

## APPLICATION TO REQUEST DATA TO THE PRCCR

This form must be completed and submitted in order to request data to the Puerto Rico Central Cancer Registry (PRCCR).

The Puerto Rico Central Cancer Registry 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.

**Level I** Reports of **aggregate data** stratified by non-confidential data fields. Variables like case counts by sex, municipality, and/or health region are available at <http://www.rcpr.org/> and do not require to fill an application. If requested data contains another specific variables (i.e. age-group) a Level I application is needed.

**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

While this data set 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, in order to request Level II data from the PRCCR, there are two items that must be included for the request to be considered.

1. **Letter of Intention (LOI)**
2. **Completed Level II Data Request Form**

The LOI 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, proposed methodology, the name of the person(s) responsible for handling the request, and how you will use the data.

- After the PRCCR receive the LOI and the Level II Data Request Form, an evaluation of the request will be performed by the PRCCR Data Request Evaluation Team (PRCCR-DRET). During this evaluation the PRCCR may communicate with the requestor to clarify any doubt.
- If the PRCCR determines to provide a research database to the requestor, a Support Letter will be sent to the PI to include during 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 process.

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 to be included in the PRCCR's reports. 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: [carlost@cccpr.org](mailto:carlost@cccpr.org)

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

**LEVEL II DATA REQUEST FORM**

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

## List of available variables:

### Patient Identification

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

### Stage at Diagnosis \*

- Summary Stage (Localized, Regional, Distant)
- Tumor Size
- Regional Nodes Examined
- Regional Nodes Positive

### 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

### 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

### Outcomes

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

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## 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.

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