Starship Foundation

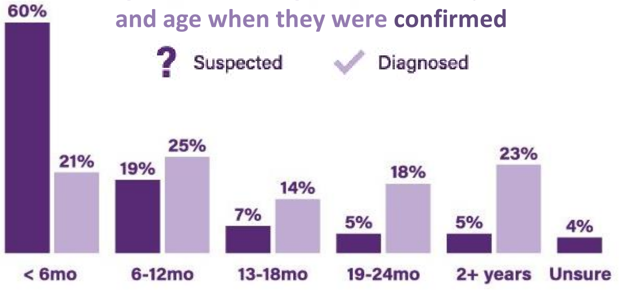
Cerebral Palsy Early Identification

Results from the **clinician** and **family surveys**

CURRENT PRACTICE

Two cross-sectional purpose designed surveys gathered information on identification of CP and family experiences of the early stages. Clinicians (n=159) and family of children with CP (n=59) provided valuable insight into factors shaping the early experience and areas for continued improvement.

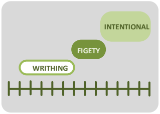
▼ Age when CP diagnoses were **suspected** and age when they were **confirmed**



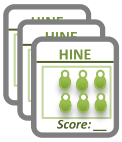
There appears to be a general 6 month 'lag' between when a family has these suspicions, and when the diagnosis is eventually given

✓ **MRI**[1]

✓ **GM's**[2]



✓ **HINE**[3]

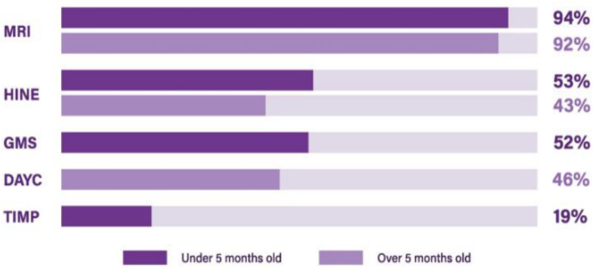


► For the detection of CP before **5 months** corrected age, a combination of history of **risk factors** and **diagnostic tools** (MRI, GM & HINE) provides >95% accuracy.[4]

Clinicians had high awareness of diagnostic tools for detection of high risk CP:

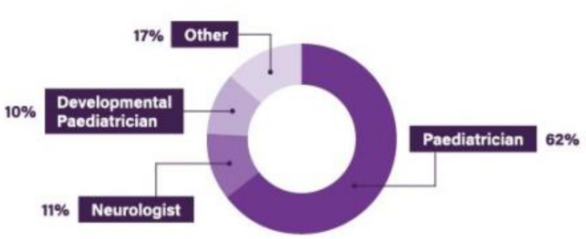
MRI 94% | GM 70% | HINE 77%

Key Tools: Percentages of clinicians who use these tools for infants



▲ Use of current best practice diagnostic tools appears low across New Zealand.

Who gives the Cerebral Palsy diagnosis?



PATHWAY TO EARLIER IDENTIFICATION OF CP

Barriers and enablers to key tools aiding cerebral palsy diagnosis:

Professional development:	Management & staff support:	Health professional knowledge & perception:
✗ Lack of trained staff	✓ Support for change	✓ Confidence in tools
✗ Funding challenges	✓ Workload management	✓ Perceived value in consequence of tools
✗ Available time for training	✓ Multidisciplinary teamwork	
✓ Management support for training	✓ Communication between teams	

✗ Barriers
✓ Enablers

▲ The 3 main barriers for clinicians can be overcome by providing diagnostic tool **training**, workplace **support** for change & continued **education** on early diagnosis.

► New Zealand health professionals recognised value and need for clear **referral pathways, guidance** and **early management** of CP.

98% felt that a more standardised approach for the management of CP would be useful across NZ

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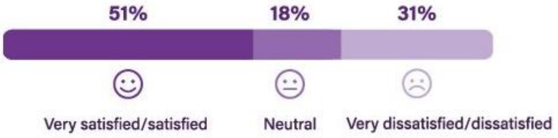
1. Magnetic Resonance Imaging 2. Prechtl's General Movements Assessment 3. Hammersmith Infant Neurological Examination

4. Novak I, Morgan C, Adde L, Blackman J, *et al*. Early, Accurate Diagnosis and Early Intervention in Cerebral Palsy: Advances in Diagnosis and Treatment. JAMA Pediatr. 2017 Sep 1;171(9):897-907.

