

STATUS	
Completed	In progress
<i>For PRCCR Use Only</i>	

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 four 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 (i.e. Rates by sex, age-groups, etc.).

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 municipality of residence, year of diagnosis, sex, and age.

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.

Level IV Files containing individual, record-level data with personal identifiers, to be used for research purposes involving **direct patient or family contact**.

LEVEL III CHECKLIST

The data set to be linked includes personal identifiers, however, once the record linkage is completed, the personal identifiers will be removed from the linked data set before it is sent to the requesting party. Therefore, in order to initiate the release of a Level III data set from the PRCCR, there are five items that must be included for the request to be considered.

1. **Completed Level III Application Form (Page 3)**
2. **Signed Assurance Form (Page 4)**
3. **Signed Certification of Confidentiality for Researchers (Page 5)**
4. **Copy of the research proposal.**
5. **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:

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Biostatistician / Analysis and Research Unit

Puerto Rico Central Cancer Registry

University of Puerto Rico Comprehensive Cancer Center

E-mail: ctorres@rcpr.org

Phone: (787) 772-8300 ext. 1112

Fax: (787) 522-3283

APPLICATION FORM FOR LEVEL III DATA

ORGANIZATION OR INDIVIDUAL REQUESTING ACCESS			
Date of request	Name of person requesting data	Title, Degree, and Rank	
Organization		Address	
Telephone number	Fax number	E-mail address	
Other person who should be contacted if more information is needed			
Name		Address (if different from above)	
E-mail address		Telephone number	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.		Individual data and period (years)	
		Cancer sites being studied	
Variables requested			
Age		Vital status	
Sex		Municipality of residence	
Date of diagnosis		Date of last contact	
Grade		Stage	
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:

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

Also each publication must include the following disclaimer:

The collection of cancer-incidence data was supported, in part, by the National Program of Cancer Registries (NPCR) of the Centers of Disease Control and Prevention (CDC) by the Puerto Rico Central Cancer Registry 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 Puerto Rico Central Cancer Registry. The ideas and opinions expressed herein are those of the author(s) and endorsement by the PR is not intended nor should be inferred.

A copy of any publication or presentation that outlines using data from the Puerto Rico Central Cancer Registry should be mailed to the Registry at:

Carlos R. Torres Cintrón, MPH
Biostatistician / Analysis and Research Unit
Puerto Rico Central Cancer Registry
University of Puerto Rico Comprehensive Cancer Center
E-mail: ctorres@rcpr.org
Fax: (787) 522-3283

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 Research and Analysis Staff of 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 CERTIFICATION OF CONFIDENTIALITY FOR RESEARCHERS

I **certify the following:**

1. That I have been notified and 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 Puerto Rico Central Cancer Registry, 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. 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.
12. 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.*)

Signature of Person Requesting Data: _____

Date: