



## RAMS Registry Usage Protocol Request Form

ramsregistry.vcu.edu • ramsregistry@vcu.edu

The mission of the RAMS Registry is to promote the health of all women, men and children by supporting research related to microbiome science, the study of the communities of microbes that live in, on and with us. The RAMS Registry fosters collaboration among researchers and sharing of data among studies to accelerate knowledge and advance health. Although the RAMS Registry focuses on research related to microbiome science, we also support other studies that seek to promote human health more generally. We strive to serve as a model for the protection and privacy of participants, and our goal is to establish lasting relationships with RAMS Registry members as partners in research.

In addition to serving as a registry with contact information for prospective studies, the RAMS Registry also houses the RAMS Repository for maintaining the integrity of data and specimens. The RAMS Repository has two arms: the RAMS Data Repository and the RAMS Biorepository. The RAMS Registry will maintain both coded de-identified data and samples and data where there is a link to identifiable information and contact information is maintained for future contact and research.

The responsibility for the integrity of the registry and the establishment of protocols for registry access lies with the RAMS Registry Executive Committee. The Executive Committee includes four voting members Gregory A. Buck, Ph.D. (PI), Jennifer M. Fettweis, Ph.D., Kimberly K. Jefferson, Ph.D., and Karen Hendricks-Munoz, M.D., M.P.H. Requests for access will be determined by a majority vote by the EC. The EC intermittently reviews and updates policies and procedures to account for new technologies and varieties of studies. Investigators who have studies that utilize the RAMS Repository as their storage system will continue to have access to their own samples and data. Usage protocols that want to use data from the either the de-identified repository or the identified/coded registry will require review of the protocol by the Executive Committee.

The Executive Committee considers the following factors, among others, when evaluating proposed usage protocols:

- Is the proposed protocol consistent with the original consent signed by the participant?
- Will the proposed protocol violate the once-per-year recontact limit for RAMS Registry participants?
- What identifiable information is being requested?
- If specimens are being requested, how much will be used?
- Has the proposed protocol been reviewed by an IRB?
- What is the status of funding for the proposed protocol?
- Do the aims of the proposed protocol compete with or duplicate the aims of existing RAMS Registry studies?
- How does the proposed protocol add value and contribute to the goals of the RAMS Registry?

Generally, peer-reviewed funded studies that are appropriately consented, and which have been approved by an appropriate Institutional Review Board will be prioritized for access to the registry. As the samples are usually irreplaceable, if specimens are requested, an evaluation of the impact of the request on the integrity of the remaining samples in the repository will be performed. The Executive Committee will assess these impacts and if access is approved, provide guidance as to the cost of access to the samples to the requesting investigator(s).



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## INVESTIGATOR INFORMATION

PI Name	
Institution	
Department	
Email	
Phone	
Address	

Are you a prior RAMS Registry contributor? Yes No

Do you plan to contribute data or specimens to the registry? Yes No

## PROJECT INFORMATION

Title	
Reviewing IRB Panel	
IRB Protocol #	
Funding	
Grant #	
Duration	

## RESOURCES REQUESTED

Population Size	
Specimen Types	
Specimen Volume	
Datasets / Fields	
Contact Information	<input type="checkbox"/> Yes <input type="checkbox"/> No

Please attach a detailed description of your study's objectives, including a justification for the samples and/or data requested.