible, without interfering with the makers' process. However, incorporating the FDA has the potential and unintended consequence of providing new avenues of unpaid research for the healthcare industry's profit. The academic exercise might inadvertently allow medical industries to circumvent precautionary measures and costs associated with clinical trials or otherwise capitalize on technologies they did not pay to develop. Engagement with the FDA undoes the value created by OpenAPS: a reparative break in the system.

Interfaces of Feeling + Refusal

OpenAPS are addressing the problem of technology – its intelligibility and effectiveness – for lives already dependent on that technology. Because their treatment relies on constant measuring, OpenAPS complies with self-monitoring. The Canaries, with illnesses like Lyme, Crohn's, Lupus, and Multiple Sclerosis, experience vague and imprecise tracking of symptoms like fatigue, diarrhea, brain lesions, and pain. The autoimmune + chronic care artist group, Canaries, are dependent on regimes of care but have a more fraught relationship with them. They oppose OpenAPS's assumption that further development of digital tracking is universally desired or beneficial. Rather than addressing a specific technological problem, Canaries are addressing whole systems: political, medical, environmental, etc. Femme and gender-non-conforming, they are bonded by an intellectual and political position. Instead of designing ways to expand what can be grasped and treated by evidence-based medicine their work suggests feeling our way in worlding projects.

Canaries experience illness as a break from reality. Part of their repair work is to reincorporate systems, divided by science and law, back into a greater wholeness. In a skype conversation, founding member Jesse Marie Cohen offered me the insight, that

> some of the best medicine that I've had is anything or anybody who has helped me integrate marginalized parts of myself. […] The individual working on wholeness within themselves is kind of a microcosm and the collective is just on another scale working on exactly the same thing and they co-arise.

This radical refusal of boundary ties into theorist Denise Ferreira Da Silva's great question, "Do you want to be somebody for the state or a nobody against it?" (2014). Canaries, in refusing the boundary of body, are taking the whole nobody thing quite literally.

Another founding member of Canaries is the artist Carolyn Lazard and her work, "In Sickness and Study", [Fig. 3] chronicles what she's read while receiving infusions (2016). Each image shows an arm with an IV drip holding up a book cover. In one way it's a parody or critical response to the trend of infusion selfies patients take that promote a drug or treatment they're receiving, but without identifying hers. Lazard plays with the history of data records over time, from books to smartphones. She offers unpaid labor (as content producer) to social media platforms, which may lead to the record's disappearance or misuse by companies. She also offers many kinds of information, including data that's messing with the legibility or monitoring of her movements. Her Instagram check-in locations disorient: a plumber or a public library will be named rather than a clinic. The smart phone used to take the images also ensures that a more accurate record of the event could be located. Despite the scrambling effect of the tags, the photo's time and GPS stamp could be uncovered in the metadata and then fed back into the healthcare regime's version of real world data. But surveillance and exploitation don't preclude the communication of refusal and healing.
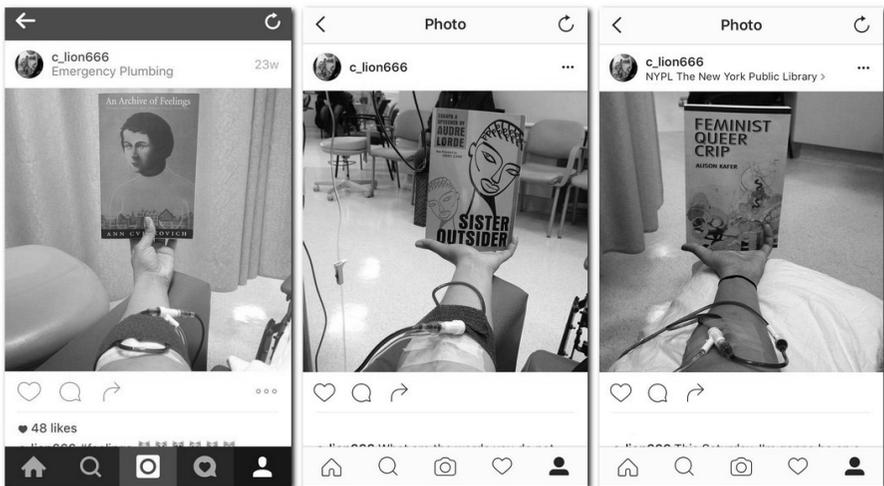

Fig. 3 Photos from Carolyn Lazard's Instagram series "In Sickness and Study," (2015-2016)

The combination of intravenous therapy and printed matter offer a mind/body approach to healing. The books, written by Audre Lorde, Alison Kafer and others (Lazard 2016), address the social and political dimensions of sickness and other forms of marginality. They offer agential space for her experience distinct from the ones provided by the healthcare industry. In a sense, Lazard's time as a patient within the health care system is layered with other evidence that refuses the infusion as the primary treatment taking place. The choice of the

word 'study' seems to come from the Harney and Moten approach to black radical study. Their book, "Undercommons", proposes a fugitive relation to institutions of learning: to be unproductive for the institution, while operating from a place within (Harney/Moten: 2013). Lazard's system of recording is unproductive for the clinical observer, but a healing library for those who refuse. Lazard's archive could also be calling for the protections of a librarian who would maintain the provenance and rights to her data with the custodial care attended to zine collections.[6]

Small data groups like Canaries or OpenAPS do not easily fit into medical accounts. Their designs are specific and point to areas where needs and vulnerabilities are heightened. For some communities, tangled, kludgy, illegibility offers an (un)intentional layer of protection or form of refusal. In considering the research done with boundary negotiating artifacts thus far, refusal ought to be added as a stage of boundary negotiating within computer-based collaborative work. Refusal was introduced by Jack Halberstam as to:

> refuse that which was first refused to us and in this refusal reshape desire, reorient hope, reimagine possibility and do so separate from the fantasies nestled into rights and respectability (Harney/Moten 2013: 12).

