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

Authors: Farhana Badar and Shahid Mahmood, Shaukat Khanum Memorial Cancer Hospital and Research Center (SKMCH&RC).
Reviewed by Dr. Aasim Yusuf and Dr. Asif Loya.
Acknowledgment: Members of the Governing Council of the Punjab Cancer Registry and staff of the Cancer Registry and Clinical Data Management unit (SKMCH&RC), Lahore.

Amendment 4: June 23, 2026:

Revisions to the wording were made in the document.

2-Standard procedures for the Punjab Cancer Registry: 'Benign and borderline primary intracranial and central nervous system (CNS) tumors with a behavior code of /0 or /1 in ICD-O-3' were also added.

Collaborating centers: …within the district of Lahore, 'and other districts that are reporting their cases to us'… was added.

4-Check for multiple primaries: Points 1-6 were added. The previous six bullets were removed.

Reference 4 was revised.

- Appendix A: Classified into A1 and A2.
    - A1: Current map of Punjab showing 41 districts.
    - A2: Previous map of Punjab showing 36 districts, retained for reference purposes.
- Appendix B: List of reportable neoplasms was updated.
- Appendix C: List of collaborating centers was updated.
- Appendix D: Data collection form was replaced with the current form, incorporating minor revisions made on June 11, 2026.
- Appendix F: International rules for multiple primary cancers were added.

Added the following sentence:
Please note that the North-West Cancer Registry will follow the same procedures outlined for the Punjab Cancer Registry to register cancer cases in the northwestern regions of Pakistan.

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

PREVIOUS CHANGES AND CONTENT

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.

CONTENT

Page	List with section nos.	Amendment 1	Amendment 2	Amendment 3
1	Title page	Minor revision	-	Minor revision
2	1-Tracking	-	-	-
3	Contents	-	-	-
4-5	2-Standard procedures for the Punjab Cancer Registry	Minor revisions	-	Minor revisions
5	3-Check for duplicate records	Minor revisions	Minor revision	Minor revision
5	4-Check for multiple primaries	Minor revisions	-	Revised
6-7	5-Measures for confidentiality	Minor revisions	-	-
7	6-Release of Registry data	Minor revisions	6-Release of Registry data-Revised	-
8	7-References			Revised
9	APPENDIX A	Table 1-Projected population of Lahore district in 2010-2011-Revised	-	Map of Punjab
10-11	APPENDIX B	Reportable diagnosis and Tables 2-4	-	-
12	APPENDIX C	Table 5-List of collaborating centers-Revised	Table 5-List of collaborating centers-Revised	Revised
13-14	APPENDIX D	Data collection form-Revised	Data collection form-Revised	Revised
15	APPENDIX E	Definitions		-
16	APPENDIX F			Added

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

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 an annual basis and to collate information on cancer site/type and incidence.
  b) To record mortality due to cancer among the residents of the district under consideration, when available.

- To promote the Registry in print and broadcast media.

- To identify the catchment population in Punjab (*Appendix A*):
  The catchment population would be a group of individuals who are residents of the district under consideration (1-2), 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) (3). Benign and borderline primary intracranial and central nervous system (CNS) tumors with a behavior code of /0 or /1 in ICD-O-3 are also included.

- To assign a unique identification number to each collaborating center (*Appendix C*), within the district of Lahore, and other districts that are reporting their cases to the central data collection office.

- To update the aforementioned list periodically.

- To conduct official visits to various collaborating centers and educate their staff on the use of paper/electronic means of data provision.

- To collect data on the data collection form designed specifically for this purpose (*Appendix D*) and define terms in a standardized way (*Appendix E (4))*.

- To bring 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 assign an exclusive ID to each patient.

- To abstract data after reviewing the pathology/radiology reports and clinical notes of SKMCH&RC patients.

- To enter the data in the cancer registry module of the hospital information system.

