Procedures for Access to and Disclosure of Confidential Data from the Punjab Cancer Registry

1-Tracking

Amendment 3: September 27, 2021- Procedures for Access to and Disclosure of Confidential Data from the Punjab Cancer Registry.

Amendment 2: July 23, 2013-Policy and Procedures for Access to, and Disclosure of, Confidential Data from the Punjab Cancer Registry.

Amendment 1: Mar. 10, 2011-Policy and Procedures for Access to and Disclosure of Confidential Data from the Punjab Cancer Registry.

First draft: Dec. 26, 2005-Policies and Procedures for Access to and Disclosure of Confidential Data from the Punjab Cancer Registry-Lahore Chapter.

Procedures for Access to and Disclosure of Confidential Data from the Punjab Cancer Registry

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Acknowledgment: Members of the Governing Council of the Punjab Cancer Registry and staff of the Cancer Registry and Clinical Data Management unit, SKMCH&RC.

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2-Standard procedures for the Punjab Cancer Registry

- To define objectives of data collection:
  a) To record new cases of cancer in a specified population, in a defined geographic area/district within the province of Punjab, Pakistan, on a yearly basis and to collate information on cancer site/type and incidence.
  b) To record mortality due to cancer in the residents of the district of Lahore.

- To promote the Registry in print and broadcast media.

- To identify the catchment population in Punjab (*Appendix A*):
  The catchment population would be that group of individuals who are residents of the district under consideration (1), who visit a facility for diagnosis or treatment, and who have either a histologically or clinically confirmed, diagnosis of cancer.

- To list reportable neoplasms (*Appendix B*):
  Any neoplasm with a behavior code (fifth digit in a complete six-digit morphology code) of '/2' (in situ) or '/3' (invasive) (2).

- To assign a unique identification number to each collaborating center (*Appendix C*), within the district of Lahore, at the assigned central data collection office.

- To update the aforementioned list periodically.

- To visit various collaborating centers to distribute the data capture forms and subsequently collect and bring the filled-out forms to the central office.

- To use official transport for these visits, maintain a log of visits including dates, centers visited, and forms distributed/collected.

- To collect data on the data collection form designed specifically for this purpose (*Appendix D*) and define terms in a standardized way (*Appendix E (3))*.

- To assign an exclusive ID to each patient.

- To include residents of that particular district diagnosed with cancer and/or treated for cancer after the Registry's reference date (February 01, 2005).

- To present year-wise aggregate data when reporting is complete/nearly complete from all collaborating centers and information has been entered into the recommended software.

3-Check for duplicate records

- Perform checks for duplicate records by comparing the following variables: *First name or initial and last name or initial, gender, date of birth, age range, telephone number, primary site, and histology.*

- In case of the non-availability of a unique identifier, checks for absolute duplicates may be difficult, though for probable duplicates may still be possible. The results may not be accurate.

4-Check for multiple primaries

- Count two or more discrete tumors of different ("three-digit") sites in any individual separately for incidence statistics. However, as per international practice, count tumors arising in sites with the same first three digits (subsite) as one (4). This may be a recurrence of the disease.

- Group different histologies from the same subsite (same three-digit site) separately. In this way, for example, a squamous cell carcinoma of a lung and an adenocarcinoma of the same or other lung arising at any time will both be counted in incidence statistics-new case of cancer.

- Tabulate lympho-hematopoietic malignancies (e.g. lymphomas and leukemias) by morphology.

- Treat the renal tract as a special case of an "extended site", whereby consider multiple transitional cell carcinomas of non-bladder sites only once.

- Treat cancers of unknown primary sites as a distinct group. Attempt to determine the true primary site.

- Cancer diagnosed in a different organ from the one before will be considered a new case. However, a malignancy arising within the same organ and subsite (recurrence) will not be considered a new case.

