

UCSF

Advancing Digital Health Humanities Institute

Title

Beyond the Medical Record: A Digital Archive of Immigrant Stories from Boston Harbor Island.

Permalink

<https://escholarship.org/uc/item/56c132s7>

Authors

Poemape Heredia, Sisary

Penner, Louise

Publication Date

2026-10-22

Supplemental Material

<https://escholarship.org/uc/item/56c132s7#supplemental>

Reflections About The Project Beyond The Medical Record

Sisary Poemape Heredia and Louise Penner

While in a faculty workshop on digital humanities, we realized we have a shared interest in global health humanities and recovering the experiences of immigrants to the US. The Boston Harbor Islands provided us with an alternative site to Ellis Island to think about what happened when ships arrived, were inspected and quarantined, and lives were upended in numerous ways as passengers and crews interacted with state institutions. We thought not just about the passengers, but also those people who were displaced in order for inspection and quarantine sites to exist on the islands, those who built and maintained the facilities, the administrators who ran the inspections and institutions, and those who provided medical and other forms of care and services to the detainees and patients, and – in some cases -- those who conducted research about disease using the patients as their subjects.

We have throughout our archival research and efforts to incorporate diverse digital tools understood the immigrant experiences especially to be overwhelmingly carceral in nature. Confinement to ships during the long passage to America; being subject to inspection stations on arrival, and, in some cases, then subjected to medical research, and, finally, held in quarantine until either the ship and/or the individual was declared to be free of disease: these were all experiences had by early 18th- 19thc and even some early 20thc immigrants, abductees, and travelers. At the same time, we knew we needed to balance our assumptions about the state's desire to contain the freedom and opportunity afforded immigrants with our understanding of how scientific medicine had, over the course of the nineteenth and twentieth centuries, come to more confident understandings of the means of transmission of different disease pathogens. For example, as leprosy gradually was understood to be far less contagious than had been earlier assumed, were strict quarantine regulations still warranted?[1] Was quarantine sometimes entirely about social control, and not primarily a public health measure? Did the immigrants living under such forms of containment sometimes experience them as a necessary price for the opportunities that immigration might provide them or did they understand the treatment as punishment for having had the audacity to come to the United States of America at all? In 1905, at a public hearing at the Massachusetts State House, debate broke out about the proposed location for a new leprosarium near Brewster, MA, with residents who lived near the proposed site arguing that the "damage which must result to this unique region when just at the point of blossoming out into a lucrative summer resort district should trump any concern for the "wellfare [sic.] of a small group of aliens" (Secretary's Report 1916). Fear of the stigma around leprosy shaped these arguments, rather than fear of the contagiousness of the disease itself, an observation supported by the residents' argument that leprosy cases should instead be treated at the state hospital (then in XX) with other patients.

Two recent world historical events have provided us with a sense of urgency for our effort to try to recover something of the perceptions and lived experiences of the people who lived, worked, and/or were treated for a time in these Massachusetts island hospitals. First, the MAGA backlash to COVID-19 public health protocols, including mass quarantine, demonstrate the danger of potentially over-emphasizing individual rights during a period that was

overwhelmingly understood by scientists to constitute a genuine public health emergency that required drastic measures to protect the public. Second, the beginning of the Trump second term administration's brutal immigration policies in which families have been separated, people deported to countries of which they have no knowledge or experience of the language and culture, and where it is evident that their health and safety will be put in jeopardy, have reminded us of the perils of state control when the state –and not experts– seize control of what counts as science, what scientific studies get supported, and how public health policy is impacted as a result.

These contemporary arguments are occurring in a context of digital utopian thinking, where it's tempting to believe that ample evidence is available (epidemiological datasets and bystander videos of illegal ICE behavior for example), but we are also, of course, living in the era of deep fake videos and battles for the responsible control and maintenance of archives, physical and digital. In other words, the public trust in the federal institutional archives is being eroded. That the Trump administration fired and replaced the National Archivist on the first day of his second term and that he is exerting control over the extraordinary Smithsonian collections in the interest of rewriting U.S. history to support a White Christian nationalist agenda speaks to the danger of our current historical moment as far as our ability to understand and interpret archival records as histories of the present. In other words, we will need to become even more rigorous and imaginative readers of archives.

