The PENN CFAR Clinical Core Cohort Registry: A 20-year Cohort of People with HIV Supported by Integrated Biostatistics and Data Science Infrastructure

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Background: The Biostatistics & Data Science (BDS) Core and Clinical Research Collaboration Unit (CRCU) provide support services and database management for the CFAR Clinical Cohort Registry. The BDS and CRCU can provide Registry data and biospecimens to enable new investigation.

Methods: The Registry opened in November 1999 across five Penn Medicine clinics and affiliates. Participants were recruited during routine HIV care and followed at six-month intervals for ten contacts, then annually for five years. At each visit standardized case report forms captured lab-confirmed HIV diagnosis; demographics; medical history; ART history; lab results, including viral load, CD4/CD8 counts and hepatitis history; metabolic monitoring; behavioral histories for alcohol and substance use, sexual history, and depression; and biospecimen collections. **A key service available is to link Registry data and specimens with clinical data in EPIC**. Optional blood specimens (20–30 cc) processed for storage by specimen type (PBMCs, plasma, and serum) are archived at the UPenn Infectious Diseases Laboratory. To date, the last patient enrolled and last biospecimen was collected in March 2020. CFAR investigators access Registry data through a query form available online, followed by iteration with the CRCU.

Results: Data and specimens are available for over 3000 participants, including 656 within the last 10 years. Over 65,000 total PBMCs, plasma, and serum specimens have been collected. The average estimated duration of HIV infection observed from diagnosis through the most recent Registry contact was 10 years.

The CFAR Registry and CRCU have provided data and services for over 100 grant proposals and funded research projects since 1999. Prior requests have supported projects investigating ART treatment efficacy in longitudinal studies and its impact on comorbidities; aging with HIV; dental care, cancer, hepatitis, smoking history and cessation in PWH, and device/lab procedure development for HIV detection and management.

Conclusion: The BDS and CRCU promote research genesis and productivity among new and established CFAR investigators, supporting over 75 investigators in the current funding cycle. BDS and CRCU collaborators utilize CFAR Registry data, Penn Medicine EMR resources, and biostatistical expertise to advance ongoing projects and future proposal development accelerating the prevention, management, and cure of HIV.