



## Cohort and Registry Administration Core

*Our mission is to serve as a central resource to help scientists discover how utilizing research registries at VCU can advance their scientific achievements, in conjunction with providing excellent support services to see projects through from nascent stage to data analysis.*



CARA team

As we round out our second year as a unified core, we're incredibly excited to continue building upon the decades of rich data housed within the Mid-Atlantic Twin Registry (MATR) and the Spit for Science registry. The CARA team is committed to providing our researchers with streamlined access, efficient processes and high-quality services.

While we're already seeing increased engagement from VCU researchers, we're eager to continue to expand our services, foster collaborations, and even explore innovative ways to link our in-house data to geospatial data that will further enhance the registries and allow for novel areas of research.

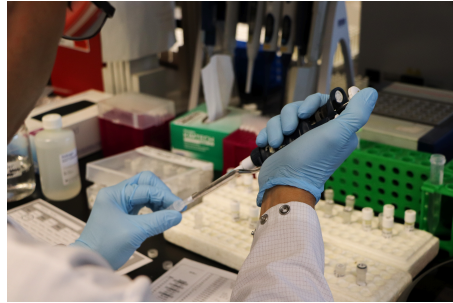
We're enthusiastic to continue this exciting work, and we encourage you to reach out and explore how we can collaborate.

Sincerely,  
Bernard Fuemmeler, Ph.D., MPH  
CARA Core Director

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## About the Core

The Cohort and Registry Administration Core serves as a central resource, educating scientists on how VCU's research registries can contribute to their scientific advancements. CARA provides thorough support services, guiding projects through each phase, from initial development to complete data analysis.



Led by director [Bernard Fuemmeler, Ph.D.](#), and associate director [Elizabeth Prom-Wormley, Ph.D.](#), the VCU CARA Core manages the [Mid-Atlantic Twin Registry](#) and [Spit for Science](#), providing researchers access to unique, large-scale registries and datasets. CARA Core delivers comprehensive support, from project initiation to data analysis, promoting population health research and collaboration. The core's array of datasets is available for access by qualified investigators for research or educational purposes. [Discover how the core can aid your research.](#)

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The MATR (est. 1975) and Spit for Science (est. 2011) registries have supported over 150 studies and over 400 publications using genetically informed registry-based data. CARA's history of success helps researchers achieve their immediate and long-term goals efficiently, on time and at cost. The registries serve dozens of researchers at VCU and outside institutions through services such as secondary data access, primary data collection, dataset creation or consulting services for researchers seeking to enhance an existing resource or build a new registry here at VCU.

- ✓ Free dataset access
- ✓ Data collection & study recruitment
- ✓ IRB submissions
- ✓ DNA / genetic samples
- ✓ GWAS / Genotypic data access
- ✓ New registry / cohort development
- ✓ Consultations
- ✓ Data management

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## Registries CARA supports:

### Mid-Atlantic Twin Registry

- ✓ Largest twin registry in the United States
- ✓ Over 60,000 twins of all age-, sex-, racial-/ethnic- and zygosity- groups
- ✓ Twin studies disentangle how measured and unmeasured genetic and environmental factors affect human health and wellbeing



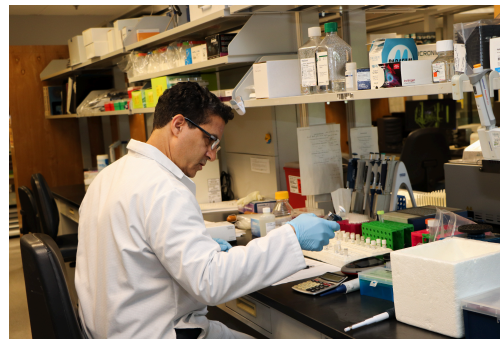
## Spit for Science: The VCU Student Survey

- ✓ Ongoing longitudinal university-wide research study open to all incoming VCU freshman (ages 18+)
- ✓ Over 15,000 participants, 47+ surveys administered since 2011
- ✓ Genotyped data from 10,000 participants
- ✓ Use of measured genetic and environmental factors can help detail how the sources influence the development of human behavior and health



## CARA Updates and News

**Data Consolidation and Accessibility:** The core is enhancing its approach to data access by developing a dynamic virtual codebook in collaboration with [VCU's Data Science Lab](#), which aggregates data across multiple legacy datasets. This will provide an online resource with survey information, variable lists, and descriptors, making it easier for researchers to identify and request data. Beta testing is underway.



