

STATUS

Completed

In progress

For PRCCR Use Only

APPLICATION TO ACCESS PRCCR DATA

This form must be completed and submitted with each proposal to use data from the Puerto Rico Central Cancer Registry (PRCCR). This is to assure that appropriate procedures are implemented for the use of PRCCR data.

Type of Proposal Submitted	
New	Amended

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 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 release this Level II data set from the PRCCR, there are four items that must be included for the request to be considered.

1. **Completed Level II Application Form**
2. **Signed Assurance Form**
3. **Signed Research Agreement**
4. **Copy of approved expedited review by an appropriate Institutional Review Board (IRB)**

As part of the application, the Puerto Rico Central Cancer Registry requests a brief description of the research project as well as a brief description of the Principal Investigator's credentials, education and research interests to be included in the Puerto Rico Central Cancer Registry's Annual Report. By signing the application, you are giving the Puerto Rico Central Cancer Registry permission to use this information in the report. The Registry does reserve the right to edit the submitted descriptions for formatting purposes.

Please enclose the requested documents and mail, fax, or 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 application process.

APPLICATION FORM FOR LEVEL II DATA

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	IRB expiration date	
Yes	No		
THE RESEARCH PROJECT			
Provide the purpose and intend of requested data.		Cancer sites being studied	
		Specifications	
Requested variables			
Age		Vital status	
Sex		Date of last contact	
Diagnostic date		Stage	
Grade			
Histology		Other:	
Diagnostic confirmation			
Provide a brief description of the Principal Investigator			

III. ASSURANCES

If data from the Puerto Rico Central Cancer Registry (PRCCR) are used in any publication (or presentation), the following statement must be included:

Data used in this publication (or presentation) were provided by the Puerto Rico Central Cancer Registry.

The citation for the reference list is:

Incidence:

Puerto Rico Central Cancer Registry. Comprehensive Center Cancer of the University of Puerto Rico. Incidence Case File (Date Release: Month, Year).

Mortality:

Puerto Rico Central Cancer Registry. Mortality File provided by the Puerto Rico Demographic Registry, Department of Health (Date Release: Month, Year).

Each publication must include the following disclaimer:

The collection of cancer-incidence data was supported, in part, by a federal grant from the National Program of Cancer Registries (NPCR) of the Centers of Disease Control and Prevention (CDC) (Award Number: 5U58-DP 003863-05) to the Puerto Rico Central Cancer Registry (PRCCR) as part of the statewide cancer reporting program mandated by the Puerto Rico State Law No. 28 of March 20, 1951, and Law No. 113 of July 30, 2010 (Law of the PRCCR). The ideas and opinions expressed herein are those of the author(s) and endorsement by the PRCCR is not intended nor should be inferred.

In case you used Claims database, each publication must also include the following disclaimer:

This work was supported, in part, by a federal grant from the Puerto Rico NCI Community Oncology Research Program Minority/Underserved-Cancer Care Delivery Research (Award Number 5UG1CA189862-02).

A copy of any publication or presentation that outlines using data from the Puerto Rico Central Cancer Registry should be mailed to **Carlos R. Torres Cintrón** (Analysis and Epidemiology Unit Coordinator) through the e-mail ctorres@rcpr.org.

Authorship for publications with data of the PRCCR

Authorship credit should be based on 1) substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data; 2) drafting the article or revising it critically for important intellectual content; and 3) final approval of the version to be published.

If the Analysis and Epidemiology Staff of the Puerto Rico Central Cancer Registry fulfills the previous description they meet the authorship criteria and must be part of the authors of the publication.

- Name of person requesting data:

- Signature of person requesting data: _____

- Date:

IV RESEARCH AGREEMENT

I _____ certify the following:

1. That I have been notified and I am very conscious that all the information about cancer patients provided by the Puerto Rico Central Cancer Registry (PRCCR) is **strictly confidential**.
2. That I will not use or allow that others use the information given by the PRCCR for any other purpose other than the one specified in the ***Provide the purpose and intend of requested data*** field from **APPLICATION FORM FOR LEVEL II DATA**, described previously.
3. That I will not present/publish information in which an individual could be identified. I will not publish any information about a particular individual including any information generated from a case by means of the list of cases given by the PRCCR. In addition, I will avoid the publication of tables that contain cell that are less than six (6) cases.
4. That I will not attempt to know the identity of any person whose information about his/her disease of cancer is obtained of the supplied records, except when the permission has been granted in written to me by PRCCR.
5. That if the identity of a person reveals itself inadvertently, I:
 - a. will not give use of the disclosed information
 - b. will have to notify the incident to the PRCCR
 - c. will not inform the revealed identity to any other person
6. That I will not reveal the information (partially or completely) nor will I allow that other people to reveal it to any one, unless that person has the written approval from the PRCCR. (Note: The information that has been delivered is for the exclusive use of the person(s) or entity that made the request. The person or entity that receives it has the obligation to keep it secured and protected. The disclosure of this information to a third party, without additional authorization from the PRCCR, is prohibited).
7. That I will not answer questions about cancer patients by telephone.
8. That I will not link or allow that any other person links the information of the PRCCR with individual files of any other data base, except with the special permission of the PRCCR.
9. When the information system is accessed in a common used computer or in the local area net (LAN) of the PRCCR, I will share neither my user's name nor password with any other person. Neither, I will allow that other persons use my computer account after having entered to the system with my user name and password.
10. I will not copy, distribute, do reverse engineering, obtain wages for the sale or the use, nor will I incorporate the electronic programs provided by the PRCCR in any other computerized system.
11. I will receive a database from the PRCCR through a Secure File Transfer Protocol. I will not send this database through email to anyone and will not share the database with third parties outside the study.
12. I will protect the study database and will store it in a password-protected computer. I will not save any copy of the database in a pen drive, neither in CD (**it has to be specified in the study proposal**).
13. As soon as the investigation is completed, I will return or destroy (as agreed) all the information that will be no longer needed for the objective specified in our request (**it has to be specified in the study proposal**).

Now, in terms of the PRCCR's research policy:

14. I am aware that I can use the provided database just to fulfill the objectives specified in the IRB. I will not use the database to other affairs.
15. I am the only person that will work with the database. If not, please specify the full names and tasks in the study for each researcher, including you (**each one have to be included in the IRB**).
16. I will submit a time table to the PRCCR's Advisory Committee. It should include:
 - a. Estimated date of data analysis
 - b. Culmination date of the research
 - c. Date of manuscript submission (If apply)
17. I will submit to PRCCR's Advisory Committee a report by _____ regarding the progress of the Research Project, all publications resulting from the research project, changes in the research project protocol or personnel, any incidents that may have resulted in the disclosure of identifiable cancer cases information, and any other information requested by the PRCCR Advisory Committee.
18. In case I do not submit the report at the date indicated before, the PRCCR's Advisory Committee will intend to contact me by email and/or phone. If I, as Principal Investigator, don't give an answer, the PRCCR have the right to perform the research or suggest the topic to any researcher/student without my consent.
19. I will first provide to the PRCCR's Advisory Committee written notice of the Researcher's intend to publish and a draft of such publication.
20. The source of information will have to be mentioned in **every work published**.
(Note: The appropriate citation must be associated with the data file used.)

PERMISSION TO COLLABORATE WITH OTHER RESEARCHERS

I **authorize** **do not authorize** the PRCCR to provide contact information to other researchers with an interest in the same research topic for the possibility of collaborations.

- Signature of person requesting data: _____
- Date: