

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 Khawaja² · Muhammad Ali² · Uzma Imam³ · Alia Ahmed⁴ · Mahwish Faizan⁴ · Palwasha Rehman⁵ · Muhammad Rafie Raza⁶ · Farhana Badar⁷ · 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.

1. Data Completeness & Overall Data Quality: Paper-based vs. EMR-based

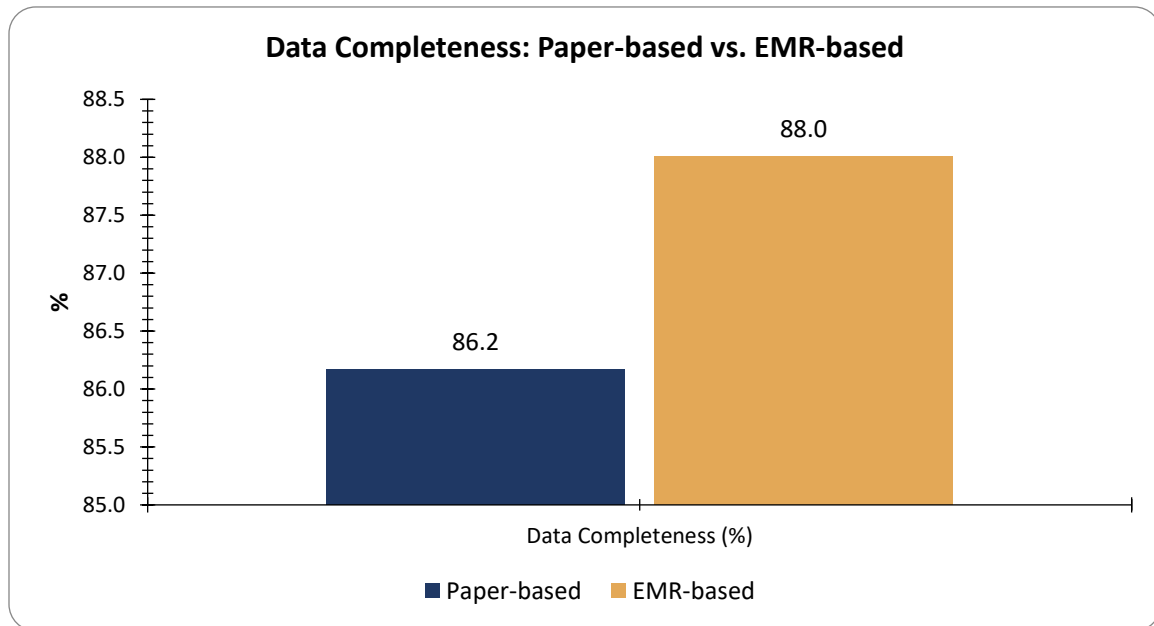


Figure 1. Data completeness (%) paper-based vs. EMR-based data collection.

