

IMPLEMENTATION OF A MULTICENTER PEDIATRIC CANCER REGISTRY IN PAKISTAN: INITIAL EXPERIENCE FROM A NATIONAL INITIATIVE BY THE PAKISTAN SOCIETY OF PEDIATRIC ONCOLOGY (PSPO)

Alina Sadaf¹ · Qurat-ul-ain Ali² · Mohiba Ali Khowaja² · Muhammad Ali² · Uzma Imam³ · Alia Ahmed⁴ · Mahwish Faizan⁴ · Palwasha Rehman⁵ · Muhammad Rafie Raza⁶ · Farhana Badar¹ · Naureen Mushtaq⁸ · Asim Belgaumi⁹

¹Shaukat Khanum Memorial Cancer Hospital and Research Centre, Lahore, Pakistan, ²Pakistan Society of Pediatric Oncology, ³National Institute of Child Health, Karachi, Pakistan, ⁴University of Child Health Sciences, Lahore, Pakistan, ⁵Shaukat Khanum Memorial Cancer Hospital and Research Centre, Lahore, Pakistan, ⁶Indus Hospital & Health Network, Karachi, Pakistan, ⁸Aga Khan University Hospital, Karachi, Pakistan, ⁹St. Jude Children's Research Hospital, Memphis, USA

BACKGROUND & AIMS

Childhood cancer survival exceeds 80% in high-income countries but remains below 20% in LMIC such as Pakistan, where reliable cancer burden, staging, treatment, and outcome data are limited. To address this gap and support the WHO Global Initiative for Childhood Cancer, PSPO launched the National Pediatric Cancer Registration Program (NPCRP) in 2023.

Objectives of NPCRP:

- Support national cancer surveillance
- Inform healthcare policy
- Advance collaborative research

METHODS

- Development of protocol**
 - Nationally representative registry steering committee convened
 - REDCap® forms developed based on IARC standards
- Grant support** 2-yr SIOP-PARC grant
- Training clinical data abstractors (CDAs)** 12-module training program
- Ethical approvals, data sharing agreements**
- OncoRegFix**
Tool developed to create unique identifiers and flag duplicates
- Data collection**
- Quality assessments and re-training**

CASE REPORT FORMS

- Demographics
- Diagnostic information
- Staging
- Treatment
- Response assessment
- Follow-up

CASE ELIGIBILITY

- NEW CANCER DIAGNOSIS**
- AGE 0–19 YEARS**
At time of diagnosis
- REPORTABLE NEOPLASM**
Diagnosed case or receiving cancer-directed or palliative therapy

RESULTS

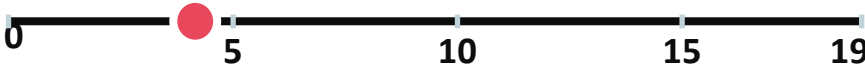
3-month pilot: 1st October to 31st December 2025

