

VPR CANCER LINKAGE SYSTEM (VPR-CLS):

BENEFITS TO CENTRAL CANCER REGISTRIES

For minimal-risk linkage studies

What is the VPR-CLS?

The VPR-CLS is a web-based, one-stop-shop designed to connect researchers performing minimal risk linkage studies with cancer registries across the U.S. The goal is to increase timely access to and use of high-quality cancer surveillance data while providing registries with a standardized, secure, automated process for performing the linkages. Cancer registries participating in the VPR-CLS agree to access study-related materials through the password protected system, perform a standard linkage using Match*Pro software, and upload aggregate match count reports (no patient records) to the VPR-CLS.

The aggregate match counts allow researchers to select which registries to approach with requests for release of individual level data on matched cases. The VPR-CLS will streamline the registry/IRB application and review process by offering optional use of vetted, standardized templated forms and a Central IRB for review of multi-state, minimal risk linkage studies.

Main features

The VPR-CLS has 4 main features (§ optional):

1. **Online application, file exchange, and tracking system:**
For requestor to track application status and registries to manage incoming linkage requests. Reminders will automatically be sent when actions are needed.
2. **Standardized linkage software and configuration files**
3. **§ Templated forms** (in lieu of state/local forms):
 - a) IRB/Registry Application for data release
 - b) Data Use Agreement
4. **§ Central IRB** (in lieu of state/local IRB review)

The VPR-CLS will also provide researchers with information on the registry contact (VPR Liaison), years of high quality data, number of annual cancer cases, potential registry/IRB fees, as well as registry requirements for data destruction, publication review, and necessary renewals for approved studies.

Benefit for registries to join VPR-CLS

1. Extend the public health mission and value of the registry
2. **Decreased registry workload** for minimal risk linkages
 - a) Use of a single VPR-CLS registry linkage file created annually during the NAACCR Call for Data
 - b) Review of linkage requests by NAACCR and a small committee of registry experts to ensure complete application materials, linkage feasibility, and appropriate use of registry data prior to notifying registries of approved linkages.
 - c) Provision of standardized, edited, validated study files
 - d) Use of the new linkage software (Match*Pro)
 - i. Fast, efficient linkages
 - ii. Pre-determined linkage configuration files
 - iii. Flexible manual review screen
 - iv. Report generation capability
3. Linkages performed behind the registry firewall
4. Eliminate unnecessary submission and review of state and local IRB/Registry requests for release of individual-level data for linkages that resulted in no matches
5. Opportunity to utilize a dedicated Central IRB (in lieu of state or local IRB) for review of minimal risk linkage studies
6. Registry funding to support participation in VPR-CLS linkages is anticipated in 2020

Bonus Feature

The VPR-CLS will also facilitate secure, de-identified inter-registry linkages as a way to detect duplicate cases between registries, identify persons with multiple primaries in different registries, and reduce death certificate only cases. The reconciliation and exchange of information on shared cases will ensure more accurate incidence, survival, and prevalence statistics. This initiative will also illuminate the extent of under-reporting of multiple primary cancers and lead to improvements that enable more comprehensive understanding of cancer risk and etiology.

How Does it Work?

Requests to link with registries are first reviewed by NAACCR and a Research Review Committee of your peers. Requestors receive feedback on the proposed use of registry data, completeness of study linkage variables, and modifications necessary to ensure a successful linkage. Once approved, researchers receive editing software for their study file, resolve edit errors, and create a standard file layout according to VPR-CLS specifications. The edited study file is securely submitted to the VPR-CLS for review and validation by IMS, Inc. (3rd party honest broker). The final study file and a standard linkage configuration file are then posted for registries to download. Registries use Match*Pro to perform the linkage behind their firewall with the annually created VPR-CLS registry linkage file. Aggregate match count reports (no patient records) are produced and uploaded to the VPR-CLS.

The VPR-CLS will show at-a-glance reports on the match counts, along with which registries can accept the Central IRB or templated forms for data release requests. This information will allow the requestor to make an informed decision about which registries to approach for individual level data files. The templated forms will be completed and routed within the VPR-CLS and local forms will be handled via email or through existing state-based systems. The Registry VPR Liaison will be prompted to populate the VPR-CLS with dates of IRB/registry approvals, DUAs, and renewals, thereby providing researchers with pertinent follow-up requirements for approved studies. Individual-level registry data files will be sent directly to the researcher rather than passing through the VPR-CLS.