

Digital Opacities: Remediating the History of Medicine

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Introduction

For a field defined by the Hippocratic oath to “do no harm”, modern medicine has a long and troubled history of exploiting the bodies of patients. From the Tuskegee Syphilis Study, to the stolen cells of Henrietta Lacks, to the organs pilfered from dead children in the Alder Hay scandal, to the atrocities committed by Nazi scientists in the second world war, medical scientists have a long and documented history of malfeasance. The codification of informed consent—or the ethical guidelines where medical subjects need to be informed of their participation in a study, how the study will affect them, and given the option to opt out of medical research—developed in response to the last of these examples, provides a framework for the ethical treatment of research subjects.

There is a problem, though, in the history of medicine, as librarians, archivists, and other knowledge workers have to work with materials stolen from the bodies of subjects without their consent. The protocols and policies of institutional review boards (IRB) and other bioethics safeguards have historically disregarded the desires and rights of the long dead and their still living communities.

The Opaque Online Publishing Platform (OOPP) was designed to reflect on and speculatively address how knowledge workers in the history of medicine might reassess their primary materials. A minimal computing, Jekyll-based web template, the OOPP was built to help scholars literalize, in their research, Édouard Glissant’s notion of opacity. A postcolonial framework, opacity refers to the ability for individual subjects to refuse to be ingested within the totalitarian extractivism of western epistemics. By practicing this opacity, the OOPP enables scholars to reflect on what might be lost when they choose to divest unethically sourced materials, and practice a history of medicine that respects the rights of the long dead.



Neurological laboratory.

The neurological lab at the Henry Phipps Institute circa 1905. In the foreground are dozens of jars with human brains, taken without consent from patients who died at the hospital. Lawrence F. Flick, director of the institute, noted in 1904 that they needed to expand the facilities to store and study the posthumous materials extracted at autopsy.

Source: Report of the Henry Phipps Institute for the Study, Treatment, and Prevention of Tuberculosis. Philadelphia: Henry Phipps Institute, 1905-1906.

Refusal as Method

The Opaque Online Publishing Platform (OOPP) provides workflows and code to make text and images opaque. Researchers are encouraged to erase what might be valuable epistemic information through the blacking out of text and parts of the image in a method that calls attention to the implicit extractivist assumptions employed by medical researchers. This responds to a larger epistemic issue regarding archival collections: no matter the ethics of their initial acquisition, the potential for novel research supersedes the harm produced at extraction.

The OOPP follows the scholarship of Indigenous scholar Kimberly Christen (who developed the *Muruktu* archival platform) and anticolonialist scientist Max Liboiron to articulate a digital practice of refusal. Refusal, via Liboiron, refers to an understanding that in order to practice anticolonialist research, scholars need to know that their potential research avenues may be denied to them, out of respect to the communities upon which their research depends. As Liboiron writes, “Giving up the entitlement and perceived right to data is central—the central!—ethic of anticolonial sciences. You will lose things in anticolonial research that you automatically get as a researcher in colonial modes of research (regardless of your heritage)” (142).

In light of contemporary scandals, regarding the theft of remains after the MOVE bombing in 1985 and the hundreds of brains maintained in the collections held at the Smithsonian, medical knowledge workers need to acknowledge their association with these practices, and more actively return and reinter materials plundered by their predecessors. The OOPP helps imagine how the history of medicine would be different should all that stolen material be removed from academic access.

Ethics Audits

The process of publishing on the Opaque Online Publishing Platform (OOPP) involves constantly reassessing the primary sources with which scholars work. Time intensive, the protocols and workflows developed for publishing a dissertation, exhibit, or blog with the OOPP’s template, ask scholars to reassess every object they use and every sentence they write. Scholars are encouraged to ask, “from whose body does this argument depend?”

An ethical audit, this reappraisal admits that this work is contingent and ongoing, while also addressing the needs and rights of subjects. The OOPP and its protocols are incomplete and insufficient, and this reflective process encourages further interventions against the implicit colonialism employed by medical researchers and the historians who document their work.

