

APPLICATION TO REQUEST DATA TO THE PRCCR

The Puerto Rico Central Cancer Registry (PRCCR) recognizes three categories, levels, or types of data that can be released for cancer surveillance and research purposes. Please choose the category/level that best fits your research request. This form must be completed and submitted in order to request data to the PRCCR.

Reports of **aggregate data** stratified by non-confidential data fields such as case counts by sex, municipality, and/or health region are available at <http://www.rcpr.org/> and does not require to complete this form.

Level I. Level I application is needed when data contains other specific variables (i.e. age-group).

Level II. Data files containing **individual, record-level data with no personal identifiers**. The files will not contain name, street address, phone number, social security number, date of birth, any reporting facility, or physicians involved in the patient's care. The files may contain other demographic and clinical information.

Level III Data files containing individual, record-level data with personal identifiers, to be used for purposes of **record linkage**, either electronic or manual, but not direct patient contact. Once the record linkage is complete, the personal identifiers will be removed from the data set. It may require a fee.

LEVEL II REQUEST PROCEDURE & CHECKLIST

Level II requests must include:

1. **Request Letter**
2. **Completed Level II Data Request Form**

The *Request Letter* must include date of request, the principal investigator (PI) information (full name, institution, and signature), the reason for the data request (objectives), type of information requested (variables from the list), the study period, the name of the person(s) responsible for handling the request, and how the data will be used. This letter must be addressed to: Diego E. Zavala, MSc, PhD (dzavala@cccupr.org), Guillermo Tortolero-Luna, MD, PhD (gtortolero@cccupr.org), and Carlos R. Torres Cintrón, MPH (ctorres@rcpr.org).

After the PRCCR receives the *Request Letter* and the Level II Data Request Form, PRCCR staff will review the request and may communicate with the requestor to clarify or request additional information. While this data set request does not include personal identifiers, it may contain information about the patient that could be linked to other data sets, thus revealing the patients identity, therefore Level II data requires an IRB approval. Once the PRCCR approves the request, a *Support Letter* can be provided to the PI to include in the IRB application submission.

After the IRB approves the protocol, the PI will send the IRB Approval Letter to the PRCCR and the PRCCR will start to develop the research database. When the database is ready to share, the PRCCR staff will explain the research database delivery process to the PI and the PI have to complete and sign the *PRCCR Assurance Form and Research Agreement*.

The database will be shared through a secure transfer protocol.

It is important to highlight some points:

- The PRCCR will not start to develop any database without an IRB Approval Letter.
- The time to deliver a database depends on the complexity of the request and the workflow of the PRCCR.
- The completeness of some variables (specifically those related to stage at diagnosis and first course treatment) may have limitations and/or high percentage of missing information.

As part of the application, the PRCCR also requests a brief description of the research project as well as a brief description of the PI's credentials, education, and research interests. This information is required to document PRCCR's support of research endeavors. The PRCCR does reserve the right to edit the submitted descriptions for formatting purposes.

Please enclose the requested documents and email to:

Carlos R. Torres Cintrón, MPH

Analysis and Epidemiology Unit Coordinator

Puerto Rico Central Cancer Registry

University of Puerto Rico Comprehensive Cancer Center

E-mail: ctorres@rcpr.org

Contact Carlos R. Torres Cintrón at (787) 772-8300 x.1111 with any questions regarding the request process.

LEVEL II DATA REQUEST FORM

ORGANIZATION OR INDIVIDUAL REQUESTING ACCESS		
Date of request	Name of person requesting data	Title, Degree, and Rank
Organization		Address
Telephone number	E-mail address	Date data are needed
Is this study externally funded?		Name of the funding organization
Yes	No	
THE RESEARCH PROJECT		
Purpose and intend of requested data		
Cancer site, histologies (if apply), and study period		
Brief description of the Principal Investigator (PI)		
Requested variables		
Please select from attached list.		

List of available variables:

Patient Identification

- Encrypted ID
- Sex
- Age at Diagnosis
- County/Region at Diagnosis

Cancer Identification

- Date of Diagnosis
- Sequence Number Central
- Primary Site
- Laterality
- Grade/Differentiation
- Diagnostic Confirmation
- Histologic Type ICD-O-3
- Behavior Code ICD-O-3

Outcomes

- Date of Last Contact or Death
- Vital Status
- Cause of Death (cancer/non-cancer)

Stage at Diagnosis *

- Summary Stage (Localized, Regional, Distant)
- Tumor Size
- Pathologic TNM
- TNM Path Stage Group
- Clinical TNM
- TNM Clin Stage Group

First Course of Treatment **

- Surgery (Yes/No)
- Date of Surgery
- Radiation (Yes/No)
- Date of Radiation
- Chemotherapy (Yes/No)
- Date of Chemotherapy
- Hormone (Yes/No)
- Date of Hormone
- Immunotherapy (Yes/No)
- Date of Immunotherapy

DISCLAIMER

* **Stage at Diagnosis** – Sensitivity and completeness of stage variables may vary by cancer site and patient characteristics. For missing/unknown information we do not know whether stage was not determined or whether it was not captured by the PRCCR.

** **First Course of Treatment** – Sensitivity and completeness of treatment variables may vary by cancer site and patient characteristics. For missing/unknown information we do not know whether treatment was not received by the patient or whether it was not captured by the PRCCR.