5-Measures for confidentiality

- Sign a confidentiality pledge/declaration at the time of employment with SKMCH&RC, which will remain in force even after cessation of employment from the Hospital/Registry.

- Maintain a list, with Security, of all employees authorized to enter the Registry.

- Do not let anyone in the office you don't know.

- Escort visitors back and forth to the door.

- Provide proof of identification to staff engaged in registration.

- Send Registry staff on official transport to distribute and collect forms from various centers and to bring them back to the central data collection office.

- Mark the folders as "CONFIDENTIAL" and keep the forms locked in a cabinet in the central data office of the Registry.

- Lock the office at the end of the day, deposit the key with Security, and maintain a list of employees who can access the office.

- Allow Registry staff to use a specific username (ID)-password to start the computer and another set of user-password controlled log in to access the Hospital information System, thus, the Punjab Cancer Registry software.

- Lock the computer by using CTL-ALT-DEL to bring up the Windows Security screen and click on the "Shut down" button when leaving the office.

- Pick up all the printouts pertaining to the Registry promptly.

- Refrain from discussing confidential data in the halls and from carrying them to break rooms or restrooms.

- Allow authorized individuals to examine collated results.

- Separate tumor-related data from key personal identifiers such as name, ID, and address, when reporting the results.

- Subject data on deceased persons to the same procedures for confidentiality as data on living persons.

- Treat all data in the Registry as confidential whether the data items are personal identifiers or not.

- Inform that confidentiality is the responsibility of all the professionals involved in cancer registration.

- Define “data” as all information, documents, reports, and files.

- Avoid transmission of information on the telephone.

- Dispose of paper-based forms once scanned; however, retain the entire information in the PCR software.

6-Release of Registry data

- Allow professionals to publish the results: All professionals involved in conducting the study and preparing the manuscript in line with the recommendations on conducting studies, data reporting, and publication of work made by the International Committee of Medical Journals Editors and SKMCH&RC, will be included as authors on the manuscript (5-6). Others will be acknowledged individually or collectively as the "Punjab Cancer Registry" in the section on acknowledgments.

- Obtain written requests for release of Registry data for research or healthcare planning.

- Ensure that ethical aspects related to the release of information are taken care of.

- Refuse requests for information on identifiable data concerning individuals (who may or may not have cancer recorded at the Registry), from agencies dealing with pension schemes, healthcare cost reimbursement, industrial disease compensation panels, and life insurance. Direct enquirer to obtain information directly from the subject or the subject’s treating physician.

- Ask nominated professionals to handle inquiries from the press about the Registry.

