New Mexico Decedent Image Database Ethics questions and answers

Q: Was a research protocol submitted to UNM?

A: Yes. This protocol was followed for the development of NMDID and is available at https://nmdid.unm.edu/docs/IRB protocol for website.pdf.

Q: Did the development of NMDID have approval from the UNM's or the UNM's Health Science Center's IRB?

A: No. Instead, the UNM IRB determined that IRB approval was not required. This determination stemmed from two facts. First, under the common rule, decedents are not human subjects. Second, next of kin who were interviewed for information were providers of data, but not subjects of research themselves.

Q: Did decedents or their families provide consent for these scans to be made available to the research public?

A: There is no consent, informed or implied, associated with NMDID. This is because deceased persons are not considered human subjects under U.S. federal laws pertaining to research on human subjects. Additionally, HIPAA protections do not apply to data obtained in the investigation of a person's death. Despite this, we implemented the research protocol we had developed, and built-in numerous privacy protections.

Q: What information available in NMDID is considered private?

A: The information available in NMDID is not private and is considered de-identified, except for scans of faces. Note that, 1) in NM, all medicolegal investigative information is accessible by anyone though the New Mexico Inspection of Public Records Act. This covers all the information available in NMDID except for that provided by next of kin, and 2) our IRB determined that next of kin were not research subjects as the questions they answered were not about them. Regardless, we followed the protocol we had developed for IRB consideration.

Q: How many next of kin were contacted? How many provided information? How many requests were there to remove cases from NMDID?

A: Our team attempted to call approximately 10,000 next of kin of the more 15,000 decedents in the database. Approximately 6,000 next of kin were successfully contacted. For the rest, phone numbers were no longer accurate. Approximately 2,000 next of kin responded to some or all of the questions in our survey and provided additional data to NMDID. One next of kin declined to participate and asked that decedent be removed from database.

Q: Is there a way I can limit my searches to include only these cases for which next of kin participated?

A: Yes. This information is available in the search engine as "Next of Kin Participated in Survey" in the Demographics section. Choosing this option will select only individuals for which the NOK participated in the survey. Note that the "Consent" option is available for future cases that might be added to NMDID. Consent does not relate to any of the cases currently available.

Q: Are there any limits on the use of data derived from NMDID?

A: Yes. Please read the data use agreement available at https://nmdid.unm.edu/resources/data-use. Additionally, since the original development of NMDID, focus groups with next of kin suggested that artistic, non-scientific uses should be prohibited.

Abbreviations used here:

HIPAA: The Health Insurance Portability and Accessibility Act

IRB: Institutional Review Board

NMDID: New Mexico Decedent Image Database

UNM: University of New Mexico