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

- To present year-wise aggregate data when reporting is complete/nearly complete, 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

1. The existence of two or more primary cancers is recognized regardless of the time interval.
2. Primary cancer originates in a primary site or tissue of origin and is not the result of an extension, recurrence, or metastasis from another primary tumor.
3. Only one tumor is recognized as arising in an organ, pair of organs, or tissue. Certain groups of codes are treated as a single organ (see ***Appendix F***, Table 1). Multifocal tumors (discrete masses, not continuous, with other primaries, e.g., those in the bladder) are counted as a single cancer.
4. Exceptions to Rule 3:
    i. Systemic/multicentric cancers: Counted once per individual as shown in ***Appendix F***, Table 2: hematopoietic tumors, groups 8–14 and Kaposi sarcoma, group 15.

ii. Different morphologies: Neoplasms of different morphologies are considered multiple cancers, even if diagnosed simultaneously on the same site.

- If morphologies fall into one category on the same site, they are considered the same. If morphologies fall into two or more categories on the same site, they are considered different and counted separately.
- A single tumor with several histologies in one group is registered as one case, using the highest ICD-O morphology code.
- If one morphology is non-specific (groups 5, 14, 17) and a specific one is available, report with the specific histology; ignore the non-specific.

5. Two tumors of the same morphology in paired organs (e.g., breast) should be registered separately unless proven to originate from a single primary.

   Exceptions (recorded as single bilateral cases):

   - Ovarian tumors of the same morphology.
   - Wilm's tumor (nephroblastoma) of the kidney.
   - Retinoblastoma.

   Note: Tumors in paired organs with completely different histology must be registered separately.

6. Cancers occurring in any 4th character subcategory of the colon are registered separately.

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 do not 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 login to access the Hospital Information System, thus, the Punjab Cancer Registry software.

- Lock the computer by using CTRL-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 on the Registry promptly.

- Refrain from discussing confidential data in the halls and from carrying it 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 or not the data items are personal identifiers or not.

- Those overseeing the CRCDM section need to make it clear to their employees that they have an obligation to maintain confidentiality, as per Hospital Policy.

- Define “data” as all information, documents, reports, and files, whether paper-based or electronic.

- Refrain from transmitting information over the phone.

- Dispose of paper-based forms in an approved manner, 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 (6-7). Others will be acknowledged individually or collectively as the "Punjab Cancer Registry" in the section on acknowledgements.

- 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.

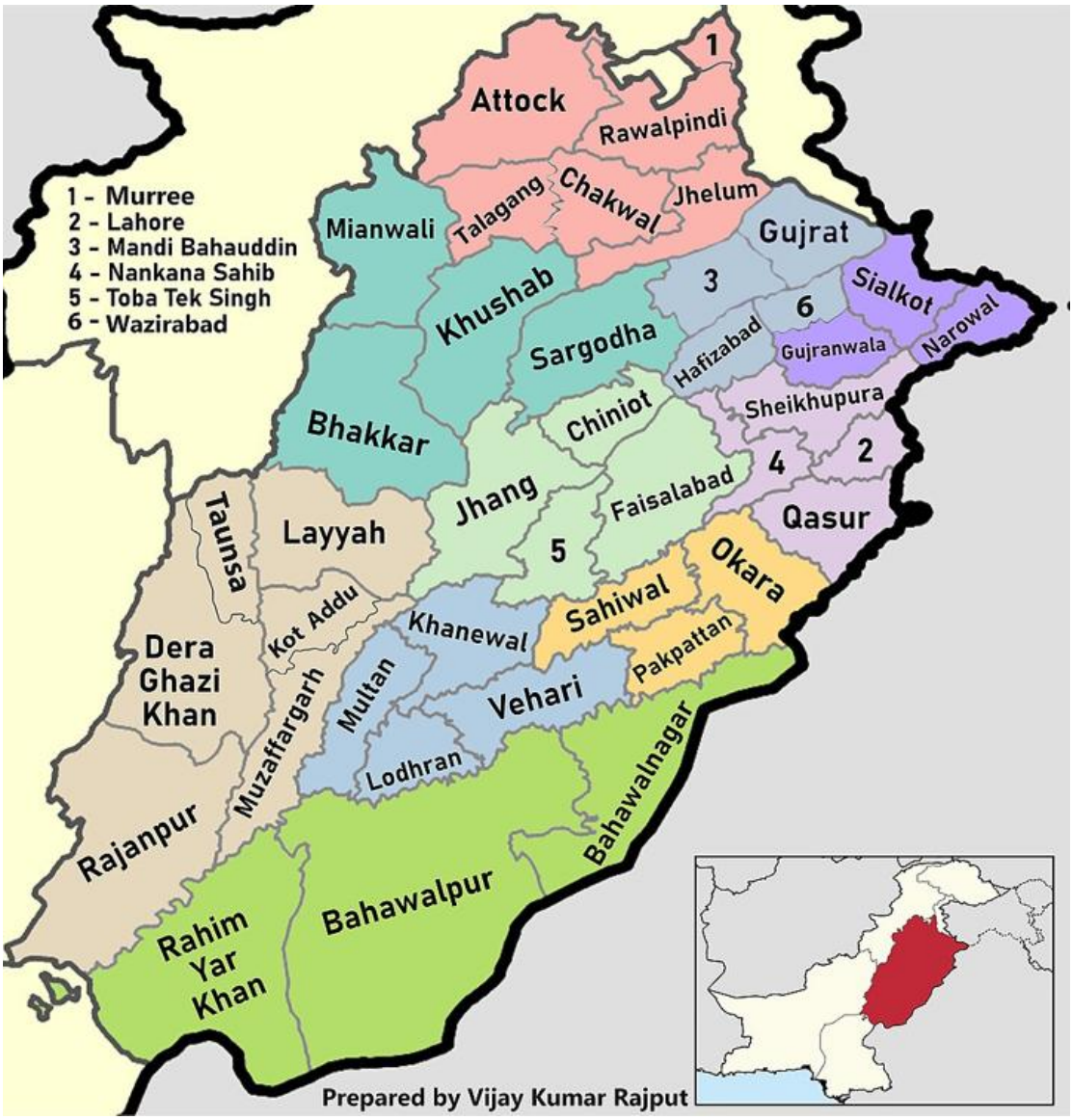
- Ask designated professionals to handle media inquiries about the Registry.

