

Strengthening Retinoblastoma Care in Pakistan: Development and Implementation of the PSPO National Standard-of-Care Treatment Protocol

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BACKGROUND

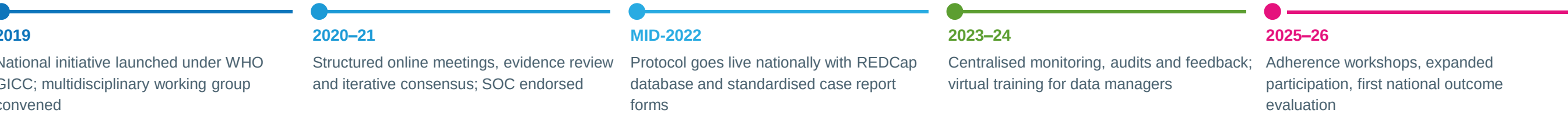
Retinoblastoma is curable where care is standardised and outcomes are measured; in low- and middle-income countries neither is assured. Across Pakistan, treatment differed between centres and records were paper-based and institutional, leaving **no national account of stage at presentation, treatment or survival**. Aligned with the WHO Global Initiative for Childhood Cancer (GICC), the Pakistan Society of Pediatric Oncology (PSPO) initiated a **National Standard-of-Care (SOC) Treatment Protocol** for RB in 2019, derived from national and international guidelines.

OBJECTIVES

To standardise RB treatment across all treating centres in Pakistan, establish a national system for prospective outcome measurement, improve survival nationally, and document implementation as a **transferable model for comparable LMIC settings**.

From consensus to countrywide practice

FIGURE 1 · IMPLEMENTATION TIMELINE



Methods

- 01

Stakeholder identification and engagement 2019

Every paediatric oncology centre treating RB engaged, plus the **Pakistan Society of Pediatric Ophthalmology** to nominate ophthalmology experts. Radiology, pathology, radiation oncology, pharmacy, an epidemiologist and a biostatistician joined the working group.
- 02

Evidence review and contextual appraisal 2020–21

Structured **national online meetings** weighed international evidence against local capacity. A messaging group carried day-to-day deliberation between meetings — low-bandwidth, high-participation.
- 03

Consensus development and formal endorsement 2021–22

An iterative consultative cycle produced **consensus national RB SOC guidelines**, formally endorsed after additional input gathered at national conferences.
- 04

Protocol implementation and data infrastructure MID-2022

REDCap database with standardised case report forms; national and institutional ethical approvals secured; **virtual training** delivered to centre data managers before go-live.
- 05

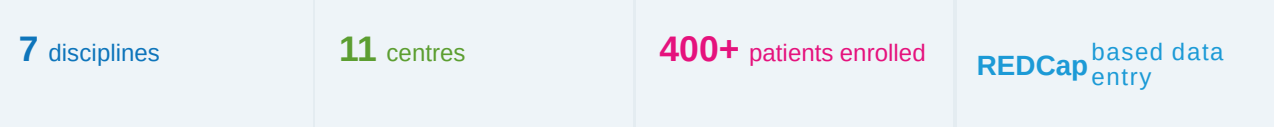
Quality monitoring and programme expansion 2022–ONGOING

A **centralised monitoring system** runs routine quality checks, audits and feedback to centres; adherence workshops keep practice aligned and bring new centres into the registry.

Setting	Data capture	
All RB-treating paediatric oncology centres, Pakistan	REDCap, standardised CRFs, prospective enrolment	National and institutional ethical approval; central audit

The multidisciplinary working group

FIGURE 2 · WORKING GROUP



TREATMENT DECISIONS

Paediatric oncology	Ophthalmology	Radiation oncology
Chemotherapy regimens, staging, follow-up schedule	EUA, eye-salvage vs enucleation criteria	Indications, dose and referral pathways

DIAGNOSTIC STANDARDISATION

Radiology	Pathology
Uniform imaging protocol and reporting for extraocular disease	Standard enucleation specimen reporting and risk-feature definitions

DELIVERY & MEASUREMENT

Pharmacy	Epidemiology & biostatistics
Drug availability, dosing safety, supply feasibility	CRF design, data definitions, monitoring plan, outcome analysis

