NPCRP

National Pediatric Cancer Registration Program

The first multi-institutional pediatric record of childhood cancer in Pakistan, and what the data already tells us.

2,154
CASES REGISTERED

12
ICCC-3 GROUPS

10
REPORTING CENTRES

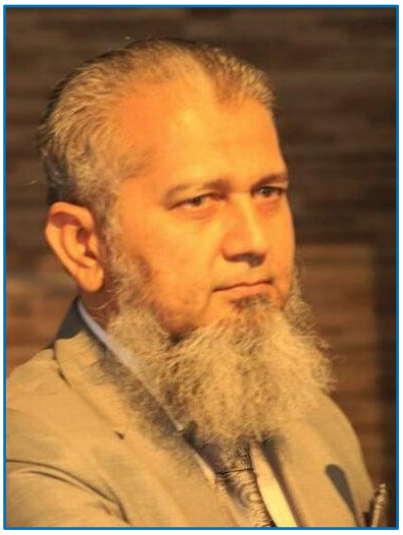
IN THIS ISSUE

Contents

This inaugural issue reports **2,154 cases** coded to ICCC-3, registered between October 2025 and July 2026 across the **10 centres.** Further centres are enrolled and onboarding. The dataset is multi-institutional, not yet nationally representative.

MESSAGE

From The President



Prof. Dr. Tariq Ghafoor

President, Pakistan Society of Pediatric Oncology

Recording today shaping tomorrow's care.

The National Pediatric Cancer Registration Program (NPCRP) is fundamental to our vision of establishing a robust, data-driven platform for pediatric oncology in Pakistan. To ensure its long-term viability, we are actively implementing a strategic resource mobilization model focused on securing sustainable financial, technological, and operational resources. A high-quality cancer registry does far more than count cases, it directly elevates clinical care and patient survival. Systematic collection of standardized epidemiological and clinical data allows us to map disease distribution, pinpoint diagnostic delays, evaluate treatment toxicities, and continuously refine therapeutic protocols. International experience clearly demonstrates that a national registry is one of the most cost-effective interventions available to transform pediatric cancer outcomes.

By establishing the NPCRP, we lay the groundwork to elevate standards of care, foster impactful clinical research, reduce treatment abandonment, and ultimately improve survival for children fighting cancer across Pakistan.

July, 2026

2,154
cases registered

99.3%
coded to ICCC-3

PSPO leadership, faculty and international partners at the society's annual conference

MESSAGE

From The Registry Chair

Every child counted, every child cared for.

Dr. Alina Sadaf
Chair, National Pediatric Cancer Registration Program
Pakistan Society of Pediatric Oncology

Every child with cancer has a unique story to tell. Not just about what happened to them, but also about the state of healthcare access, delivery and outcomes for childhood cancer in Pakistan. Each story on its own, and when combined with the stories of thousands of children across the country reveals where the work needs to be done. It tells us where national policy is lacking, and where capacity building can make a difference. This is the essence of a cancer registry, and it's mission to save lives. There is consensus among members of the Pakistan Society of Pediatric Oncology (PSPO) that if we are to move forward on the World Health Organization's Global Initiative for Childhood Cancer (GICC), we need to establish a national database for childhood cancer that defines the burden of disease and tracks outcomes. There are many challenges to establishing a population-based cancer registry in Pakistan, but a hospital-based cancer registry is possible and will closely mimic population-based capture as healthcare access to cancer centers in concentrated in a few major facilities across the county. To realize this dream, we've established the National Pediatric Cancer Registration Program of Pakistan (NPCRP). We are grateful to the Program for Advancing the Research Capacity Award (PARC) by the International Society of Pediatric Oncology (SIOP) which has supported the NPCRP through a 2-year grant. In addition, the St Jude Children's Research Hospital, particularly their SJCARES registry team, has provided valuable technical support for the development of the data collection tools and training modules. The NPCRP has successfully completed its pilot phase across four cancer centers, capturing data from Khyber Pakhtunkhwa, Punjab and Sindh, with operation in public and private healthcare systems and across both paper-based and electronic medical record systems. We are now well into our expansion phase, and have more than a dozen centers enrolled, trained several registry personnel and developed a data dashboard that signals a bright future for childhood cancer in our country. The future of the NPCRP, and our children, is bright! What is the way forward for us? We need the continued engagement of healthcare leaders and physicians, patients and their families, and the necessary funding to sustain our efforts. We hope that this newsletter will inspire you to join our mission through donations, outreach, and advocacy.

