



“FINDER” ORGANIZATIONS AND PARTICIPANTS LOST TO FOLLOW-UP OR WITHDRAWN

11/20/2023

This policy, developed in coordination with the Duke University Health System Office of Counsel, addresses the use of private, “finder” organizations to access publicly available information in order to continue collecting information about participants who have withdrawn their consent for participation or participants who are lost to follow-up.

For participants lost to follow-up:

For studies planning to continue searching publicly available data and databases, the consent form should indicate that publicly available databases will be searched and provide examples of such databases when possible, and clearly delineate the parameters of the search (e.g., survival status). The consent form must also state what identifiable information will be shared with the external “finder” entity (e.g., name, DOB, etc.).

For participants who have withdrawn consent:

In consideration of privacy concerns and in accordance with federal regulations, DUHS IRB will not approve the transfer of identifiable patient/participant information to a private, “finder” entity after participants have withdrawn consent from a study. Study teams themselves may use reasonable means for obtaining publicly available data about withdrawn participants, if the continued use of the participant’s identifiable data is clearly stated in the consent form with examples of the public databases to be used (when possible), and the consent form specifies the data/databases to be searched and the parameters of the search.

This policy will be effective for all studies prospectively reviewed by the DUHS IRB wherein DUHS IRB is the IRB of record for either the entire project or for Duke as a participating site. Studies approved prior to the issuance date of this policy will be permitted to continue following the study specific, IRB-approved plan.

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