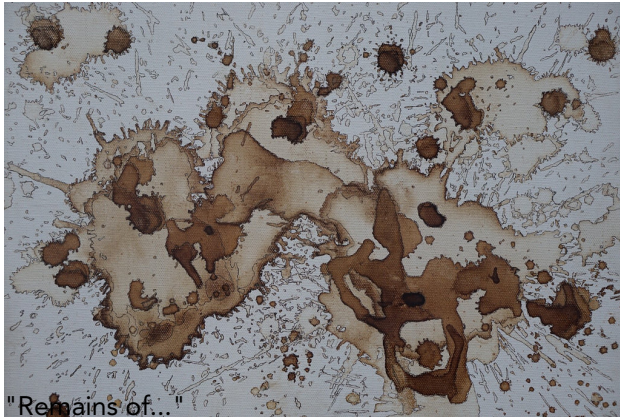


Technological Residues

Brittany Fiore-Gartland

The care managers glanced anxiously at the two tall stacks of white envelopes that a clinic admin had just dropped off in their office. These envelopes contained letters informing a cohort of chronically-ill patients enrolled in a telehealth program called Health@Home that their Health@Home devices needed to be returned to the clinic. Medicare was terminating the program and these letters made explicit that the telehealth devices, once intimate fixtures in patient's homes and integral parts of their daily routines, were no longer theirs and no longer functioned as their connection to care. The patients who had come to depend on the program wondered why no one had asked them how they felt about it. For patients, Medicare's decision highlighted the fact that their health and well-being were part of a larger experiment, what Medicare would call a demonstration project, in which they didn't seem to have a voice. The care managers that developed their practice of care management and their organizational network with and around this technology for the last several years, felt powerless in the face of this decision and the looming crisis of, now what?

This demonstration project is not nearly alone in its fate. In fact, this Health@Home case that I followed for two years was part of a broader comparative study of digital health across the U.S. and India. On a global scale, demonstration and pilot projects in the technology for development arena are notorious for their high failure rate^[1]. Many development professionals referring to the phenomena in the mobile health field as "pilotitis," referring to the NGO "graveyard" of pilot projects in developing countries that never make it to scale or that burn out at the end of the project funding cycle^[2]. One global health funder and practitioner I interviewed referred to this well-rehearsed practice as the orphan model, in which "you hand it off to whoever is there, in our case [the local NGO], and you walk away and who knows what happens to that. Yes, you orphan it, and that's the model that most of our systems operate under."^[3] This orphan model produces a commonly heard story depicting piles of mobile phones, gadgets or other high tech equipment that sit disconnected, unused, or collecting dust in a drawer, since the funding and organizational support for projects ended. The Health@Home demonstration project offers an important counterpoint around what happens when technological infrastructures are discontinued and forces us to take seriously what remains after technology dies.



"Remains of..."
Brian Fiore-Silfvast, Coffee stains on canvas

The Health@Home Program: An Introduction

The Health@Home program^[4] uses information gathered in the home via the Health@Home device to manage chronically-ill patients through an integrated care management program. The Medicare demonstration project was implemented by River Medical, a large rural healthcare delivery system providing primary and specialty care to residents in the region. In order to lower Medicare costs, this technology system, combined with intensive care management, targeted high-risk, high-cost patients to reduce the utilization of high-cost medical care, including ER visits and inpatient hospital stays. Through a series of educational dialogues, the home-based handheld device collects patient-generated data on a daily basis and asks questions about symptoms, vital signs, health behavior, and knowledge tailored to the patient's diagnoses. The primary diagnoses include Diabetes Mellitus (DM), Chronic Obstructed Pulmonary Disease (COPD), and Congestive Heart Failure (CHF). The patient-generated data is sent to a server and coded algorithmically for low, medium, and high risk. This risk assessment is then displayed on a color-coded dashboard as part of the Health@Home web-based application for care managers to review and monitor.

Health@Home began as a technology to support care management, yet as the technological and organizational structures co-evolved over time, Health@Home transformed care management and the wider network of organizational practice. Health@Home provided the care managers with a tool for extending care into everyday interactions and spaces outside of the formal clinical setting and provided an opportunity to intervene or act on

data at the appropriate times. Care managers used the patient-generated data as a way to initiate conversation and develop a relationship with patients. The care managers responded to patients' daily data collection through sending personalized messages through the device or in a phone call to let patients know there was someone who cared on the other end of the line. As one care manager put it "a small way everyday of saying 'I care, we care.'" This social connection and relationship that developed over time with the care managers motivated patients around tracking their data and their health more closely. The patient-generated data also served as the basis for intervention for care managers. The risk assessments triggered care managers to look more closely at the data and then reach out to patients over the phone to learn more about what was going on. The data were also part of making clinical decisions across the care provider team of physicians, nurses, and social workers. When the program first began the contextual, narrative knowledge that the care managers developed about their patients through daily conversations wasn't actionable within River Medical's clinical decision-making structure. Communication pathways and protocols around how to manage these data and how to integrate the knowledge into clinical decision making did not exist. Through the advocacy work of the care managers, a process was initiated by which care managers and physicians co-designed protocols and established communication pathways. This co-design process transformed the way they worked together and initiated a team-based approach to care.

Beyond the significantly improved health outcomes, I witnessed the value and transformative quality of this program across all stakeholders. Which is why I was shocked to hear about Medicare's decision to discontinue funding. The financial compensation routines of formalized medicine did not find the project cost-effective, deeming the care management team too expensive. In the aftermath of this decision the care managers had to slowly wean all their patients off the program, and River Medical had to redefine what care management was without the Health@Home technology. This is how I found myself unexpectedly back in the field attending a workshop at River Medical aimed at articulating just that. In addition to conducting observations of this workshop and of care managers doing care

management without the Health@Home technology, I also conducted a set of interviews with care managers and physicians affected by the termination.

The Aftermath

The workshop brought together administrators and care managers to re-articulate care management for River Medical without the Health@Home technology, redefining the role of the care manager, the practice of care management, and the care management patient populations. As it turned out, the care managers found it very challenging to define their role or their practice without the Health@Home. In one care manager's words, "Health@Home made us the care managers we are today." The routines and practices that they knew to be care management had co-evolved with the technological system. For instance, when discussing how to define different care management populations, an administrator suggests they divide the care management sub-populations into categories of chronic disease management and acute conditions. The administrator asks the care managers to list the diseases and conditions that would be subsumed under each category in an effort to differentiate between and bound the acute and chronic populations. This process quickly leads to confusion for care managers who keep thinking of particular Health@Home patients that don't fit neatly into categories of acute and chronic conditions. After much discussion of what counted and what didn't, the care managers finally decide that it is easier to define the chronic disease management population in Health@Home terms: as "Health@Home people." The care managers agree that the chronic disease management category could be most effectively understood and operationalized if the defining question for each patient was, "If you had a device to put in her home, would you?" At this point the lead care manager writes on the white board, next to "chronic disease management," "(anybody that would need a Health@Home)." With this parenthetical definition, the chronic disease management population was clear to the care managers. The boundaries of this population had co-evolved through the use of the Health@Home in practice. Health@Home patients had become an identifiable group to the clinical

team in terms of their own care management relationship facilitated through Health@Home.

What does the practice of care management look like without the technology that had co-produced it? Care managers expressed how conversations with patients were more difficult without the daily data collection with Health@Home as a spark, or basis, for inquiry. A care manager, Beverly, commented that it felt much more like cold calling because you had to ask how they are doing with no data, whereas "with the Health@Home you had concrete data so you could start the conversation with 'I see you have gained 6 pounds since the last time we spoke...'" In my observations of care managers talking to patients on the phone, I hear them encouraging the patients to continue self-monitoring at home, even though there was no device to input the data or any guarantee that a care manager would be tracking it. I notice the care managers asking patients many of the same questions that had been part of the Health@Home educational dialogues. Nancy, another care manager, explains, "I want them to still continue with that thought process that Health@Home gave them." Then I notice she is reading from a piece of paper on her desk full of hand-copied notes. After the call she explains how much patients had enjoyed the Health@Home's trivia questions so she decided to hand-copy them off the device before they had to return them. She likes to offer them to patients at the end of her phone conversations. The care managers were transcoding particular affordances of the technological system into human labor in order to repair their function in the absence of the technology.

The Health@Home system's mechanisms for prioritizing, documenting, and interpreting patient information became inextricable from the practices of care management. All the care managers agreed that their work wouldn't have been possible without the Health@Home. As one care manager described:

"If I had to manage 100 patients and do it all by calling them on the phone and saying, 'how are you today? what's your weight?'—I wouldn't get to them all in one day, and I'd never be able to prioritize which ones needed help today versus just calling them and saying, you know, 'how are you doing today?'"

Care managers reflected on how the Health@Home system trained them to be effective care managers by demonstrating through its program architecture and algorithms how to prioritize patients, organize patient information, and intervene effectively with patients. In the absence of the Health@Home, care managers tried to repair some of the prioritizing and documenting practices core to care management work even without the supporting technical structures for doing so.