> Both record systems are represented : **1,424 cases** from six paper-based centres and **730 cases** from four centres on electronic medical records.

MESSAGE FROM THE VICE CHAIR

How NPCRP Was Conceptualised

Dr. Uzma Imam
Vice Chair, National Pediatric Cancer Registration Program
Pakistan Society of Pediatric Oncology

Historically, pediatric cancer tracking in Pakistan has relied on scattered, single-center data. Only high-volume institutions maintain specialized internal software or electronic medical records. Considering accurate data crucial for effective cancer control and policymaking, the Pakistan Society of Pediatric Oncology (PSPO) as the primary national stakeholder for childhood cancer care took the lead in establishing the National Pediatric Cancer Registration Program (NPCRP). Driven actively by PSPO governance and supported by global entities, including SIOP and St. Jude Global, the NPCRP has become a centralized repository that unifies these scattered nodes. This is not a temporary database project; instead, it is a strategy built on institutional growth. By standardizing information entry across different regions, the registry maps baseline geographic clusters, clinical characteristics, and treatment outcomes unique to the local population. Ultimately, the registry will enable true longitudinal tracking by monitoring cohorts sequentially over years. This national-level platform facilitates clinicians and institutions tracking children from the day of diagnostic staging, through complex multimodal treatment cycles, and into long-term survivorship.

This process helps them measure critical long-term milestones. through complex multimodal treatment cycles, and into long-term survivorship. This process helps them measure critical long-term milestones. A major historical challenge in Pakistan is treatment abandonment. A uniform tracking framework helps identify when and why patients drop out of care. Addressing abandonment is key to achieving the WHO Global Initiative for Childhood Cancer (GICC) goal of a 60% global survival rate by 2030.

NPCRP leadership also prioritizes capacity building and scalability. Supported by PSPO and global partners, the program hired dedicated data managers and trained cancer registrars. The leadership team also provided standardized nomenclature, software modules and data entry training to participating public and private sector hospitals to ensure data quality and accuracy.

The ultimate aim of this multi-institutional national initiative is to establish a feedback loop that informs policy on cancer trends and treatment efficacy. By enabling evidence-based policymaking and effective resource allocation, it will help bring childhood cancer survival rates closer to global goals.

10
CENTRES REPORTING DATA

4
PROVINCES & REGIONS COVERED

2
RECORD SYSTEMS IN USE

REGISTRY INSIGHT

Registry Overview

NPCRP is a multi hospital-based registry of childhood cancer, established by the Pakistan Society of Pediatric Oncology to record every paediatric cancer diagnosis in participating centres using one standard dataset and ICCC-3 coding. Ten centres contributed data to this first reporting window; the registry is expanding towards national coverage.

OUR MISSION

To give Pakistan a single, reliable count of childhood cancer and to make that count useful.

01 Quantify the national burden of childhood cancer

02 Describe the diagnostic mix and stage at presentation

03 Set a baseline for survival and treatment abandonment

04 Support research, planning and policy with real data

WHAT IS COLLECTED

- Demographics and geography
- Diagnosis coded to ICCC-3
- Date of diagnosis and treating centre
- Treatment status
- Outcome and follow-up

HOW IT WORKS

- Trained data officers at each participating centre
- Central data quality review by the registry team
- Governance by the PSPO Cancer Committee
- Annual reporting to members and partners

PSPO
National Pediatric Cancer Registration Program

Timeline Of Development

2023

Idea proposed

Need for a national childhood cancer registry raised within PSPO.

2023

Concept presented

Proposal presented to the membership and the Cancer Committee.

PSPO leadership faculty

2024

Protocol & dataset

Standard dataset, ICCC-3 coding and ethics approvals finalised.

Discussion for NPCRP Sustainability

May 2025

PARC grant secured

A two-year PARC grant from SIOP for capacity building and implementation (May 2025 – May 2027), secured before the pilot.

Oct 2025

Pilot centres

First centres onboarded; data officers recruited and trained. Four centres reported in the opening month.

Onboarding meeting at a participating center.

Jul 2026

Centre onboarding

Nine centres reporting in the month; 2,154 cases registered to date and further hospitals onboarding.

MOU Signing Ceremony at a participating center.

2027

First report

First full annual report of the registry.

GOVERNANCE

Registry Steering Committee

REGISTRY CHAIR

Dr. Alina Sadaf

Pediatric Hematologist Oncologist, Head of Department, Shaukat Khanum Memorial Cancer Hospital, Lahore

VICE CHAIR

Dr. Uzma Imam

Chief Oncologist, Head of Department (Child Aid Association), National Institute of Child Health, Karachi

MEMBERS

Dr. Naureen Mushtaque

Associate Professor of Pediatric Neuro-oncology / Oncology, Aga Khan University and Hospital

Dr. Alia Ahmed

Professor of Pediatric Hematology / Oncology, The Children's Hospital Lahore

Dr. Asim Belgaumi

Director, St. Jude Global Eastern Mediterranean Regional Hub

Dr. Muhammad Rafie Raza

Consultant Pediatric Hematology Oncology, Indus Hospital and Health Network, Karachi

Dr. Farhana Badar

Senior Biostatistician and Cancer Epidemiologist, Shaukat Khanum Memorial Cancer Hospital and Research Centre

Dr. Mohiba Ali Khowaja

Research Director, Pakistan Society of Pediatric Oncology

REGISTRY OFFICE

Ms. Qurat-Ul-Ain Ali

Registry Manager, , Pakistan Society of Pediatric Oncology

Mr. Muhammad Ali

Data Quality Officer, , Pakistan Society of Pediatric Oncology

The Registry At A Glance

Oct 2025 – Jul 2026

TOTAL CASES REGISTERED

2,154

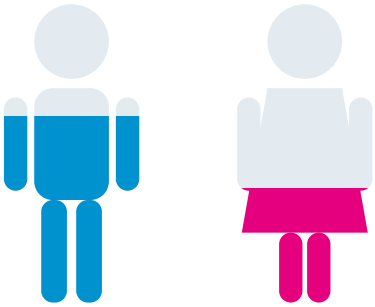
Children with cancer, coded and verified across 10 reporting centres