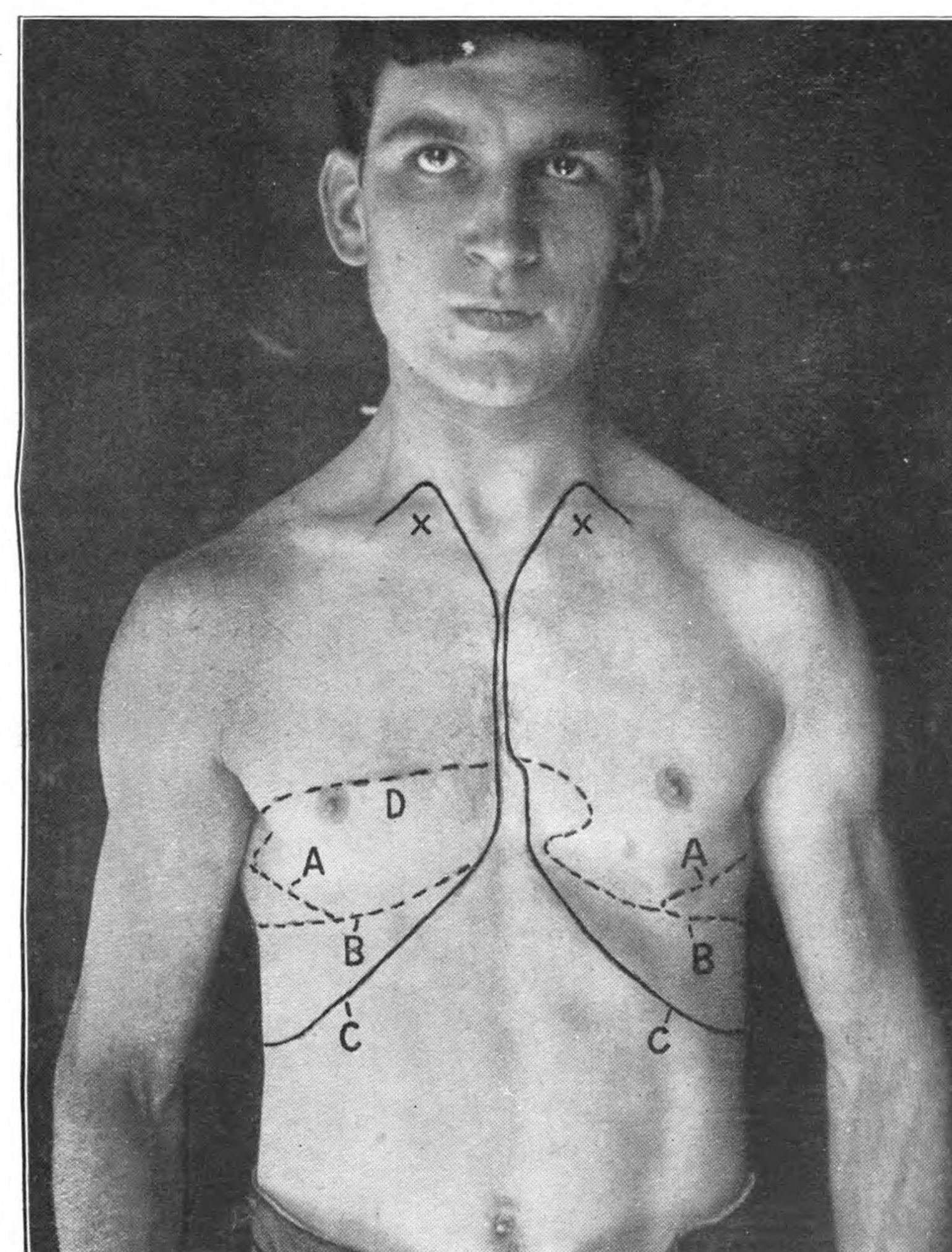


FIG. IV.—Front of Chest.

Images are applied with increasing amount of opacity.

Left: No opacity. The image is exactly as it was found in the original text. **Middle:** Opacity has been applied to provide anonymity to the photographic subject, but keep the epistemic value of the image in tact. **Right:** All information from the subject has been removed from the image.

Source: Crofton, W. M.. *Pulmonary Tuberculosis: Its Diagnosis, Prevention and Treatment*. Philadelphia: P. Blakiston's Son & Co., 1917.