In the absence of the Health@Home system, I observed care managers developing alternative systems for prioritizing patients and documenting patient information through a patchy combination of paper-based notes and inbox reminders. Care managers use paper to jot down observations from the conversations with patients. These notes remained accessible on their desk for when they followed up (if they remembered to), but there was no place separate from the Electronic Medical Record to store extensive patient notes, including relevant clinical and non-clinical information. In practice, they simply didn't record this information, making it difficult to monitor important changes outside of the medical chart and to develop personal relationships with patients, which often relied on engaging in the patient's personal narrative. Care managers also set inbox reminders to alert them with whom to follow up and when instead of having a Health@Home's color-coded risk assessment across their case load that made it easy to know who to call first. Collectively, these small repairs represent an attempt to bootstrap the functions afforded by the Health@Home technology in its absence. Even as many of the affordances of the Health@Home system could not be repaired, this patchy system revealed the extent to which they had adapted their care management practice around the Health@Home technology.



45 Moons: Stasis

Brian Fiore-Silfvast, Coffee stains on paper

Technological Residues

This case presents an opportunity to understand what happens when technology is discontinued, yet organizational structures must be repaired and re-articulated. Accounts of technological innovation don't often examine what remains in the wake of so-called failed technological infrastructures. Even though this may be the part from which we can learn the most about technology and innovation. In the wake of Health@Home's termination, repair labor emerges and materializes as organizational ontologies, transcoded dialogues, and patchy systems of information management. We can conceptualize these repairs/remains as technological residues. Each repair reinvents or preserves a technological affordance, highlighting both the essential nature of repair labor and the persistent agency of technology even in its physical absence.

It was in the absence of the technological affordances of Health@Home, and through the instances of repair work that the co-evolution of technological and organizational structures became visible. In the aftermath, we can see which organizational structures and routines of the program become unworkable. We can also see which remain workable but reliant on repair labor and a different, patchier materiality. Important to recognize here is to whom the burden and responsibility of repair falls. In this case, as is often the case, this burden falls to those care managers that felt they didn't have a voice, and whose work is most impacted by the change. As key innovators throughout the demonstration project, in the aftermath this innovation continued as repair labor that materialized as technological residues.

Technological residues are an important part of the aftermath that demand a longer-term view of technology and innovation. They can help us refocus on important ethical and practical questions about what happens after technology projects fail or are discontinued and who is responsible. How do communities and organizations adapt to a broken or failed state of things? What can we learn about processes of innovation through examining the aftermath of failed or discontinued technological infrastructure? Jackson^[5] calls for scholarly attention to this aftermath in order to remedy a productivist bias in studies of technology innovation. Residues can provide insight into the processes of innovation and the extent to which organizational and technological co-evolution has occurred. The residues build upon the ongoing repair and maintenance work which "occupies and constitutes an aftermath, growing at the margins, breakpoints, and interstices of complex sociotechnical systems as they creak, flex, and bend their way through time."^[6] This repair and maintenance work is intimately involved in why in some cases technology and organization will co-evolve to the extent that the ontological boundaries between them shift or dissolve, making visible what Suchman^[7] has described as the "dynamic and multiple forms of constitution" and the ongoing process of boundary making. The concept of technological residues can help us notice and understand how affordances of technological infrastructures can operate through repair labor. This allows us to have an eye towards who bears responsibility for that labor, whether it is visible,

and whether their voice is being heard. A closer examination of the repair and maintenance labor involved throughout can help us understand why some projects leave residues and others do not.

REFERENCES

- [1] Kentaro Toyama, "Technology as Amplifier in International Development," in *Proceedings of the 2011 iConference* (ACM, 2011), 75–82, <http://dl.acm.org/citation.cfm?id=1940772>
- [2] See Erica Kochi, "Building the mHealth Ecosystem" *Stanford Social Innovation Review*, February 20, 2013, https://ssir.org/articles/entry/building_the_mhealth_ecosystem
- [3] For a more extensive discussion of these issues, see the author's dissertation, Brittany Fiore-Silfvast "The Frictions and Flows of Data-Intensive Transformations: A Comparative Study of Discourses, Structures, and Practices of Digital Health in the U.S. and India" (2014), 210-278.
- [4] Pseudonyms are used to reference the particular programs and healthcare systems observed in order to protect confidentiality.
- [5] Steven Jackson, "Rethinking repair," in *Media technologies: Essays on communication, materiality, and society*, eds. Tarleton Gillespie, Pablo Boczkowski, & Kirsten Foot, (Cambridge, MA: MIT Press, 2014), 221-223.
- [6] *ibid*
- [7] Lucy Suchman, *Human-machine reconfigurations: Plans and situated actions*. (Cambridge; New York: Cambridge University Press, 2007), 268.