10
REPORTING CENTRES

12
ICCC-3 GROUPS Clasiification

SEX DISTRIBUTION

1.62 : 1 Male to Female

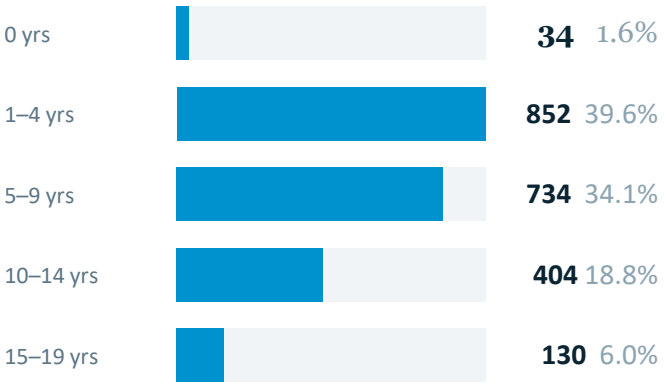


61.8%
1,332 Male

38.2%
822 Female

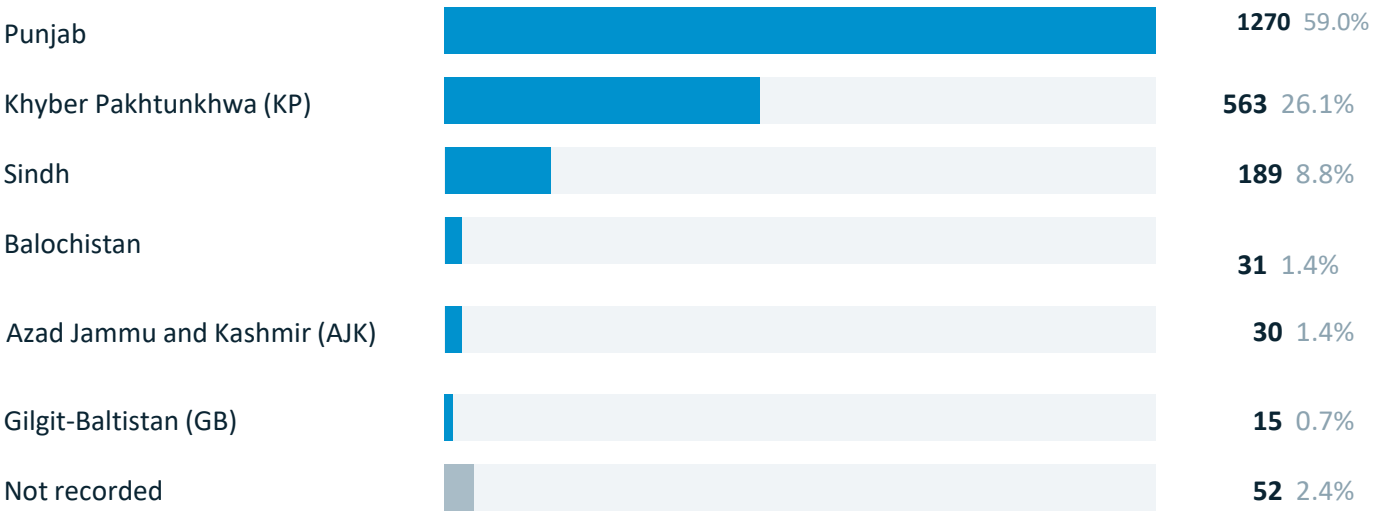
Each figure filled to its share of registered cases

AGE AT REGISTRATION



Mean age 6.6 years · median 6 years · range 0–18

PROVINCE OF RESIDENCE



This data reflects the patient province of residence, not the facility where patient present.

Diagnostic Distribution

ICCC-3 · n = 2,154

CASES BY ICCC-3 MAIN GROUP

I	Leukaemias, myeloproliferative & myelodysplastic	**788**	36.6%
II	Lymphomas & reticuloendothelial neoplasms	**503**	23.4%
III	CNS & intracranial / intraspinal neoplasms	**196**	9.1%
VI	Renal tumours	**123**	5.7%
VIII	Malignant bone tumours	**113**	5.2%
IX	Soft tissue & extraosseous sarcomas	**98**	4.5%
V	Retinoblastoma	**94**	4.4%
X	Germ cell, trophoblastic & gonadal neoplasms	**88**	4.1%
IV	Neuroblastoma & peripheral nervous cell tumours	**63**	2.9%
VII	Hepatic tumours	**39**	1.8%
XI	Other epithelial neoplasms & melanomas	**25**	1.2%
XII	Other & unspecified malignant neoplasms	**24**	1.1%