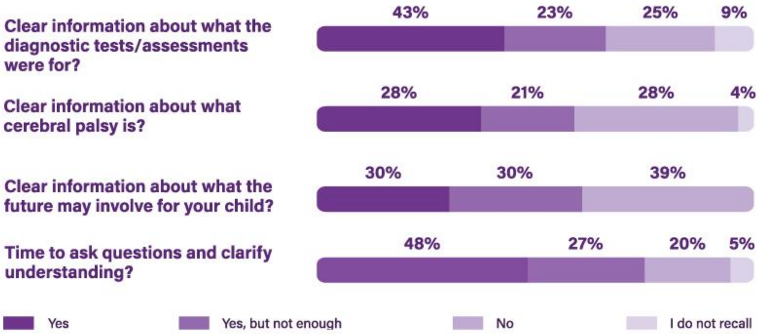
NEED FOR INFORMATION & COMMUNICATION

Families satisfaction level with how the diagnosis was delivered



▲ **Common themes impacting family experiences of diagnosis were the provision of thorough information and direct ongoing communication style with their clinicians.**

At the time of diagnosis and the following months, were you (families) given:



PATHWAYS FOR THE FUTURE

POSITIVE

Time to diagnosis

- Information about what the clinician was observing for
- Transparent open communication with as much certainty as possible
- Responses describing an early or ongoing diagnosis used the words:

Prepared

Expected shock

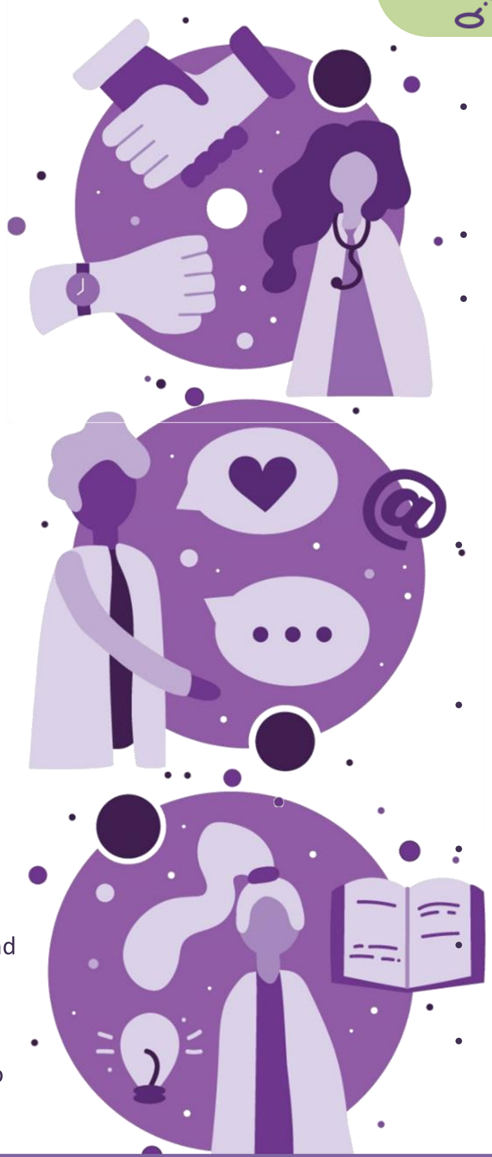
Gentle approach

Health professional communication

- Caring and sensitive manner
- Honest, informative, detailed and clear communication
- Direct communication approaches about potential different diagnoses
- Awareness of diagnosis surveillance period
- Clinician involved family in diagnosis as observer

Information

- Families received sufficient information during consultation
- Families felt informed
- Families had time to ask questions and felt supported with information they received
- Families valued realistic optimism about what their child may be able to achieve



ROOM FOR IMPROVEMENT

Time to diagnosis

- Health professional resistance to formally diagnose or perception that rushed diagnosis discourages further investigation
- Lengthy diagnosis meant families were under considerable stress
- Responses describing a lengthy diagnosis had the words:

Horrendous

Devastating

Had to fight for it

Health professional communication

- Families with poor experiences noted lack of conversation about possible diagnoses and lack of information on what CP is and how it affects their child
- Accidental discovery of CP diagnosis that was not communicated directly

Information

- Families not receiving enough information about their child's condition
- Families resorted to crude online searches of the unfamiliar CP diagnosis
- Difficulty in understanding information and what it means for them

Future knowledge translation can consider clinician barriers and enablers to using clinical tools and support clinician's in providing CP information to patients and families

Williams, S.A.; Mackey, A.; Sorhage, A.; Battin, M.; Wilson, N.; Spittle, A.; Stott, N.S. Clinical practice of health professionals working in early detection for infants with or at risk of cerebral palsy across New Zealand. J. Paediatr. Child Health 2020, 7.

Williams, S.A.; Alzaher, W.; Mackey, A.; Hogan, A.; Battin, M.; Sorhage, A.; Stott, N.S. "It should have been given sooner, and we should not have to fight for it": a mixed-methods study of the experience of diagnosis and early management of cerebral palsy. J. Clin. Med. 2021, 10.