

Fee Estimates for Researchers (updated 10/24/24)

The following information is designed to help researchers understand and plan for potential fees associated with cancer registry linkages through the VPR.

VPR-CLS Fee for Use: For federally funded studies, there is no fee to use the VPR-CLS to facilitate linkage with registries. However, researchers will need to budget staff time for someone to manage the VPR-CLS and the associated activities (e.g. submitting the Phase I linkage application, uploading supporting documents, and completing any Phase II documents necessary to request individual-level data from participating registries, including data use agreements). We suggest at least a 0.25 FTE with the understanding that the percent effort will ebb and flow depending on the phase of the workflow.

Registry and IRB Fees: During VPR development, all registries performed linkages for free; however, with the official launch of the VPR some registries may re-institute their fee policy, so researchers should budget some funding to be paid directly to registries. Currently, federal agencies are exploring ways to provide ongoing support for registry participation in the VPR, potentially eliminating the need for registries to assess their own fees. Until this dedicated funding is in place, the researcher may incur registry fees. Below is a list of anticipated fees that we are aware of, but others may apply:

- **Local/State IRB Review:** We are aware of two states (FL and NJ) that have IRB fees totaling \$1,000, but there may be other registries with IRB fees we are not aware of.
- **Study Linkage Fees:** To date, registries have not charged for the Phase I linkage and provision of match counts. We are only aware of a few registries charging a fee for VPR linkages that proceed to Phase II request for individual-level data. This includes Arkansas (\$750), Alabama (\$1,250), New Jersey (see Appendix 1), and New York (see Appendix 2). Illinois charges a fee for VPR studies based on number of hours to complete the request. Pennsylvania charges .005 per record requested to link (initial and recurring linkages). Florida only participates in Phase I of the VPR and charges no fee for this service; however, when the researcher requests individual-level data from Florida outside the VPR, the registry will charge a fee, but it may be reduced based on the number of matches found in the Phase I VPR linkage. See the link below for the usual Florida fee structure:
<https://fcds.med.miami.edu/downloads/datarequest/Data%20Request%20Fees%206%202016%20Rev.pdf>
- **Uncertain Match Adjudication and Data Release Fees:** The majority of VPR studies simply request the high-quality matches (a.k.a. true matches) that the linkage software automatically identified. In rare cases, when the study linkage variables are not complete, the study is small, and/or the linkage sensitivity is low, a study may request that all registries adjudicate the uncertain matches to identify additional true matches. Registries may assess a fee for this service. In addition, registries may have a fee associated with navigating the study request through the approval process and creating a file of matched cases for transmission to the study requestor (e.g. data curation steps may be required in some states and they may wish to recoup their costs).

Optional Flat Funding to Support Registries: If a study has a lump sum of money budgeted for registry fees, NAACCR has a mechanism in place to disperse funds to registries in equal amounts (e.g. \$2,000 per registry). These funds will provide all registries, except those assessing their own fee, with revenue that they normally would have acquired from billing researchers directly. In a registry survey from 2018, the average fee to link with a cohort of 50K members was \$2,828 (n=13 registries with a fee).

Appendix 1: New Jersey Fee Structure for VPR-facilitated Studies

Virtual Pooled Registry (VPR) Phase 1 linkage*	\$0
VPR Phase 2 linkage	\$4,546
VPR add on: Manual review	\$1,387
VPR add on: Relinkage within 4 year DUA, NO manual review	\$972
VPR add on: Relinkage within 4 year DUA, w/ manual review	\$1,953
VPR add on: IRB initial review fee (non-federal sponsor)	\$750

* Percent effort for VPR Phase 1 costs are covered by NCI SEER

Note: Estimates are for linkages occurring between July 1, 2024 and June 30, 2025. Any changes may require budget adjustments.

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Appendix 2: New York Fee Structure for VPR-facilitated Studies (as of 11/21/23)

Phase 1 Linkage	No Charge
Phase 2 Linkage (no manual review)	\$3,000 flat fee
Phase 2 Linkage with Manual Review	\$3,000 flat fee plus \$14 per record reviewed after the first 100 records