PLEASE NOTE THAT THE NORTH-WEST CANCER REGISTRY WILL FOLLOW THE SAME PROCEDURES OUTLINED ABOVE FOR THE PUNJAB CANCER REGISTRY TO REGISTER CANCER CASES IN THE NORTHWESTERN REGIONS OF PAKISTAN.

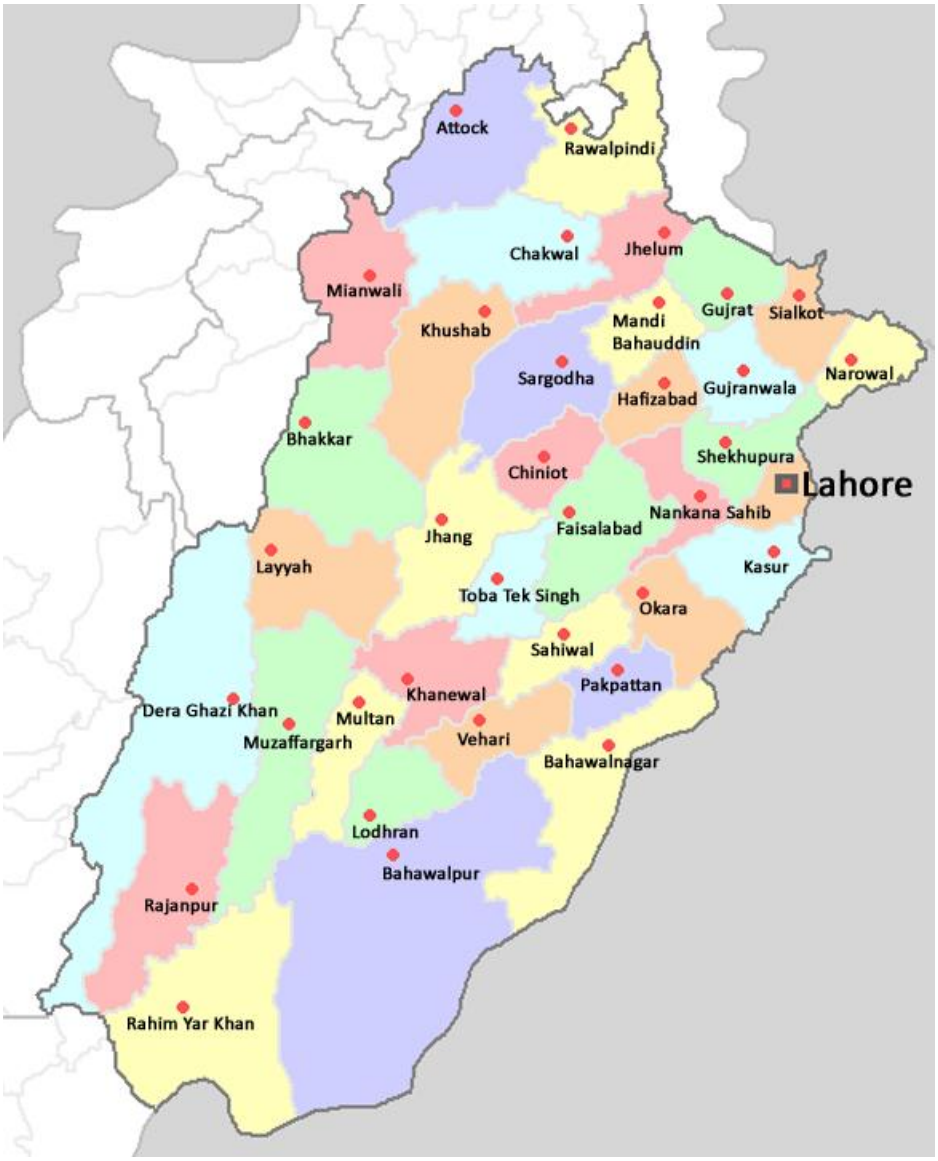
7-References

1. List of districts in Punjab, Pakistan. New District wise map Punjab province 2022-Prepared by Vijay Kumar. By Vk8435820 - Own work, CC BY-SA 4.0, https://commons.wikimedia.org/w/index.php?curid=126047889. Accessed: June 23, 2026.
2. Mineral Map. https://cim.punjab.gov.pk/mineral_map. Accessed: Sep. 24, 2021.
3. SEER Program Coding and Staging Manual 2026-REPORTABILITY. SEER Program Coding and Staging Manual 2026 Accessed: Jul. 31, 2026.
4. Working Group of the International Agency for Research on Cancer; World Health Organization; International Association of Cancer Registries; European Network of Cancer Registries. International rules for multiple primary cancers (ICD-O third edition). Lyon: IARC; 2004. Internal report No.: 2004/02. Available from: http://www.iacr.com.fr/images/doc/MPrules_july2004.pdf. Accessed: Jun. 24, 2026.
5. 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.
6. ICJME-International Committee of Medical Journal Editors. Defining the Role of Authors and Contributors. http://www.icmje.org/recommendations/browse/roles-and-responsibilities/defining-the-role-of-authors-and-contributors.html. Accessed: Sep. 28, 2021.
7. Shaukat Khanum Memorial Cancer Hospital and Research Center. Guidelines for Research-Authorship. https://shaukatkhanum.org.pk/authorship/. Accessed: Sep. 28, 2021.