59.9%

of all cases are leukaemias or lymphomas

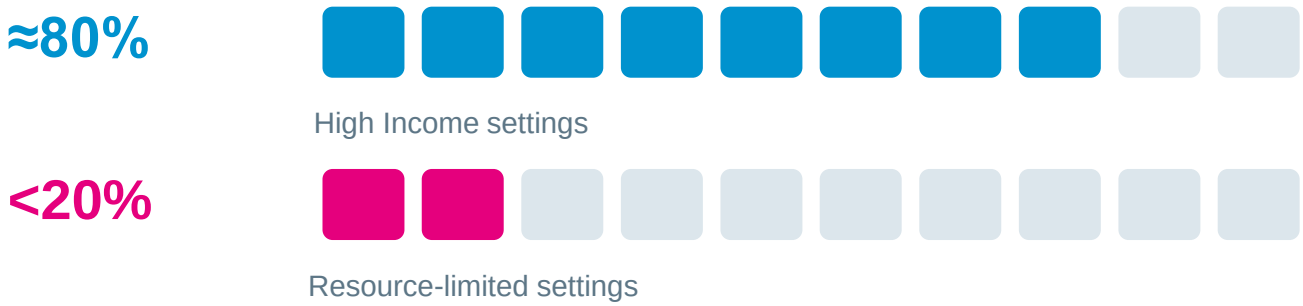
TOP THREE SUBGROUPS

605
(1a) Lymphoid leukemias · 28.1%

349
(IIa) Hodgkin lymphomas · 16.2%

163
(1b) Acute myeloid leukemias · 7.6%

There is also a lack of data on childhood cancer burden in LMIC for strategic cancer planning.