Ruha Benjamin's medical justice work on 'biodefecters' locates refusal within clinical discourse with 'informed refusal' as added corollary to 'informed consent' (2016:16). Benjamin addresses a need "by those who attempt to resist techno-scientific conscription [and] expose the limits of individual autonomy as one of the bedrocks of bioethics" (2016:1), suggesting that refusal goes beyond individual choice to potential collective forms of conscientious objection. Designs that allow for questioning and disagreement would reduce harm and violent norming by honouring and protecting the embodied experiences that make data real.

Conclusion

> Responsibility – the ability to respond to the other – cannot be restricted to human-human encounters when the very boundaries and constitution of the 'human' are continually being reconfigured. (Barad 2007: 392)

The case studies were offered to investigate the digital boundaries and tools of collective care groups. I am learning that even when the intended focus is to investigate digital boundaries/tools, many still feel the need to first interrogate the illness, its causes, definitions, etc. Oftentimes questioning the legitimacy of sickness and people's ways of coping with chronic conditions is perpetuating violence against people already socially deemed hysterical, unproductive, malfunctioning, disposable, and a burden. I am connected to these groups, but I am not a spokesperson. I am responsible for how I have presented and interpreted their work. With their flaws, these groups are making each other's lives more livable. In the process they complicate my paths of institutional criticisms.

OpenAPS offers a tech-positive stance on medical surveillance technologies in contrast to Canaries' general distrust of tech-solutionism. Both present alternate values for knowledge production that reroute and redistribute data. In their small specificity they make a case for the need for diverging paths of medical information rather than ever bigger, universal data systems. The variety of collective care groups demand an equal variety of careful responses.

Participatory design spaces often poach patient data for industry initiatives (Lowe et al. 2016). This is enabled by "a lack of means to address privacy concerns that change across the evolving collaboration context" (Chung et al. 2016: 771). Under the Health Insurance Portability and Accountability Act (HIPAA) guidelines, "self-tracking data should only be accessed by the individual or their provider", (ibid: 779) but once data is brought into clinical and other realms rules are blurred. The FDA states that they won't regulate mobile apps being used like medical devices but researchers say, "more clarity is needed around self-tracked data transfer and storage" (ibid: 779). While the FDA is working toward incorporating real world data into their processes[7] (increasing the medical regime's drive for patients to share more and more), new kinds of protections for privacy, confidentiality, and function creep will follow. The way sick bodies share online only amplify and complicate the stakes of system bias and neoliberal trends of individuated and precarious work. There are opposing motives for (non)disclosing data and future repercussions are unknown.

Patients processing and sacrificing their data need a variety of protections. Librarians –guardians of critical, contextual approaches to information – can provide boundaries required for real world data by drawing sharp distinctions between raw data and knowledge gleaned. Their expertise could inform "the highest levels of design to ensure that preservation standards are reflected in the structure of metadata" (Mattern 2016). As GIS Methodologist Leah Meisterlin puts it, "data tells the story of how it's collected" (2016). And data protection does not begin with its processing but already during data generation and collection. By taking care, we might still design research methods that reduce harm and burden for sick bodies, and offer value generation and remuneration for their labor. Sharing embodied experiences through digital tools offers knowledge and healing which reimagine ways of being together in the world.

As I continue to grapple with boundary objects, I chose not to reproduce the infusion selfie described in the introduction. Inclusion here would strip the image of its context and community. The benefit to me would exceed the benefit to the subject. So I, as a researcher, self-impose limits to accessing digital artifacts to put to practice theories that value and honor vulnerabilities. Suchman describes people and machines as contingently stabilized through particular arrangements "whose reiteration and/or reconfiguration is the cultural and political project of design in which we are all continuously implicated" (2006: 285). Critical feminist materialism can inform our approach to designs by and for groups of sick people: sensitive to moments of agency when bodies encounter systems. This perspective will allow us to recognize areas online where interfacing improperly redirects power.

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Remarks

1 'De-identifying data' is part of the HIP-PA privacy rules establishing national standards to protect individual medical information https://www.hhs.gov/hipaa/for-professionals/privacy/special-topics/de-identification/index.html.
2 Taraneh Fazeli wrote, "find agency in dependency and further complicate the polarities that suggest individualism or independence must be counter to reliance on others" (2016).
3 Angie Kafer in her disabilities studies criticism of Haraway's cyborg recognizes "the potential to interact unfaithfully with the medical system" (2013).
4 Manuel Arturo Abreu wrote, "our digital footprint must align with the state's identification system in the wake of the Real ID Act of 2005 and the FBI's Activity-Based Intelligence paradigm, launched in 2010" (2016).
5 Donna Haraway uses the term of trouble calling us to complicate and elaborate paradox in order to support world-making projects.
6 The code of ethics used by zine librarians strives to balance availability of content with the safety of its creators/culture. Crucially, the code includes a right of refusal for zinesters (Robertson 2016).
7 The top programmatic priority of FDA Commissioner Robert Califf is leveraging real world evidence to inform FDA decision making (Brennan 2016).

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