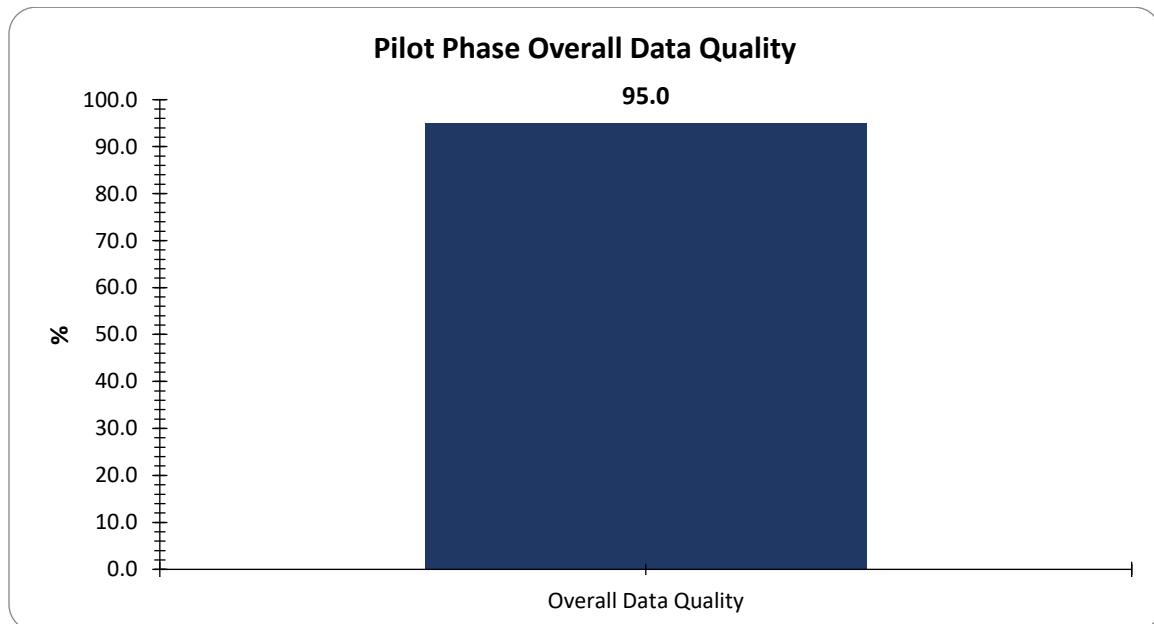


Figure 2. Pilot phase overall data quality score, reflecting accuracy of registered cases.

Method	Data Completeness (%)
Paper-based	86.17
EMR-based	88.01

Table 1. Data completeness (%) paper-based vs. EMR-based data collection

2. Pre- vs. Post-Training Evaluation

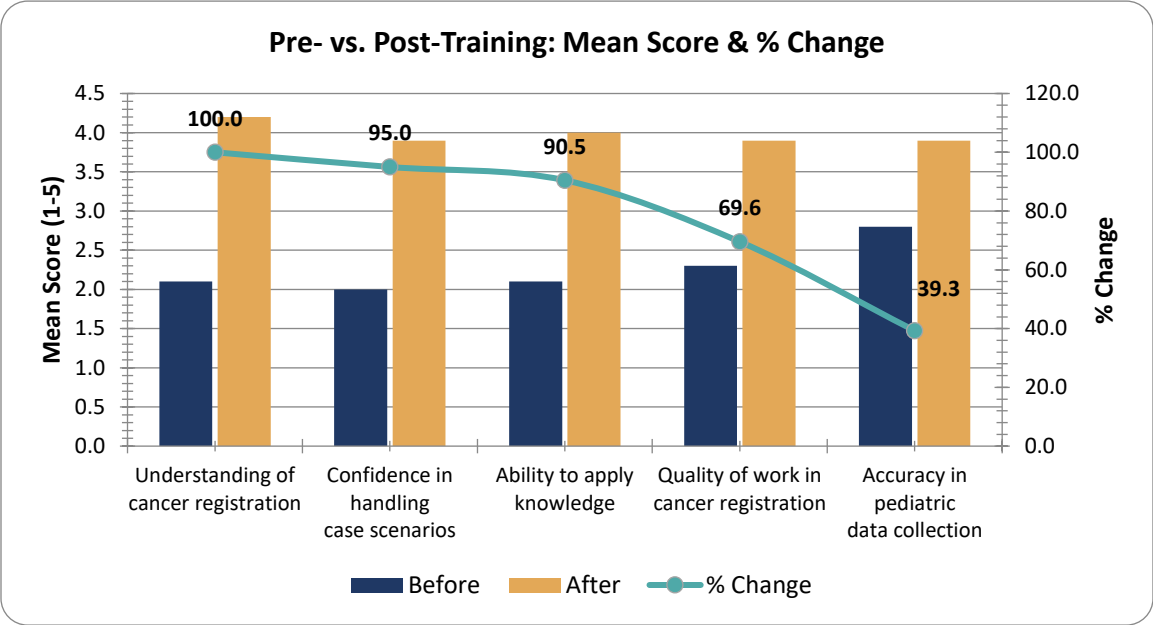


Figure 3. Mean scores before and after training, with percentage change, across five evaluation domains (self-reported, 1-5 scale).

Metric	Before Mean	After Mean	Absolute Change	% Change
Understanding of cancer registration procedures	2.1	4.2	2.1	100.0
Confidence in handling case scenarios	2.0	3.9	1.9	95.0
Ability to apply knowledge in real cases	2.1	4.0	1.9	90.5
Quality of work in cancer registration	2.3	3.9	1.6	69.6
Accuracy in pediatric cancer data collection	2.8	3.9	1.1	39.3

Table 2. Mean scores before and after training, with percentage changes, across five evaluations domains (self-reported 1-5 scale)

3. OncoRegFix Platform



OncoRegFix - National Pediatric Cancer Registry

First Name *

Middle Name

Last Name

Father/Mother/Legal Guardian Name *

Date of Birth *

DD-MMM-YYYY

National Identification Number *

☐ NIC not available

12345 1234567 1

Presenting Hospital *

Select Presenting Hospital

Assigned to your account and cannot be changed.

Presenting Disease *

Select Disease

Source of Case *

Select Source

Submit

Figure 4. OncoRegFix case registration form, capturing demographic and clinical intake fields with built-in field validation.