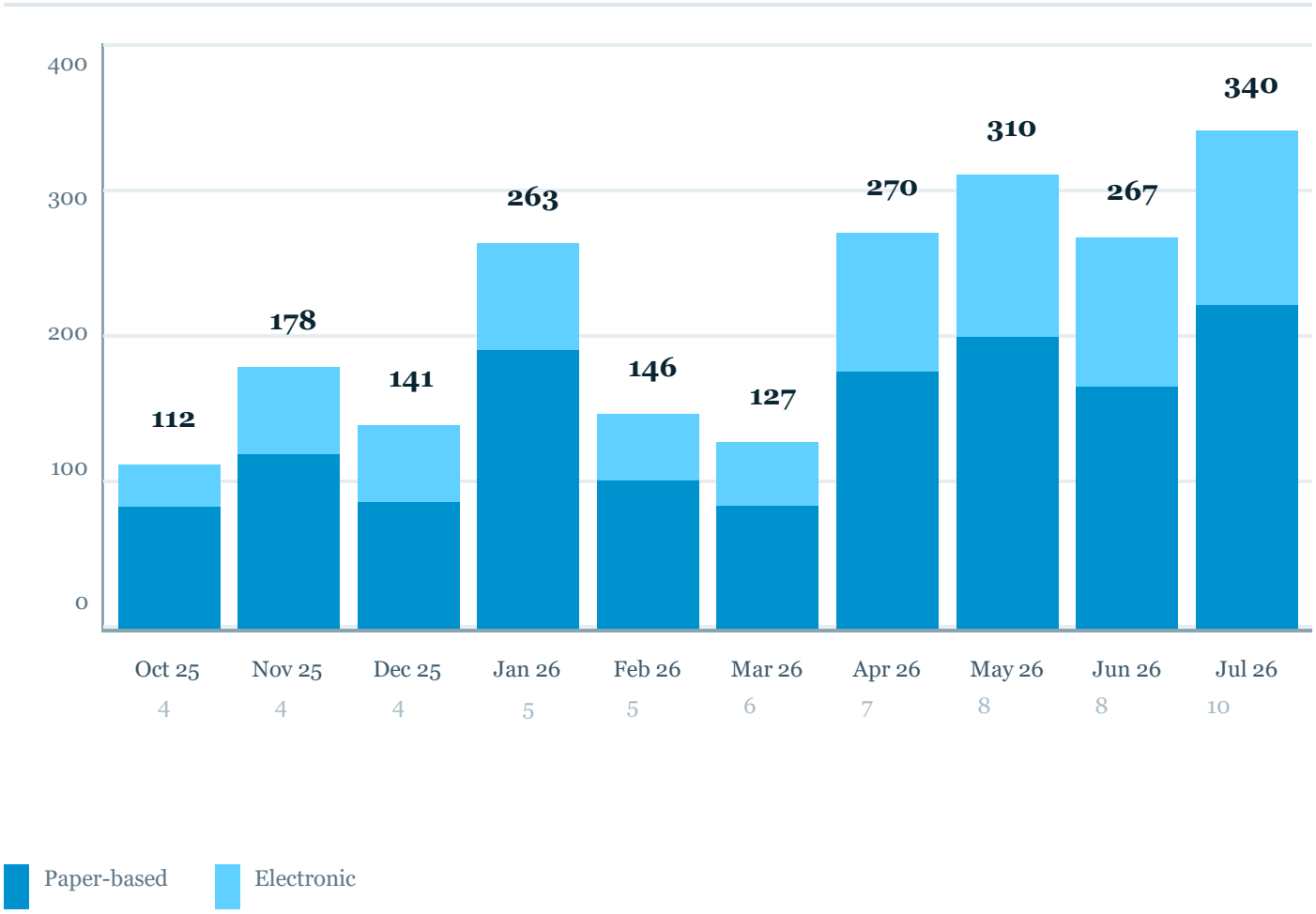


Cases Enrolled Across Centres

by month of entry

Enrolment is counted from the date a case was entered in the registry. Centres joined at different points, so each month reflects both case load and how many centres were reporting. Volumes are therefore not comparable across centres at face value.

CASES ENROLLED PER MONTH



Few centers' joined earlier but the first case registration was after couple of months.

DATA QUALITY

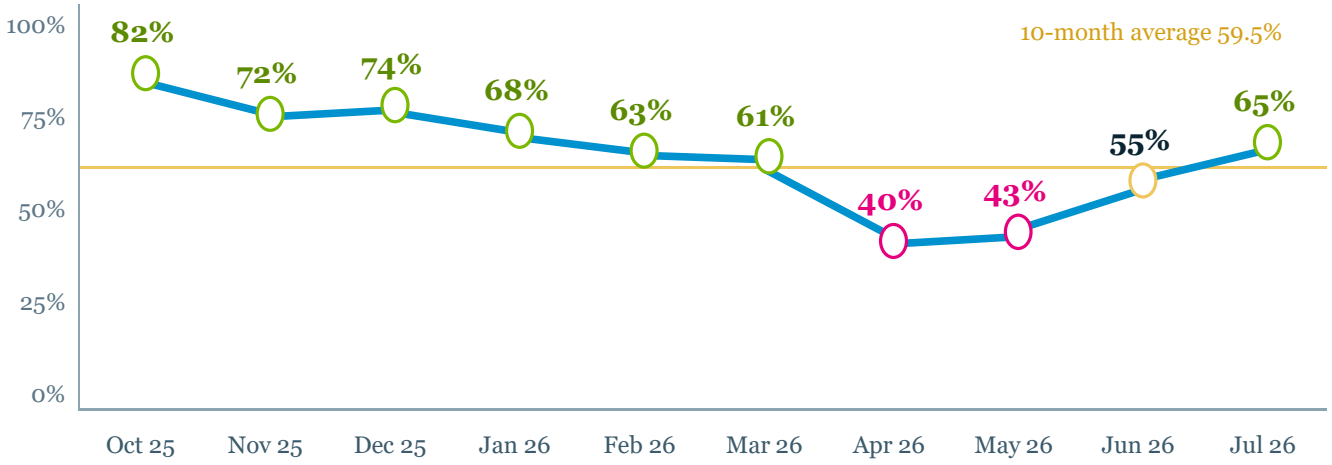
Timeliness Of Registration

Target: 30 days

59.5%	40.5%	≤30
CASES MEETING THE 30-DAY TARGET	CASES OUTSIDE THE 30-DAY TARGET	MEDIAN REGISTRATION LAG, DAYS, WITHIN TARGET

59.5 % of cases fall in the 0 to 30 day band, so the median lag sits inside the 30-day target;

TIMELINESS RATE BY MONTH OF REGISTRATION



Why the rate fell in April and May. Two high-volume centres were without an abstractor for part of the period, one on leave and one being replaced, so cases waited to be entered. The rate recovered to 64.9% in July.