Looking back, for Louise, it was while writing about the absence of positive data around incest and sexual abuse in the nineteenth century that I first encountered Holocaust historians, such as Dominic Lecapra, and theorists such as Eve Kosovsky Sedgwick who were asking the kinds of "questions of evidence" that theorized about the impacts of archival absences in our attempts to understand the history of the present. They highlighted in different ways personal and collective racial, ethnic and other experiences in which vastly uneven power dynamics had allowed for instances of abuse to go unnarrated and disbelieved. Benjamin, Foucault, and Derrida have perhaps been the most influential scholars to theorize the extraordinary power conveyed by and through institutional archives. As important as institutional archives are, and as damaging as the state's destruction and manipulation of those archives are, ongoing work on personal scrapbooking, commonplace books, natural history cabinets, and other everyday personal ephemera which tend to fall under the radar of Christian nationalist censors, continue to allow for insights into the lived experiences of historical people through attention to their habits of collecting and of establishing and adapting particular text/image relationships. For Sisa, José Esteban Muñoz's work in "Ephemera as Evidence" was key in thinking about what to do when grappling with archival silences and suggests we look into relationality and communities of care to content with what is not readily identified as archiving-worth evidence. Also, to look at how the archival materials we are presented with can contain more that they suggest if taken at face value as pieces of Truth.

Digital tools have encouraged different ways to imagine both documenting large numbers of archival records and absences, and imagining what might be the untold stories that these records and archival absences would together prompt us to construct. We liked the idea

that in digital storytelling, as Jessie Marie Johnson writes, viewers and readers can be provoked to think beyond any particular linear narrative and/or narrative voice: “Lost is the single author who, in cahoots with an editor and publishing entity, guides a reader down a distinct and clear path” (Johnson 2018, 59). Johnson calls not just for attentiveness to the ways historical narratives are shaped over time by those who tell and retell them, but she also insists that readers consistently interrogate “the stability of what has been or can be categorized as data, the uses the idea of data has been put to, and the stakes underlying data’s implicit claim to stability or objectivity” (2018, 58).

In our work, focused on immigrants and others who were subject to quarantine in New England from Colonial times through the early 20thc, the work of Black digital humanities scholars like Johnson has most inspired our thinking and our processes for pursuing a digital archive that would provoke rich sets of possible stories, informed by archival data and artifacts, but pushing for a deeper consideration of the probable and the possible lived experiences of the patients and immigrants at the center of our study. The collective, XX, authors of “Doing Digital Wrongly” provided inspiration in their willingness to “create in spite of,” to defer the conventional processes of research, data collection, analysis and presentation in their creation of a digital archive that centers and celebrates the experiences of black girls. (Brown et. al 2019). Their commitment to the people whose experiences they wish to honor without sanitizing or serving the purposes of others is what inspires. And their critique of DH is sound:

“Dominant digital humanities narratives and practices often focus on the creation of new technologies or the technological affordances of digital devices and instruments, but we have found that tech-driven projects give the illusion of advancement based on specialized (often elite) expertise about a machine at the expense of people.”(Brown et al 2019)

Following this line of thought, we have sought to use digital tools to attempt to understand lived experiences that we cannot witness or read first-hand accounts about, nor are we likely to find definitive archival evidence about those experiences. Instead we use the digital tools to try to construct from the available materials multiple possible narratives or speculative histories that neither deflect nor select in the interests of furthering positivist conventional ways of understanding the experiences of immigrants, patients, etc.

ArcGIS Storymaps offered several affordances for speculative history writing that we felt complimented what we had most admired in the work of writers such as Sadiyia Hartman whose method of “critical fabulation” has been at the root of our practice both in conceptualizing our own Storymap and assigning digital Storymaps to students our medical humanities course, “Outbreak: Exploring Narratives of Infectious Diseases.” The ability to organize narratives via selection and arrangement of images, video, voice, timelines, and maps provided us ways to allow our reader to encounter our archival materials as if viewing them through a prism, where any given light source we might provide could bring out an entirely different facet and tone in the narrative the viewer might construct from an archival thread.

