

# **Boston Puerto Rican Health Study**

## **Data Use Agreement**

### **Introduction**

The Boston Puerto Rican Health Study is a longitudinal study of an established cohort of 1500 older Puerto Rican adults residing in the Greater Boston area. The overall goal of this cohort study is to examine the role of psychosocial and physiologic stress, health and health behaviors, nutritional status, genetic and other personal health variations, and how social and community supports impact health disparities, such as diabetes, hypertension, obesity, and cardiometabolic outcomes, experienced by this population. There are four waves of data collected over ~13 years that focus on outcomes such as cognitive function, stress, cardiovascular health and overall health outcomes in relation to diet, health disparities and aging. The Boston Puerto Rican Osteoporosis Study (BPROS) is an ancillary study to the BPRHS. The BPROS collected additional measurements, including bone mineral density (BMD) and bone strength.

**To protect the confidentiality and privacy of BPRHS (and BPROS) participants, investigators granted access to BPRHS and/or BPROS data and materials must adhere to requirements of this data use agreement. Failure to comply with this agreement could result in termination, denial of further access to BPRHS resources and may result in legal action. Further, journals or conferences where unapproved papers appear will be contacted, and a request will be made for removal of the work.**

### **Agreement**

1. The BPRHS data management team will provide the recipient (lead author) with data as described on the data request proposal form upon approval of the data request form by the BPRHS leadership committee.
2. The data will be used by the recipient (lead author) solely for the research project, as named and described in the data request proposal form with approval. If any aspect of the research project is to be performed by any entity other than the recipient (lead author) that entity needs to be named in the data request proposal form.
3. The recipient (lead author) agrees that the data received are to be used only for the approved analysis on the data request proposal form. Each additional research project requires separate data request proposal form submissions and approval.
4. The recipient agrees that any substantive changes made to the research project will need to be approved by the BPRHS leadership committee.
5. The recipient agrees not to share BPRHS and/or BPROS data received with any other entity or individual without prior approval from the BPRHS leadership committee.
6. All publishable work (including but not limited to abstracts, presentations and manuscripts) associated with this data request will be reviewed by the assigned BPRHS PI prior to publication/presentation.

## Conduct of Research Project

The recipient (lead author) is responsible for conducting the research project and is responsible for ensuring that any co-investigator complies with the terms of this data agreement.

## Acknowledgements

The recipient (lead author) agrees to acknowledge the BPRHS and/or BPROS in all oral and written presentations, disclosures and publications resulting from any and all analysis as described in the data request form. Please work with the project's assigned BPRHS PI to ensure the acknowledgement language is correct and associated grants are recognized.

## Distribution and Confidentiality

The recipient (lead author) agrees to retain control over BPRHS and BPROS data and derivatives thereof. The recipient also agrees not to transfer data or materials and derivatives thereof, with or without charge, to any other entity or individual. Additionally, the recipient agrees to keep data confidential and encrypted.

## Return of Final Dataset(s)

The recipient will return a final dataset with newly derived variables to the BPRHS study team at time of manuscript submission via email or OneDrive file share.

## Signature Page

### Recipient (Lead Author):

I agree to abide by the terms and conditions laid out in this agreement and I am responsible for the BPRHS and/or BPROS data and/or materials for the duration of this agreement. I am also responsible for my own actions and those that I supervise or that are working under my direction.

Name and Title of Recipient: \_\_\_\_\_

Email Address of Recipient: \_\_\_\_\_

Telephone Number of Recipient: \_\_\_\_\_

Signature of Recipient and Date: \_\_\_\_\_

### BPRHS and BPROS Leadership Representative:

Name and Title of Representative: \_\_\_\_\_

Signature of Representative and Date: \_\_\_\_\_

This Data Use Agreement is entered into as of: \_\_\_\_\_(effective date)