APPENDIX A1-Recent map of Punjab, Pakistan. As of January 2023, Punjab has 41 districts.



APPENDIX A2-Map of Punjab, Pakistan-previous version retained for reference (36 districts).



APPENDIX B-Reportable diagnoses

Reportable diagnoses-SEER PROGRAM CODING AND STAGING MANUAL 2026.

1. <u>In situ and malignant/invasive histology</u>

   Report all histology with a behavior code of /2 or /3 in the ICD-O-Third Edition, Second Revision Morphology (ICD-O-3.2). 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).
2. Report benign and borderline primary intracranial and central nervous system (CNS) tumors with a behavior code of /0 or /1 in ICD-O-3 (effective with cases diagnosed 01/01/2004 to 31/1/2023) or ICD-O-3.2 (effective with cases diagnosed 01/02/2023 and later).
   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*.
   c. Benign and borderline tumors of the cranial bones (C410) are not reportable.
   d. Benign and borderline tumors of the peripheral nerves (C47_) are not reportable.

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, and other parts of the central nervous system	Spinal cord	C 720
	Cauda equine	C 721
	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, and pineal gland	Pituitary gland	C 751
	Craniopharyngeal duct	C 752
	Pineal gland	C 753

3. The ICD-O-3 is published by the World Health Organization and is the accepted reference for determining malignancy.
4. All skin cancer are reportable to the Punjab Cancer Registry.

