EHDI Programs Risk Indicator Monitoring Practices

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Purpose

The purpose of the literature review was to conclude which risk indicators from the JCIH 2007 Position Statement should be monitored based on evidence based research.

Purpose of survey development: To determine if EHDI programs across US and Canada monitor and track risk indicators for congenital or delayed-onset hearing loss

JCIH (2007) guidelines indicate to provide continued surveillance of children who have risk indicators for delayed onset hearing loss, but description to complete the monitoring is limited.

Methods

A review of the literature was completed on the risk indicators found in the JCIH 2007 Position Statement.

Data collected from October 2016-January 2017
Survey sent to:

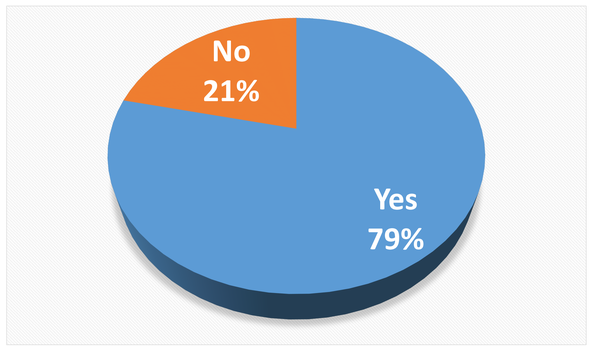
- 66 EHDI coordinators across United States
- Unknown number across Canada (*11 territories*)

42 responses received

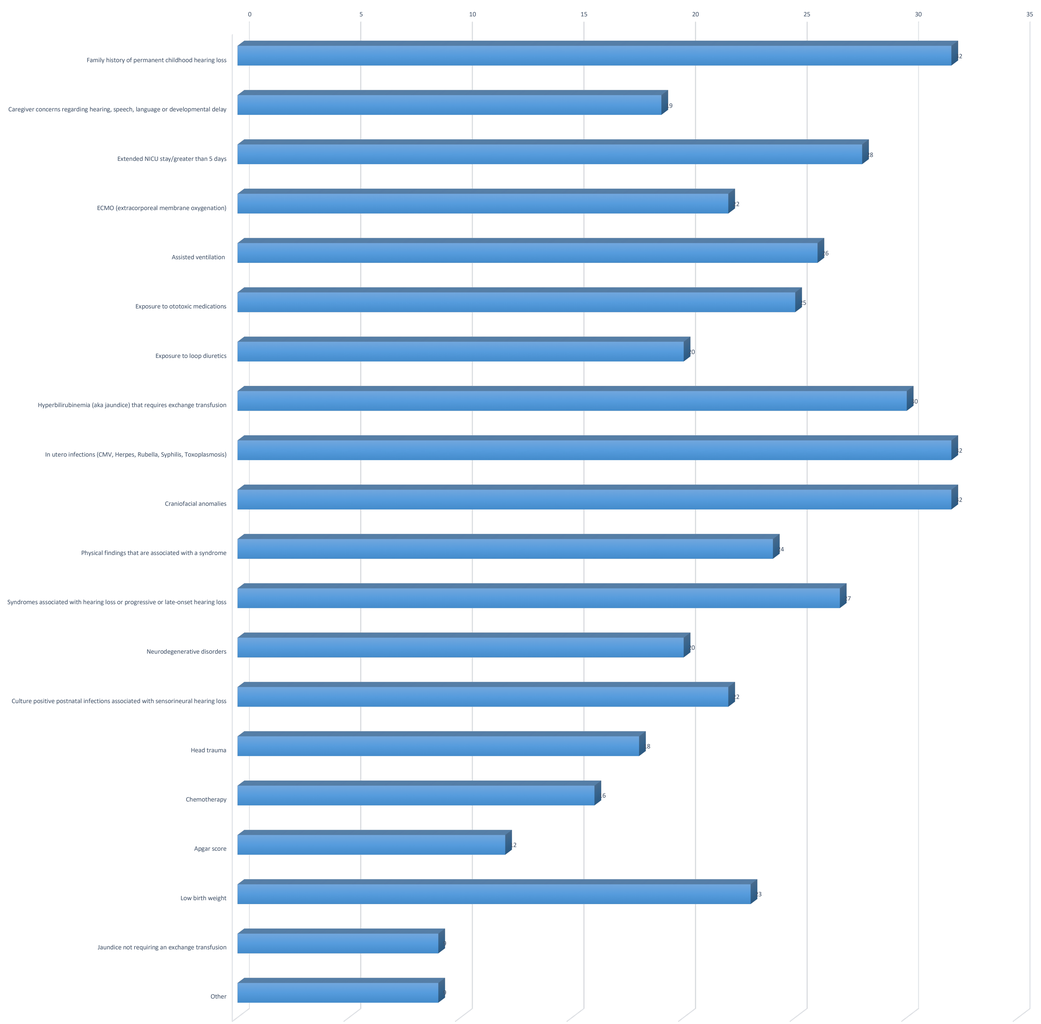
- 37 from US (response rate of 56.1%)
- 5 from Canada (response rate of 45.5%)

Survey Results

Does your EHDI program monitor risk indicators for delayed-onset and/or progressive hearing loss?



Which risk indicators does your EHDI program monitor?



Current Risk Factors Found on JCIH 2007 Position Statement

1. Caregiver concerns regarding hearing, speech, language, or developmental delay
2. Family history of permanent childhood hearing loss
3. Neonatal intensive care of more than 5 days or any of the following regardless of length of the stay: ECMO, assisted ventilation, exposure to ototoxic medications or loop diuretics, and hyperbilirubinemia that requires exchange transfusion
4. In-utero infections, such as CMV, herpes, rubella, syphilis, and toxoplasmosis
5. Craniofacial anomalies, including those that involve the pinna, ear canal, ear tags, ear pits, and temporal bone anomalies
6. Physical findings, such as white forelock, that are associated with a syndrome known to include a sensorineural or permanent conductive hearing loss
7. Syndromes associated with hearing loss or progressive or late-onset hearing loss, such as neurofibromatosis, osteopetrosis, and Usher syndrome; other frequently identified syndromes including Waardenburg, Alport, Pendred, and Jervell and Lange-Nielson
8. Neurodegenerative disorders, such as Hunter syndrome, or sensory motor neuropathies, such as Friedreich ataxia and Charcot-Marie-Tooth syndrome
9. Culture-positive postnatal infections associated with sensorineural hearing loss, including confirmed bacterial and viral (especially herpes viruses and varicella) meningitis
10. Head trauma, especially basal skull/temporal bone fracture that requires hospitalization
11. Chemotherapy

Discussion

Common risk indicators that are found on the position statement, but are not being monitored by most programs included: (1) caregiver concerns, (2) exposure to loop diuretics, (3) neurodegenerative disorders, (4) head trauma, (5) chemotherapy, (6) Apgar score, (7) jaundice not requiring exchange transfusion, and (8) others that were listed in the comment section.

One thing that stood out during the course of this research was the fact that cleft palate and cleft lip are not explicitly stated in any of the risk indicators. The prevalence of cleft lip and palate are quite significant and the occurrence of otitis media with effusion is even more significant. By not specifically monitoring children with cleft lip and/or cleft palate, some may fall through the cracks. It is recommended that cleft lip and/or cleft palate be added to the JCIH risk indicator list either under its own risk indicator or clearly stated under craniofacial anomalies. It is also recommended that each risk indicator become more specific in what should plainly stated.