On Provenance

Our archive began with a file from the Massachusetts State Archives consisting of a set of patient records (with patient names redacted) from the Penikese Leprosy Hospital, a 1916 hospital report written by a Secretary of the Massachusetts State Board of Charity, and other ephemera, including a brief newspaper article on the Penikese graveyard, a hand drawn map of that graveyard with the deceased' last names provided, and copies of two pieces of legislation, H.R. 20004, An act to provide for the care and treatment of persons afflicted with leprosy and to prevent the spread of leprosy in the United States (Feb 25, 1915) and an accompanying report, 1286, "Prevention of Leprosy in the United States." Because Massachusetts has no " " date, when medical records can become available for public view, the redaction by archivists of names and identifying details from the patient records was the only reason we were able to see the file.

We quickly realized that while the Massachusetts archives provided us with terrific information about state-run institutions, such as Penikese Leprosy Hospital, many of the quarantine stations and hospitals that pre-dated Penikese by over a century were presided over by state institutions, such as the XX, and were thus located in the much more recently established Boston City Archives.

Future directions

There are two important contextualization efforts we would like to include in a future version of our work regarding institutional expectations and previous leprosarium institutional locations at the national level. First, we would like to provide further some contextualization for our "Beyond the Medical Record" Storymap project by providing an account of how the earlier New England Harbor Island quarantine stations and hospitals set particular kinds of expectations for how such spaces would operate. But, we also want to be able to emphasize how unique leprosy was in the amount of anxiety it raised. While patients with far more contagious diseases, such as smallpox, were expected to be sent to the City Hospital, leprosy patients had to be taken far from the city to the island quarantine hospital.

We also wish in future to contextualize our Storymap featuring the Penikese patients within the far more abundant histories of the Molokai leprosy colony in Hawaii (the only other leprosy hospital in the US prior to Penikese) and also the National Leprosarium or Gillis W. Long Hansen's Disease Center in Carville, Louisiana, which began as a home in 1895, but became the Federal leprosarium in 1921. For example, the story of a Penikese physician who was not allowed to practice in Louisiana and fought to keep Penikese open for his patients warrants its own section in the visual narrative. In each of the above efforts, we will continue to center the lives and stories of the Penikese patients because of their unique historical circumstances and the depth of the stigma they faced in early 20thc New England.

In our effort to continue developing a critical digital humanities perspective, we see our project's future centering a reflection on the accessibility of our platform, its relationship to the general public, and as a pedagogical tool. ArcGIS is a virtual space that we continue to use for

the affordances it allows us to engage with in a more micro scale than its most popular uses for geo spatial, large scale data set display. In that sense, we are always eager to create more ways to convey visually and textually the probable experiences of patients. For our first attempt we have been careful in intentionally juxtaposing visual, textual, and aural grammars to convey a message less interested in mapping magnitude at a large scale, and instead privilege a more in depth reflection of the possible lives and experiences of the peoples within the island. It is within that spirit that we will both continue to explore the platform for its more humanistic centered affordances and search for alternatives with similar tools that our public university can support with companies far less interested in the potentially harmful effects of prioritizing a hyper focus on the gains of large scale data collection and visualization.

Regarding accessibility to the general public, we want to continue to pursue partnerships with local institutions such as the Massachusetts Archives and community organizations for ways to bring the material to the general public, who visit the Boston Harbor Islands and Woods Hole, MA. In an effort to think critically about audience engagement for our first iteration of the project we develop audio accompanying texts provided and would like to continue the effort for the visual aspects by incorporating alternative text describing images. We are always interested in enriching the ways in which the accessibility of our project can learn from the lens of disability perspectives. These are conversations that we are interested in sustaining alongside other academics interested in digital storytelling and Global Health Humanities. As a pedagogical tool, taking our experience from incorporating the StoryMaps element into two sections of 200 level college classrooms, we wish to continue imagining ways to get our students interested in speculative history and imagining the lived experience of historical people, particularly immigrants and those who experienced illness, quarantine, and ostracization, and thus our knowledge of their lives has been limited to institutional records.