**Expanding Collaborations:** CARA is actively seeking national collaborations, including with NIH and other institutions, leveraging the unique strengths of current registries for future opportunities and partnerships.

**Supporting New and Existing Registries:** The CARA team is available to share their expertise in supporting the development of new cohorts and registries. In addition, the team offers consultation for existing registries, offering guidance on data and registry management.

**New Cohorts:** [This past fall](#), Spit for Science invited a new cohort of VCU freshmen to take part in their research, allowing for the collection of survey data on topics like cannabis use, social media and mental health. More than 1,700 students took part in the survey, and over 1,400 provided DNA saliva samples. This cohort was then invited to take part in a survey this spring and will be invited each subsequent spring during their college career, resulting in rich longitudinal data that is available for research.



**CARA Grant Retreat:** CARA recently hosted a grant retreat to bring together collaborators interested in developing studies utilizing CARA's resources. This event was in conjunction with the OVPRI Research Development team, who cultivated a list of funding opportunities that could be matched with CARA-centric study designs. CARA plans to provide support to the teams that coalesced at the retreat in order to help transition study ideas into grant proposals. More retreats are being planned, and investigators are invited to reach out if they would like to be included!

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## CARA Researcher Highlight

Now serving as the CARA core's associate director, Elizabeth Prom-Wormley, Ph.D., previously worked solely as a researcher, utilizing the Mid-Atlantic Twin Registry in her work. This work led to an R01 grant for her study exploring factors influencing resistance to substance use.

Dr. Prom-Wormley's project aims to understand and identify the factors in psychoactive substance use (SU) resistance into early middle adulthood (30-40 years old), with a special focus on potentially modifiable factors. Data from MATR will aid in the creation indexes of "High Outset Resistance" (resisting early experimentation) and "High Realized Resistance" (resisting despite early risk), with the ultimate goal of pinpointing modifiable factors that can be targeted in prevention and treatment to reduce SU and addiction.

*"The CARA team wants to get the work done ethically. They want to get it done on time, on budget, and they always do it with the spirit of support."*

### Publications of this research:

[Using a Genetic Approach to Understand Factors Influencing Resistance to Substance Use](#)



Elizabeth Prom-Wormley Ph.D., M.P.H.

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## CARA Internship Program and Opportunities

The CARA core engages student researchers through its internship opportunities, offering invaluable hands-on experience in registry operations, data stewardship and collaborative research infrastructure development. Interns contribute to diverse projects, from enhancing data accessibility through the development of tools like dynamic codebook dashboards and investigator data intake forms to exploring innovative methods such as generative AI for data extraction.

"My work at MATR exposed me to the wealth of data stored in legacy systems like registries that need to be extracted into machine-readable formats to promote access and reuse for research. The methods we explored included Natural Language Processing and generative AI in parsing static data formats like PDFs, which have aligned well with my research interests in using and building machine learning models for improved health outcomes and streamlining processes. My time at CARA has shown me how we can use innovative methods to fill crucial gaps in research activities like data harmonization and extraction."



Jerry John Rawlings Mensah



*Maria Fatima Ali*

"My time with CARA taught me that impactful research is grounded not only in data but in trust, structure, and thoughtful collaboration. It is the work behind the scenes that truly drives meaningful scientific progress."

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## Meet the Directors



*From L-R: Emily Lilley, Bernard Fuemmeler, Elizabeth Prom-Wormley, Karen Chartier,*

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