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Title: Where are we now? VPR pilot testing progress

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Background: The Virtual Pooled Registry Cancer Linkage System (VPR-CLS) is an online service that efficiently connects researchers with multiple U.S. state/regional cancer registries to perform minimal risk linkage studies. The VPR-CLS uses a standard methodology and streamlined two phase application process. Phase I supports a secure, standardized linkage and provision of aggregate match counts by registry. Phase II streamlines the ensuing registry and IRB requests for individual-level data on the matched cases from Phase I.

Purpose: The authors will describe the pilot testing process, focusing on the recent Phase II testing.

Methods: Over the past year, Phase I testing was completed with five studies, ranging in cohort size from 38K to 1.2M. The Childhood Cancer Survivor Study and the Transplant Cancer Match Study have proceeded to Phase II testing, initiated by the online submission of the Templated IRB/Registry Application (TIRA). The TIRA is a single application accepted by a subset of registries in lieu of their state-specific application(s). Remaining required state-specific documents must be submitted outside VPR-CLS. The VPR-CL summarizes the requirements, including URLs and contact information for each registry, to facilitate submission. Following submission, the researchers and registry liaisons will enter key pieces of information into the VPR-CLS to track the request status across registries. Detailed system workflows and automated notifications for both researchers and registries are built into the system to ensure timely progress.

Results: The Phase I testing demonstrated the feasibility of using standardized linkage software (Match*Pro), timely upload of match count reports, and utility of the counts to guide registry selection for inclusion in Phase II. The Phase II testing is currently in progress. Of the 38 participating registries, 32 agreed to accept the TIRA, significantly reducing the number of unique applications. Up-to-date details on the status of the requests across registries, value of the tracking system, and release of individual-level data to the study will be presented at the time of the conference.

Conclusions: The VPR-CLS has been well-received by registries and researchers alike. Pilot testing has been successful, helping to fine-tune and identify areas for system enhancements in advance of its official launch.