426

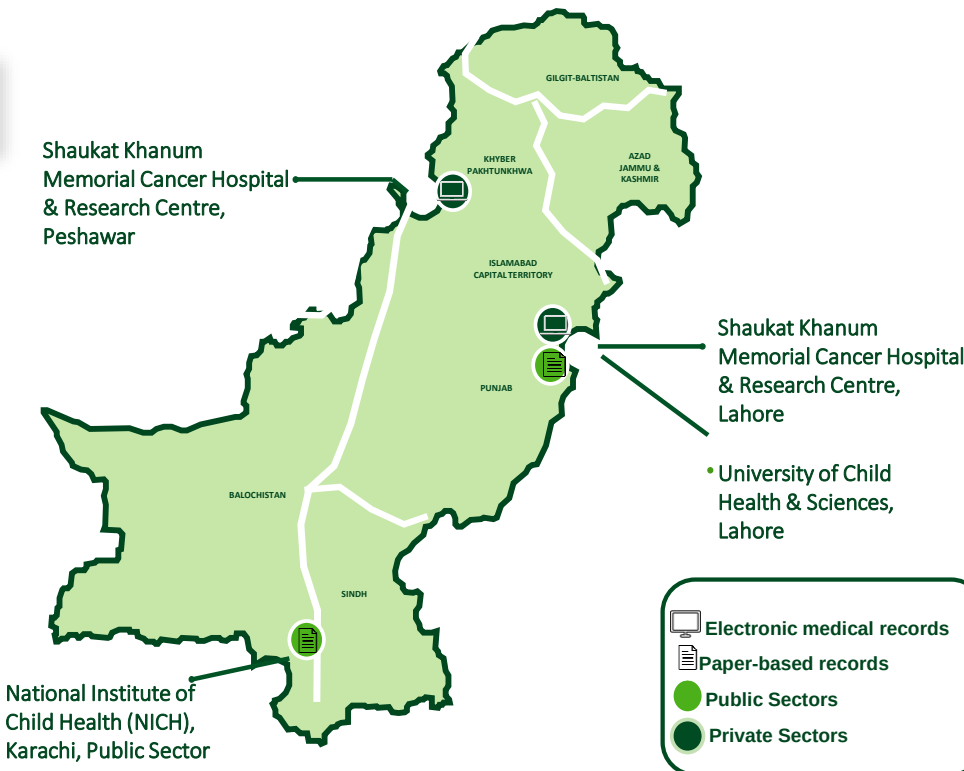
NEW PEDIATRIC
CANCER CASES
REGISTERED

283 Males • 143 Females

Median age = 4.16 years Age range 0–19 yrs



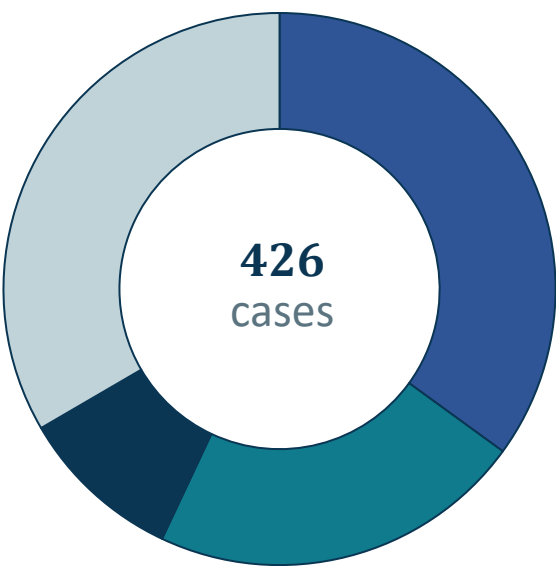
4 CENTERS IN 3 CITIES



13
DAYS

MEDIAN TIME FROM
PRESENTATION TO ENTRY IN
CANCER REGISTRY

MOST COMMON CANCER
DIAGNOSES



Acute leukemia
N= 155 (35%)

Lymphoma
N= 97 (22%)

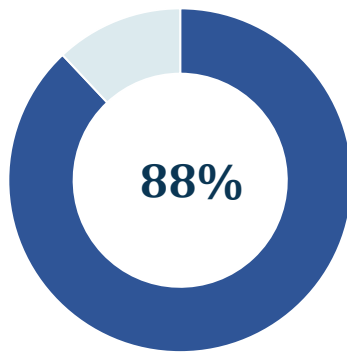
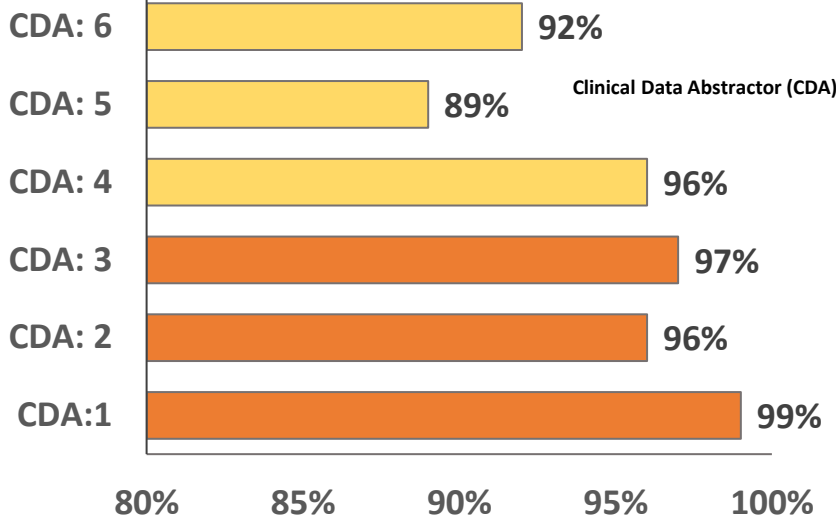
Brain tumors
N= 42 (9.6%)

Other diagnoses
N= 132 (33.4%)

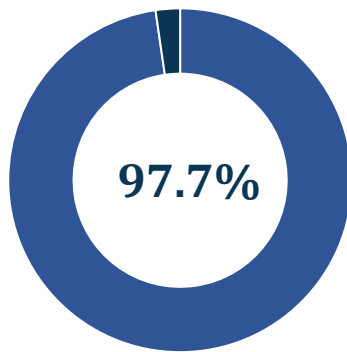
OncoRegFix
FLAGGED 88 CASES FOR REVIEW:
1 VALIDATION FAILURE
1 DUPLICATE CASE

QUALITY OF DATA ENTRY

Quality of Data Abstraction %



Overall chart completeness



Completeness of essential
data

98% OF CASES MET THE
TIMELINESS BENCHMARK

CHALLENGES

- PAPER-BASED RECORDS
- INTERNET CONNECTIVITY
- VARIATION IN SITE & CDA PRODUCTIVITY

CONCLUSIONS

The NPCRP pilot confirms that a coordinated, hospital-based pediatric cancer registry is feasible in Pakistan in sites with both paper-based and electronic medical records. In 4 centers across Pakistan, the program achieved high data completeness, reliable pre-set, logic-based duplicate detection and timely case registration.

NEXT STEPS

- Scale nationwide
- Sustain data quality
- Enable outcomes research

ACKNOWLEDGMENTS

Supported by PSPO and SIOP-PARC grant. We are grateful to St. Jude Global and the SJCARES Registry for their technical support. We thank the clinical and registry personnel at all pilot sites for their participation.



Scan for the supplementary information & NPCRP webpage

Correspondence:

Dr. Alina Sadaf

Head of Department of Paediatric Oncology, Shaukat Khanum Memorial Cancer Hospital and Research Centre, Lahore, Pakistan
Registry Chair, NPCRP, Pakistan Society of Pediatric Oncology

✉ alinasadaf@skm.org.pk

☎ +92-42-35905000