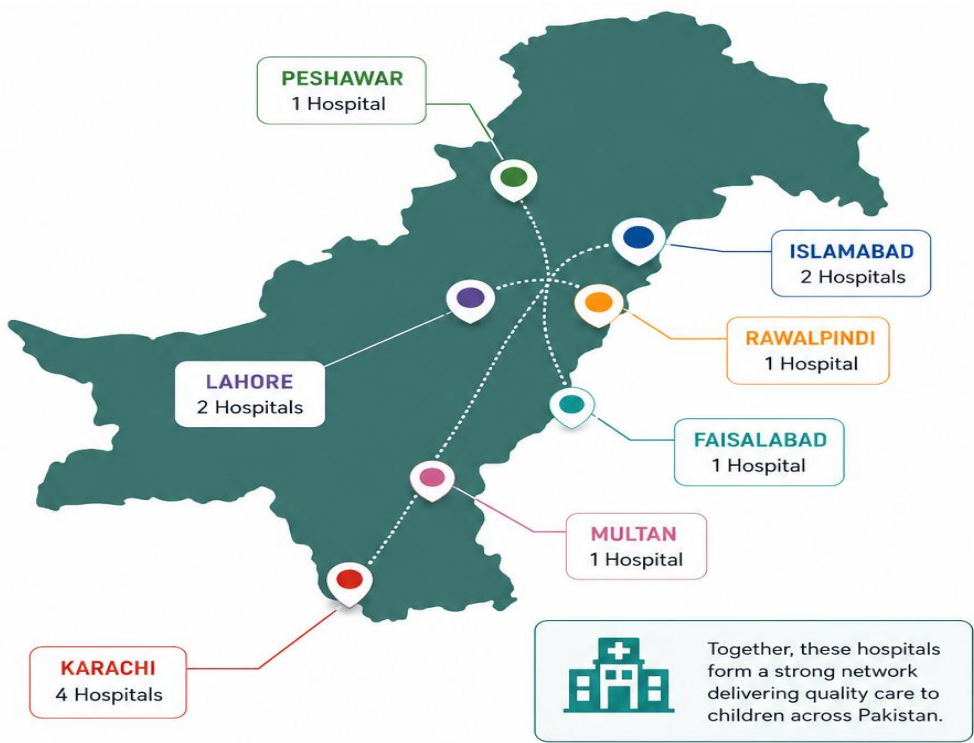
Convened by PSPO with the Pakistan Society of Pediatric Ophthalmology; all disciplines contributed to every consensus round.

Results

The protocol was implemented across Pakistan in **mid-2022**. **Eleven centres** participated, enrolling **over 400 patients**. Standardised treatment and structured data systems improved collaboration, consistency of care, and made **national outcome evaluation** possible for the first time.

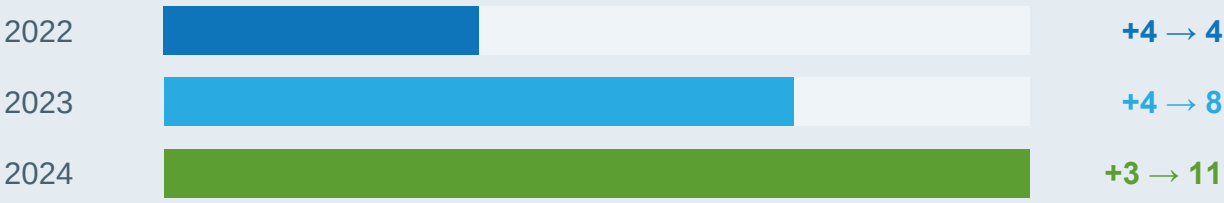
Geographic distribution of centres

FIGURE 3 · NATIONAL NETWORK



Centres joining the protocol

FIGURE 4 · NEW → CUMULATIVE



Eleven centres enrolling by 2024, from four at launch in mid-2022.

What changed in practice

FIGURE 5 · BEFORE vs AFTER SOC

BEFORE 2022	WITH NATIONAL SOC
Centre-specific treatment practice	National consensus protocol for unilateral disease
Fragmented paper records	REDCap registry with standard CRFs
No routine data verification	Central monitoring, audit and feedback
Outcomes reportable only per institution	National outcome evaluation possible

Transferable framework

WHAT OTHER LMIC PROGRAMMES CAN REUSE

- 1

Convene every treating centre before writing the protocol, not after
- 2

Use low-bandwidth tools (online meetings, messaging) to sustain consensus
- 3

Launch the protocol and the registry together, with data-manager training
- 4

Fund central monitoring and feedback from day one to protect data quality

CONCLUSION

National SOC guidelines for RB have **materially improved the infrastructure and feasibility** of standardised care in a resource-constrained setting. The model offers a **scalable framework** for improving retinoblastoma outcomes and a template for other paediatric oncology programmes in similar contexts.

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