7-References

1. Mineral Map. https://cim.punjab.gov.pk/mineral_map. Accessed: Sep. 24, 2021.
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3. Johnson C, Peace S, Adamo P, Fritz A, et al. Multiple Primary and Histology Coding Rules, January 01, 2007. National Cancer Institute, Surveillance Epidemiology and End Results Program, Bethesda, MD. https://seer.cancer.gov/tools/mphrules/2007_mphrules_manual_08242012.pdf. Accessed: Nov. 16, 2017.
4. Policies and Procedures for Access to and Disclosure of Confidential Data from the California Cancer Registry. CCRPoliciesProcedures_v05.2_3-19.pdf. Accessed: Sep. 27, 2021.
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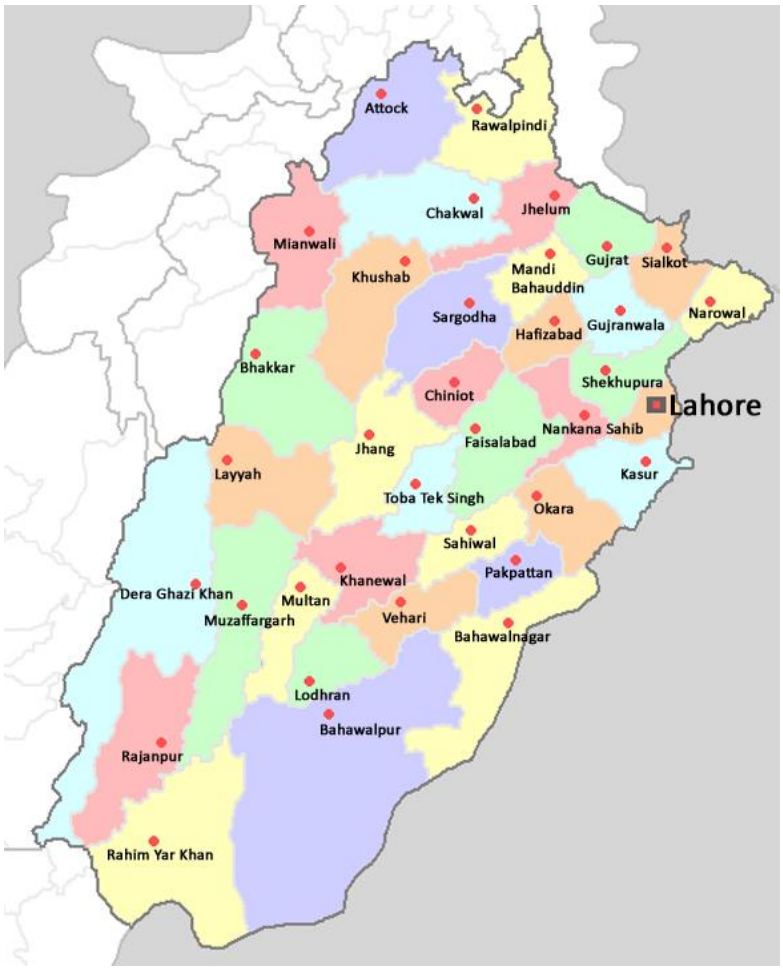
6. Shaukat Khanum Memorial Cancer Hospital and Research Center. Guidelines for Research-Authorship. https://shaukatkhanum.org.pk/authorship/. Accessed: Sep. 28, 2021.

APPENDIX A

Map of Punjab, Pakistan



APPENDIX B

Reportable diagnoses-SEER PROGRAM CODING AND STAGING MANUAL 2021.

1. In situ and malignant/invasive histology

   All histologies with a behavior code of /2 or /3 in the International Classification of Diseases for Oncology, Third Edition (ICD-O-3), including the following:
   i. Carcinoma in situ of the cervix (/2) or cervical intraepithelial neoplasia (CIN III) of the cervix (C530-539).
   ii. Prostatic intraepithelial neoplasia (PIN III) of the prostate (C619).
   iii. Benign/non-malignant histology.
   a. Pilocytic/juvenile astrocytomas are reportable; code the histology and behavior code 9421/3.
   b. Benign and borderline primary intracranial and CNS tumors with a behavior code of /0 or /1 in ICD-O-3 are collected for the following sites. See the table below for *required sites*.

Table 2. Required sites for benign and borderline primary intracranial and central nervous system tumors.

General term	Specific sites	ICD-O-3 Topography code
Meninges	Cerebral meninges	C 700
	Spinal meninges	C 701
	Meninges, NOS	C 709
Brain	Cerebrum	C 710
	Frontal lobe	C 711
	Temporal lobe	C 712
	Parietal lobe	C 713
	Occipital lobe	C 714
	Ventricle, NOS	C 715
	Cerebellum, NOS	C 716
	Brain stem	C 717
	Overlapping region of the brain	C 718
	Brain, NOS	C 719
The spinal cord, cranial nerves,	Spinal cord	C 720
and other parts of the central	Cauda equine	C 721
nervous system	Olfactory nerve	C 722
	Optic nerve	C 723
	Acoustic nerve	C 724
	Cranial nerves, NOS	C 725
	Overlapping region of the brain and central nervous system	C 728
	The nervous system, NOS	C 729
Pituitary, craniopharyngeal duct,	Pituitary gland	C 751
and pineal gland	Craniopharyngeal duct	C 752
	Pineal gland	C 753

2. *Note: Benign and borderline tumors of the cranial bones (C410) are not reportable.*

3. The ICD-O- is published by the World Health Organization and is the accepted reference for determining malignancy.

Table 3. ICD-O-Behavior Codes.

