Development and User Insights of a Novel Real-World Treatment Registry that Combines Germline Hereditary Cancer, Tumor Mutational Landscape, and Homologous Recombination Deficiency Data with Patient Clinical Characteristics

Lynette Poyser1, Jeff Jasper1, Jeffrey Tratner1, Elizabeth S. Cogan1, Ronald D. Alvarez2, Adam Brufsky3, John Chan4, Robert L. Coleman5, Martin F. Dietrich6, Margarett C. Ellison7, Ramez N. Eskander8, Jason L. Gillman9, Melissa Hodeib10,


OBJECTIVES
To address this need, we created a data-sharing platform from reliable patient datasets that combines germline and tumor genetic test results, family history, management, and outcomes.

RESULTS

Current research platform capabilities include filtering for real-time cohort comparisons across clinical variables (e.g., viewing genomic instability HRD scores associated with specific germline gene variants). Affiliations of access-requesting users included academic institutions (35%, N=30), community hospitals (57%, N=49), and other (e.g., laboratory, pharmaceutical, private clinician, etc., 8%, N=7) (Figure 2).

The top three themes cited by users for accessing the database included clinical research, patient care, and genetic testing.

METHODS

A steering committee of gynecologic and medical oncologists advised on registry structure.

An IRB-approved de-identified research registry was developed, and data were housed using the DNAnexus cohort browser platform (Figure 1).

The browser was loaded with clinical data and test results from individuals who received both germline and tumor testing from Myriad Genetics between Nov 2013 - Mar 2022.

Statistics

Descriptive statistics were used to summarize registry characteristics and access-requesting user demographics as of 1/23/23.

Reasons for requesting access to the database were evaluated using thematic analysis.

Ovarian, Fallopian, Peritoneal 3,245
Endometrial/Uterine 1,444
Deleterious 721
Suspected Deleterious 65
VUS 1,217
Suspected Deleterious 2,937
Deleterious 632

Table 1. Patient Characteristics (Total Registry Cases N=4,521)

Academic Institutions (N=30)
Community Hospitals (N=49)
Other (N=7)

In partnership with a steering committee and DNAnexus, we successfully launched a cloud-based registry to advance world insights surrounding cancer genomics and treatment.

Access interest spanned a broad range of clinicians with varying research interests.

While the majority of the registry currently comprises ovarian cancer cases, future versions will include data from patients with all solid tumors and will incorporate thematic desires of users.

The registry will also be populated with patient management and outcomes over time.

This registry has the potential to be an invaluable tool for facilitating high-quality, multifaceted research in the field of real-world precision medicine.