Completeness Of The Dataset

99.7%	98.2%
ESSENTIAL FIELD COMPLETENESS, 10 FIELDS	ALL REQUIRED FIELD COMPLETENESS, 19 FIELDS

The ten essential fields are effectively complete at 99.7%, and the full set of 19 required fields sits at 98.2%. The remaining gap is concentrated in conditional fields rather than in core identification, diagnosis or date fields.

Registry Star

Every case in this newsletter was read, coded and checked by a person. Each issue we name one data abstractor whose work stood out for accuracy, completeness and persistence.

REGISTRY STAR · VOLUME I

Iqra Arshad

Data Abstractor · UCHS, Lahore

"Cancer registry abstraction isn't just entering data for me. It's making sure every patient's story is counted, seen, and remembered. Behind every code and date is a real person and a family. It makes me passionate knowing our work helps drive better treatment, research, and hope. We turn data into impact."

THE DATA ABSTRACTION TEAM

Abstractors at every active centre, trained on the standard dataset and ICCC-3, working alongside the site Principle investigators.

Junaid Jamshed
Pakistan Institute of Medical Sciences, Islamabad

Adnan Ghafoor
Armed Forces Bone Marrow Transplant

Mehwish Waeem
Shaukat Khanum Memorial Cancer Hospital

Furqan Hussain
Children Hospital Multan

Saira Airaf
Shaukat Khanum Memorial Cancer Hospital

Ghazal Fatima
National Institute of Child Health, Karachi

Anam Mustafa
Children Hospital Faislabad

Rameen Anwer
University Child Health Sciences, Lahore

Silah Qayyum
National Institute of Child Health, Karachi

From Inception To Execution

Ms. Qurat-Ul-Ain Ali

Registry Manager, NPCRP

I still remember when this was first shown to me just an idea, nothing more. And I knew right away I wanted to be part of it. The first multi-institutional pediatric cancer registration program in Pakistan. We had nothing to start with. No local protocol, no CRFs, no example to follow. So we just started. Piece by piece. A lot of trial and error, a lot of redoing things we thought were finished. We took help from SJ Cares' CRFs and changed them until they actually worked for our local hospitals and patients. trained our clinical data abstractors, and honestly, watching them go from confused to confident has been one of the best parts of this whole thing. There were times it felt like too much. Like maybe it wasn't going to come together. But we kept showing up. Every small win gives us big hope. Every new institute that joins gives us this excitement, like we're actually getting closer to the goal. It's still a long run, we know that. But the thought the one that was just an idea on paper has become real. And every child we add to this registry is a real child, a real story, not just a number in a system.

We built this from nothing, and we're not stopping now.

Training

Data officers trained on the standard dataset and ICCC-3 coding.

Data quality

Central validation, de-duplication and query resolution.

Reporting

Annual national report and data requests from members.

The registry team, Workshop 2025

Achievements

2,154	99.3%	10	12
CASES ENTERED INTO THE REGISTRY DATABASE	OF CASES SUCCESSFULLY CODED TO ICCC-3	CENTRES CONTRIBUTING DATA IN THIS VOLUME	DATA OFFICERS TRAINED AND CERTIFIED

Oct 2025

A system that works in every kind of Pakistani hospital

The dataset, abstraction rules and reporting workflow were built to run on paper and electronic records alike, in public and private sector centres, without requiring new infrastructure at the site.

Oct 2025

Pilot phase completed successfully

Four cancer centres across Khyber Pakhtunkhwa, Punjab and Sindh completed the pilot, showing that a national childhood cancer registry is achievable in Pakistan despite the hindrances.

Jan–May 2026

Expansion to further centres under way

Six additional centres joined the network, taking the registry to 10 reporting centres, with onboarding of new sites continuing.

2025

OncoRegFix, a custom tool to eliminate duplicates

The registry developed its own tool, OncoRegFix, to detect and remove duplicate registrations across centres, so each child is counted once.