Code	Definition
0	Benign
1	Uncertain whether benign or malignant
2	Carcinoma in situ
3	Malignant, primary site
6	Malignant, metastatic site
9	Malignant, uncertain whether a primary or metastatic site

4. Although the following malignant conditions with the ICD-O-3 behavior codes /2 and /3 are not required by the Commission on Cancer (COC), the PCR will include the following for incidence statistics:
Localized basal or squamous cell carcinoma of non-genital skin sites (C44.0-C44.9).

Table 4. Comparison of Cancer Reportability in ICD-O-3[1].

Type of cancer	COC	SEER [2]
CIS & CIN III(Cervix)	No	No
PIN III (Prostate)	No	No
VIN III (Vulva)	No	Yes
VAIN III (Vagina)	No	Yes
AIN	No	Yes
Skin cancers	C440_with morphology (8000-8110) and AJCC stage group 0 or 1 not reportable.	C44_ with morphology (8000-8110) not reportable.

Basal and squamous cell carcinoma of the non-genital skin sites occurs frequently. Most cancer registries do not collect them as basal and squamous cell carcinomas of the skin have a better prognosis than most other invasive cancers. The patients are often treated only in the physician's office, which makes it difficult to get complete and accurate information. *The COC requires that basal and squamous cell carcinoma of the non-genital skin sites be included when, at initial diagnosis, it has invaded regional tissue or lymph nodes, or metastasized.*

[1] North American Association of Central Cancer Registries. Guidelines for ICD-O-3 implementation: Prepared by the NAACCR ICD-O-3 Implementation Work Group: Nov. 27, 2000. https://www.facs.org/~/media/files/quality%20programs/cancer/coc/naaccr.ashx. Accessed: Sep. 27, 2021.

[2] SEER is an acronym for Surveillance Epidemiology and End Results.

APPENDIX C

S. No.	Collaborating center
1	Shaukat Khanum Memorial Cancer Hospital & Research Center
2	Institute of Nuclear Medicine & Oncology, Lahore
3	Ittefaq Hospital, Lahore
4	Sheikh Zayed Hospital, Lahore
5	Chughtai Lab
6	Fatima Jinnah Medical University, Lahore
7	Jinnah Hospital, Lahore
8	The Children's Hospital & the Institute of Child Health, Lahore
9	Services Institute of Medical Sciences, Lahore
10	Fatima Memorial College of Medicine & Dentistry, Lahore
11	Shalamar Medical & Dental College, Lahore
12	Allama Iqbal Medical College, Lahore
13	King Edward Medical University, Lahore
14	Social Security Hospital, Lahore
15	Akhtar Saeed Medical & Dental College, Lahore
16	Postgraduate Medical Institute, Lahore
17	Combined Military Hospital, Lahore
18	Indus Lab, Lahore
19	Pride Lab, Lahore
20	Doctors Hospital
21	Hameed Latif Hospital, Lahore
22	University Medical and Dental College, Faisalabad
23	Children Hospital, Faisalabad
24	Excel-labs
25	Lahore General Hospital
26	Pakistan Kidney and Liver Institute and Research Center, Lahore

APPENDIX D

PUNJAB CANCER REGISTRY

DATA COLLECTION FORM

HISTOLOGY NO._____ HISTOLOGY DATE: _____/_____/_____

CENTER I.D. NO._____ PATIENT I.D NUMBER: _____
← (To be allocated by †PCR Central Office) →