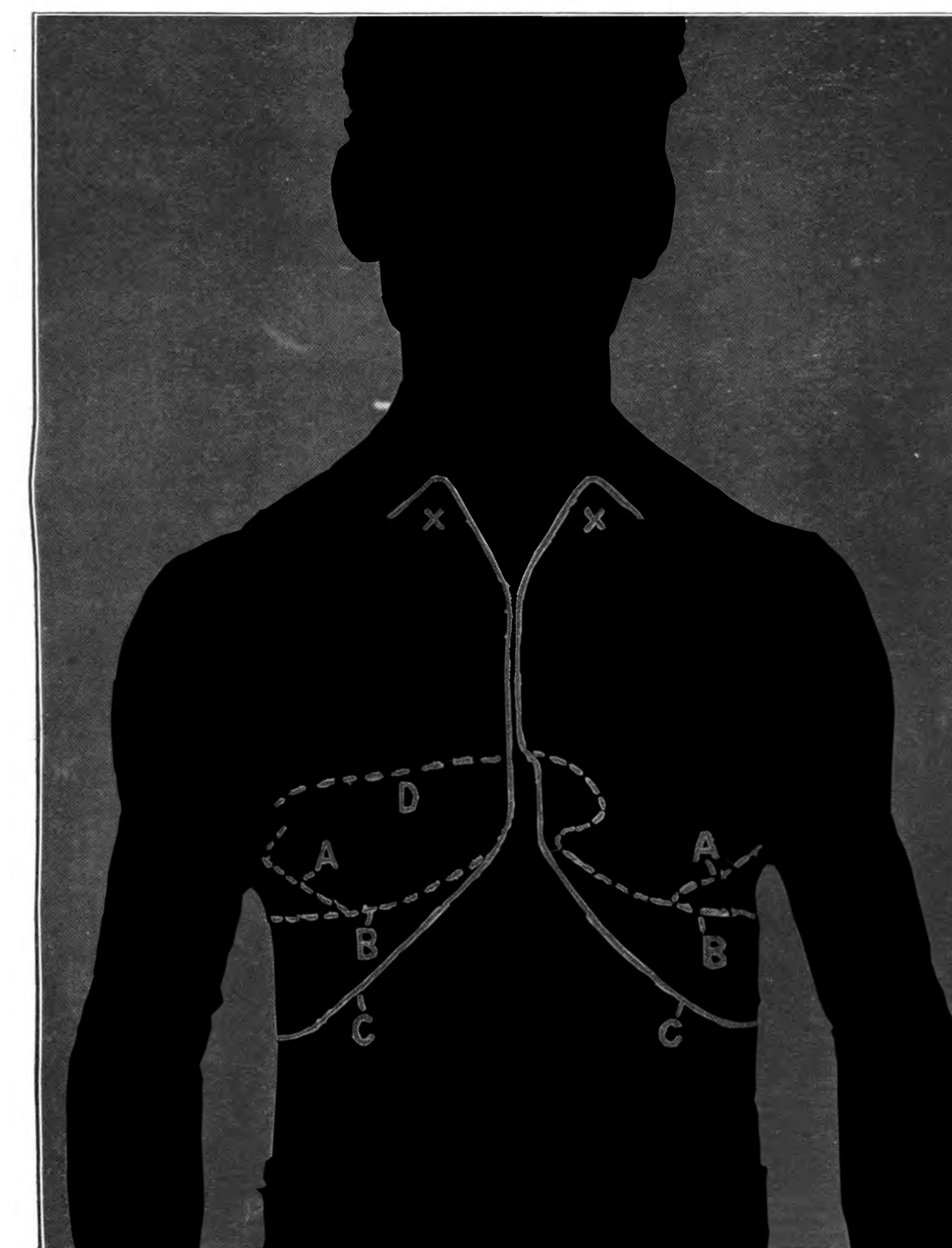


FIG. IV.—Front of Chest.