CAPACITY BUILDING

Workshops And Training

A registry is only as good as the people entering the data. Training sessions across participating centres standardise abstraction, coding and quality control.

Essentials of Data Collection in Pediatric Oncology

16–17 June 2025

Standard dataset, case definitions and abstraction rules for data officers.

ICCC-3 coding training

July, 2025

Applying the International Classification of Childhood Cancer to real case records.

Data quality and validation session

November, 2025

De-duplication, query resolution and completeness checks with the central team.

Site visits to participating centres

February, 2026

On-site support, record review and onboarding of new centres.

Essentials of Data Collection in Pediatric Oncology, June 2025, Marriott Hotel Karachi · participants and faculty · certificates of participation awarded

> Training shows in the data: the 10 mandatory registry fields are 99.7% complete across all centres, and no site code or ICCC-3 subgroup label fell outside the registry's lookup tables.

MILESTONE

Presented At PSPOCON 2026

The early experience of the programme's pilot phase was presented to the PSPO membership at PSPOCON 2026.

PSPOCON 2026

Dr. Alina Sadaf presenting Pilot phase results.

SEPTEMBER · CHILDHOOD CANCER AWARENESS MONTH

Go Gold

Gold is the colour of childhood cancer awareness, the metal chosen because children are precious. Every September, families, clinicians and hospitals wear it to make a disease that is often invisible in national conversation visible for a month.

400,000

children and adolescents aged 0–19 develop cancer each year worldwide

60%

survival for children with cancer by 2030, the WHO Global Initiative target

2,154

children now counted in Pakistan by this registry, each one a record that did not exist before

WHY COUNTING IS AWARENESS

Awareness campaigns ask people to care. Registries tell them what to care about: how many children, in which cities, with which diagnoses, and how many finish treatment. Gold September gives the registry its audience; the registry gives Gold September its evidence.

HOW TO TAKE PART

01 Light your hospital gold, or hold a gold day for patients and staff

02 Share your centre's registry numbers with your community

03 Enrol your centre in NPCRP so your patients are counted too

04 Support a data abstractor post, the role that makes the count possible

The registry team and centre abstractors in gold, marking the start of the implementation phase

WITH THANKS

Acknowledgements

PARTICIPATING HOSPITALS

Our thanks to all participating hospitals, and to the clinicians and data officers at every enrolled centre who record each case.

University Child Health Sciences, Lahore

Shaukat Khanum Memorial Cancer Hospital, Lahore

Shaukat Khanum Memorial Cancer Hospital, Peshawar

National Institute of Child Health, Karachi

Children Hospital Multan

Combined Military Hospital

Pakistan Institute of Medical Sciences, Islamabad

Children Hospital Faisalabad

Al-Shifa Trust Eye Hospital

North West General Hospital, Peshawar

PARTNERS AND SUPPORTERS

SIOP, for the two-year PARC grant supporting capacity building and implementation (May 2025 – May 2027). St. Jude Global, for technical guidance and support to the registry through the Eastern Mediterranean Regional Hub.

PSPO LEADERSHIP

The Executive Members and Cancer Committee of the Pakistan Society of Pediatric Oncology.

PARTICIPATING CENTRES

Tell Us What You Think

This is the registry's first newsletter. Comments on what is useful, what is missing and what should be reported next issue go directly to the registry office and shape Volume II.

REGISTRY OFFICE

Ms. Qurat-Ul-Ain Ali

Registry Manager, NPCRP

Quratulain.ali@pspo.org.pk

DATA REQUESTS

Researchers and member centres may request aggregate registry data through the registry office.

ENROL YOUR CENTRE

Hospitals treating children with cancer can join the registry and receive dataset training and onboarding support.

SUPPORT THE REGISTRY

Donations, advocacy and sponsorship of a data abstractor post keep the count running.

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NPCRP

National Pediatric Cancer Registration Program

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PSPO Pakistan Society of Pediatric Oncology

PSPO

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