PATIENT'S NAME_____ _____ _____
FIRST MIDDLE LAST

SEX: MALE ☐ FEMALE ☐ NEUTER (MUKHANNAS) ☐ FATHER'S NAME _____

BIRTH DATE _____ AGE _____

N.I.C. NUMBER (FOR CHILDREN ≤ 18 YEARS, ID OF MOTHER/FATHER) _____

PERMANENT ADDRESS (HOUSE AND STREET NO.) _____

_____

CITY/TOWN _____ POSTAL CODE_____

HOME/CELL TELEPHONE WITH AREA CODE_____

↓ARE YOU A RESIDENT OF (Please tick one): LAHORE ☐ SHEIKHUPURA ☐ KASUR ☐
NANKANA SAHIB ☐ FAISALABAD ☐ GUJRANWALA ☐ HAFIZABAD ☐ OTHER ☐

کیا آپ لاہور/ قصور/شیخوپورہ/ ننکانہ صاحب/فیصل آباد/ گوجرانوالہ/ حافظ آباد یا کسی اور ضلع کے رہائشی ہیں؟

DURATION OF STAY IN THE ABOVE-MENTIONED DISTRICT (months/years):_____

↓HAVE YOU COME TO THE ABOVE-MENTIONED DISTRICT FOR TREATMENT/DIAGNOSIS ONLY? (YES/NO)

کیا آپ اوپر لکھے گئے ضلع میں تشخیص یا علاج کے لئے آئے ہیں؟

Procedure/surgery done at (hospital)…….
Name of surgeon……
Cytology/histopathology done at (lab.) …….

PRIMARY SITE_____ DATE OF DIAGNOSIS _____

SITE OF BIOPSY_____ MORPHOLOGY _____

LATERALITY (where applicable) _____ METASTATIC_____ (YES/NO) BEHAVIOR_____

GRADE _____ STAGE (when available) _____

*MOST VALID BASIS OF DIAGNOSIS (Please see the list below)_____

FOR PCR CENTRAL OFFICE USE ONLY
STATUS AT LAST FOLLOW-UP _____

DATE OF DEATH _____ PLACE OF DEATH _____

†PCR is an acronym for the 'Punjab Cancer Registry'.
*0: Death Certificate Only; 1: Clinical; 2: Clinical investigation; 4: Specific tumor markers; 5: Cytology; 6: Histology of a metastasis; 7: Histology of primary tumor; and 9: Unknown.

Form revised on Jan. 07, 2015
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APPENDIX E

Definitions

- "PCR data" means all information collected at any time by the Punjab Cancer Registry under the authority of Societies' Registration Act of Pakistan, XXI of 1860, whether or not such information identifies an individual or could be used to identify an individual. PCR data also means all documents, files, or other records, regardless of format or medium, containing PCR data (whether alone or in combination with other data).

- "Access to data" means the right to examine data.

- "Disclosure of data" means the granting of the right to examine data and the right to create and retain a copy.

- "Research" means the release of publications and presentations containing aggregate data and conclusions drawn from studying the PCR data, including journal articles, summary reports, special analyses, studies, and other documents, and presentations to professional organizations, the news media, and the public. These publications may contain case counts, rates, and survival analyses derived from the PCR incidence and mortality data. Individual cases or individual sources of information shall not be identified in any way.

- "Aggregate data" or "Collated results" means statistical information derived from PCR data that does not include any individual item of data representing a person, whether identified, identifiable or anonymous, and from which no information about an identifiable or anonymous person can be obtained in any manner.

- "Reports and statistical information" means reports, articles, special analyses, studies, and other publications and communications that contain aggregate PCR data.

- "Sources of information" or "collaborating centers" means hospitals and other facilities or agencies, (be these private or government), providing diagnostic or treatment services to patients with cancer, and physicians, surgeons, dentists, podiatrists, and all other healthcare practitioners diagnosing or providing treatment for cancer patients, that have provided information contained in PCR data files.

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