## Experiences from a health-worker led congenital anomaly screening program in Pakistan

Mahwish Fatima¹, Shazia Junejo¹, Ammar Ali Muhammad¹, Maryam Sherwani¹, Felicity Mehendale², Lubna Samad³

<sup>1</sup>Interactive Research and Development (IRD) Pakistan, <sup>2</sup>Usher Institute, The University of Edinburgh <sup>3</sup>Interactive Research and Development (IRD) Global, Singapore





Globally, 8 million children are born with congenital anomalies (CAs) annually<sup>1</sup>; 94% are from developing countries<sup>2</sup>. Neonatal screening is imperative for early diagnosis to prevent mortality and disability. Orofacial clefts (OFCs) contribute significantly to this burden.

We aimed to establish a newborn screening program for external CAs, including OFCs, by training health workers (HWs) to identify, counsel and refer affected newborns.



HW training: An educational intervention was developed to enable screening of newborns for external CAs, which included subject knowledge, head-to-toe examination, counselling and referral guidelines. Pre- and post-tests were conducted to assess HWs' knowledge, followed by an evaluation to assess concordance in anomaly identification between them and the specialists.

Implementation: The program was conducted at three high-volume facilities. Newborns were enrolled after obtaining caregiver consent and all identified anomalies were documented. Parents of affected babies were counseled and referred using standardized expert-developed guidelines.

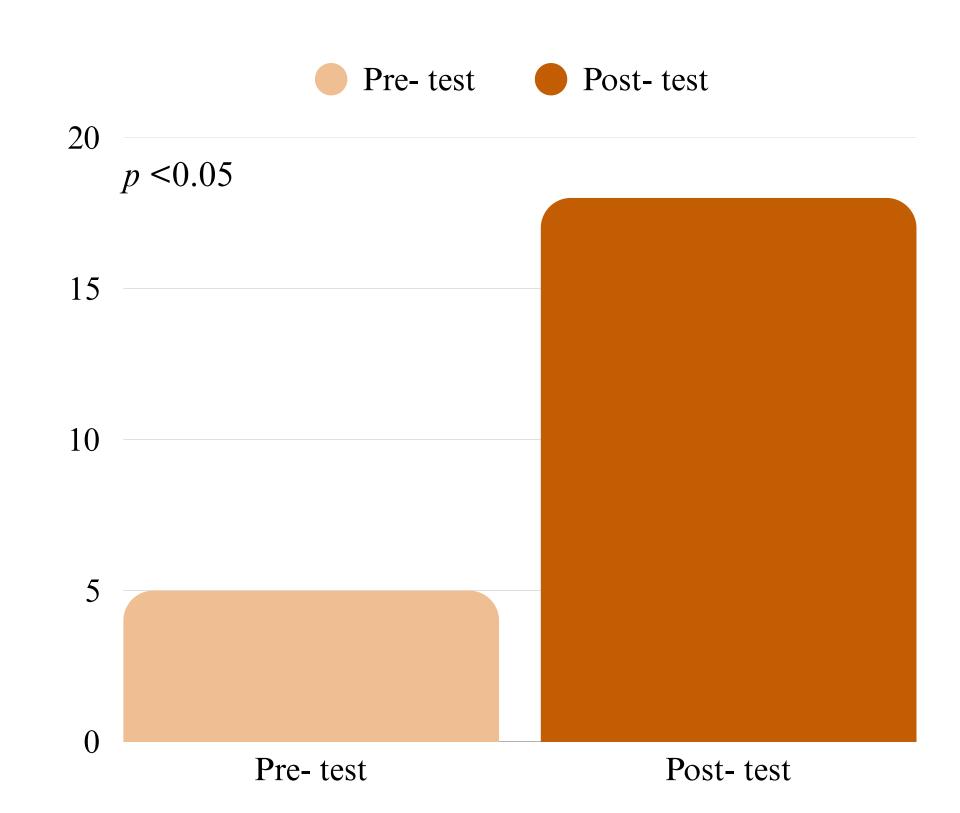


Fifteen HWs underwent classroom training; thirteen were selected based on performance. A statistically significant increase in median knowledge score was observed in the pre and posttest assessments (5.0 vs 18.0) (Figure 1).

From the 18,728 births screened, 3,730 (19.9%) were identified with anomalies, 334 (1.8%) major and 3,384 (18.1%) minor anomalies. OFCs (n=45) represented 13.5% of all major anomalies.

The concordance of OFC identification between HWs and photographic review by specialists was 98%.

Figure 1: Median knowledge score pre- and post-intervention





Capacity building of HWs is an effective and feasible strategy for reliable newborn screening for external CAs, including OFCs, linking them to care pathways.