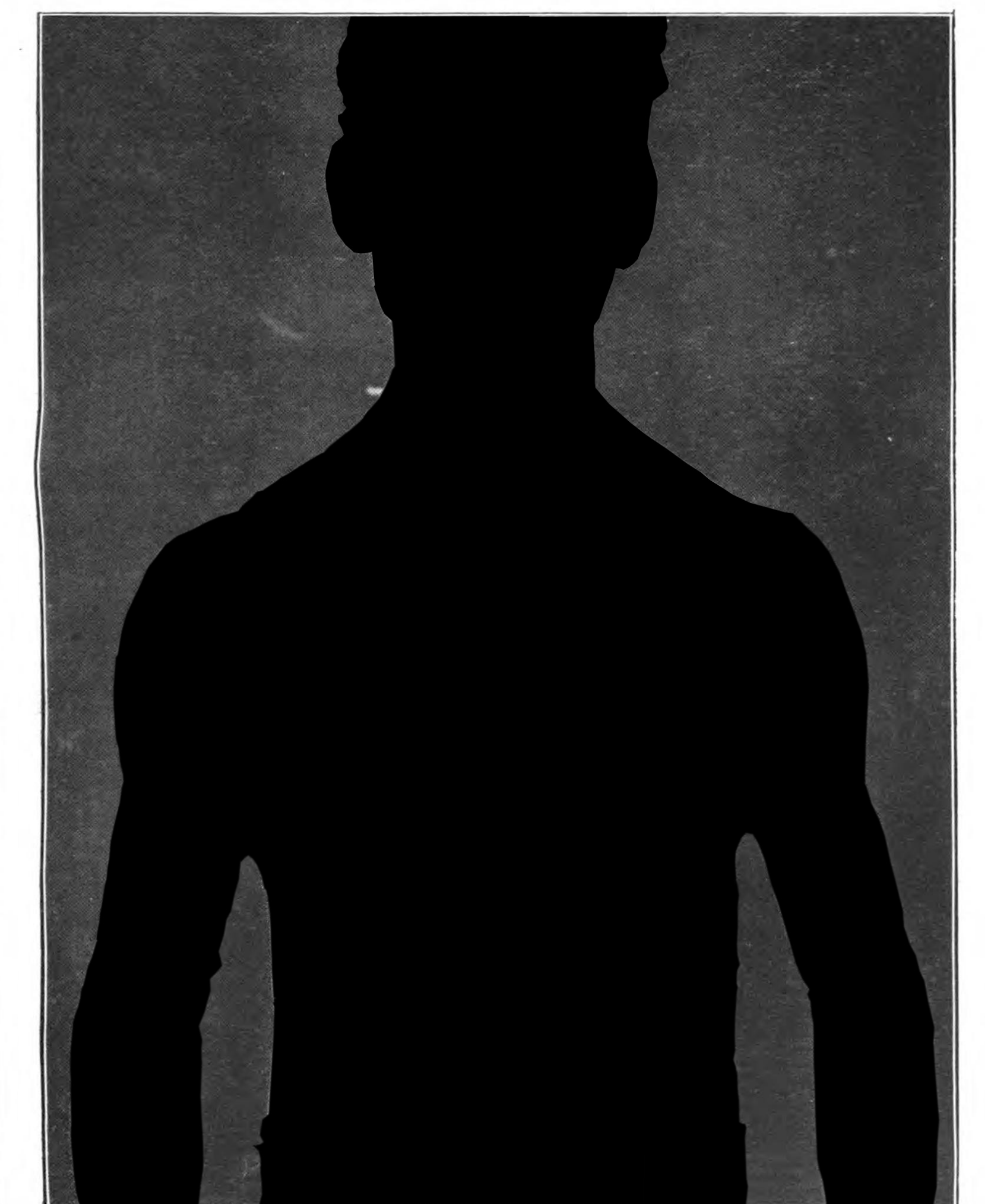


FIG. IV.—Front of Chest.

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Guidelines for Applying Opacity

The transparent, semi-opaque, and opaque categories are determined based on the following criteria:

1. Non-opaque adds no filtering whatsoever to the images or text. It is just as they were originally written.
2. Partial opacity is used to protect the privacy of the patient, but keeps the scientific information gleaned from the subject in tact. This corresponds with contemporary norms regarding privacy and images.
3. Full opacity takes into consideration that the subject probably didn't consent in the first place, and erases all index of the body (direct or indirect) from the image itself.



Go to the Demo Page

Works Cited: Christen, Kimberly. "Does Information Really Want to Be Free?: Indigenous Knowledge Systems and the Question of Openness." *International Journal of Communication* 6 (2012): 2870-93; Colwell, Chip. "Curating Secrets: Repatriation, Knowledge Flows, and Museum Power Structures." *Current Anthropology* 56, no. 12 (2015): S263-75; Glissant, Édouard. *Poetics of Relation*. Translated by Betsy Wing. Ann Arbor: University of Michigan Press, 1997; Liboiron, Max. *Pollution Is Colonialism*. Durham & London: Duke University Press, 2021.