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

APPENDIX C-List of collaborating centers

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 and Medical Center, Lahore
21	Hameed Latif Hospital, Lahore
22	University Medical and Dental College, Faisalabad
23	Children Hospital, Faisalabad
24	Excel-labs
25	Meezan Lab, Faisalabad
26	Mughal Lab, Lahore
27	Pakistan Institute of Medical Sciences, Islamabad
28	Aga Khan University Hospital
29	Lahore General Hospital
30	Pakistan Kidney and Liver Institute and Research Center, Lahore

APPENDIX D-Data collection form

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/TYPE_____ DATE OF DIAGNOSIS _____

SITE OF BIOPSY _____ MORPHOLOGY/DIAGNOSIS _____

LATERALITY (where applicable) _____ METASTATIC _____(YES/NO) BEHAVIOR _____

GRADE _____ STAGE (when available) _____

*MOST VALID BASIS OF DIAGNOSIS _____

*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.

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'.

Form revised June 11, 2026
Central Office at Shaukat Khanum Memorial Cancer Hospital and Research Center, 7-A, Block R-3, M. A. Johar Town, Lahore, Pakistan
Phone: +92-42-35905000 Ext. 4243; 4246. Email: pcr@skm.org.pk

APPENDIX E-Terms used in the document

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, laboratories, and other facilities or agencies, (whether 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, who have provided information contained in PCR data files.

APPENDIX F-Tables 1-2: International rules for multiple primary cancers (ICD-O-3).

Table 1. Groups of topography codes are considered a single site in the definition of multiple cancers.		
C01	Base of tongue	
C02	Other and unspecified parts of tongue	C02.9
C00	Lip	
C03	Gum	
C04	Floor of mouth	
C05	Palate	
C06	Other and unspecified parts of mouth	C06.9
C09	Tonsil	
C10	Oropharynx	
C12	Pyriform sinus	
C13	Hypopharynx	
C14	Other and ill-defined sites in lip, oral cavity, and pharynx	C14.0
C19	Rectosigmoid junction	
C20	Rectum	C20.9
C23	Gallbladder	
C24	Other and unspecified parts of biliary tract	C24.9
C33	Trachea	
C34	Bronchus and lung	C34.9
C40	Bones, joints, and articular cartilage of limbs	
C41	Bones, joints, and articular cartilage of other and unspecified sites	C41.9
C65	Renal pelvis	
C66	Ureter	
C67	Bladder	
C68	Other and unspecified urinary organs	C68.9

Table 2. Groups of malignant neoplasms considered to be histologically 'different' for the purpose of defining multiple tumors.	
Carcinomas	
1. Squamous and transitional cell carcinoma	8051-8084, 8120-8131
2. Basal cell carcinomas	8090-8110
3. Adenocarcinomas	8140-8149, 8160-8162, 8190-8221, 8260-8337, 8350-8551, 8570-8576, 8940-8941
4. Other specific carcinomas	8030-8046, 8150-8157, 8170-8180, 8230-8255, 8340-8347, 8560-8562, 8580-8671
5. Unspecified carcinomas (NOS)	8010-8015, 8020-8022, 8050
6. Sarcomas and soft tissue tumors	8680-8713, 8800-8921, 8990-8991, 9040-9044, 9120-9125, 9130-9136, 9141-9252, 9370-9373, 9540-9582
7. Mesothelioma	9050-9055
Tumors of hematopoietic and lymphoid tissues	
8. Myeloid	9840, 9861-9931, 9945-9946, 9950, 9961-9964, 9980-9987
9. B-cell neoplasms	9670-9699, 9728, 9731-9734, 9761-9767, 9769, 9823-9826, 9833, 9836, 9940
10. T-cell and NK-cell neoplasms	9700-9719, 9729, 9768, 9827-9831, 9834, 9837, 9948
11. Hodgkin lymphoma	9650-9667
12. Mast-cell tumors	9740-9742
13. Histiocytes and accessory lymphoid cells	9750-9758
14. Unspecified types	9590-9591, 9596, 9727, 9760, 9800-9801, 9805, 9820, 9832, 9835, 9860, 9960, 9970, 9975, 9989
15. Kaposi sarcoma	9140
16. Other specified types of cancer	8720-8790, 8930-8936, 8950-8983, 9000-9030, 9060-9110, 9260-9365, 9380- 9539
17. Unspecified types of cancer	8000-8005

---END OF DOCUMENT---