Mild HIE Cooling Transfers: Explaining Therapeutic Drift to Parents

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Observations 2006 - 2025

- Transport
- TOBY trial
- Cooling as accepted practice
- Development of cooling in transport
- Cessation of TOBY register
- Decline in assessment rigour
- Therapeutic drift
- Resource limitations

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Therapeutic Drift in Neonatal Therapeutic Hypothermia (HIE)

- What is therapeutic drift? Widening use of cooling beyond trial criteria (e.g., mild HIE, later initiation)
- Observed in registries & cohorts: widespread TH in mild HIE (CHNC, Japan Registry)
- Impact on outcomes & trials: pilot RCTs show no biomarker benefit, increased interventions
- Ethical concerns: risks of overtreatment, lack of evidence, harder trial recruitment
- Communication with parents: trauma-informed, clear rationale, document reasons, explicit consent

Key refs: Rao 2022; Montaldo 2024; Kumar 2021; Tsuda 2017; Laventhal 2012; BAPM 2020; Lemmon 2017; Craig 2019; Sagaser 2022

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Aims

- To examine adherence with the BAPM guidelines, specifically round cooling in mild versus moderate or severe HIE in special care unit (SCU) and local neonatal units (LNU) in London

- To compare the modified Sarnat staging performed by referring units with the assessment by Neonatal Transport Service (NTS) clinicians

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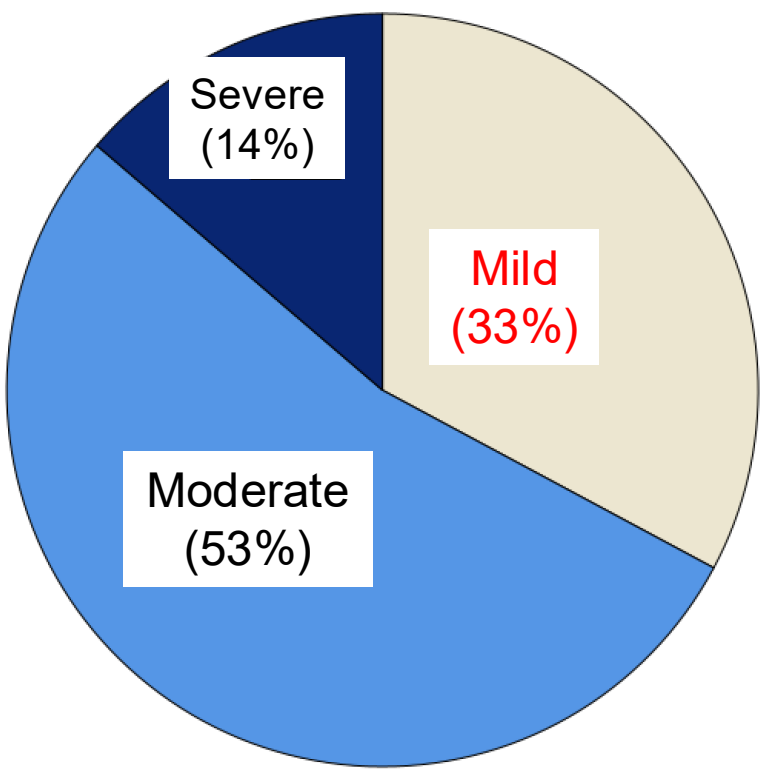
Methods

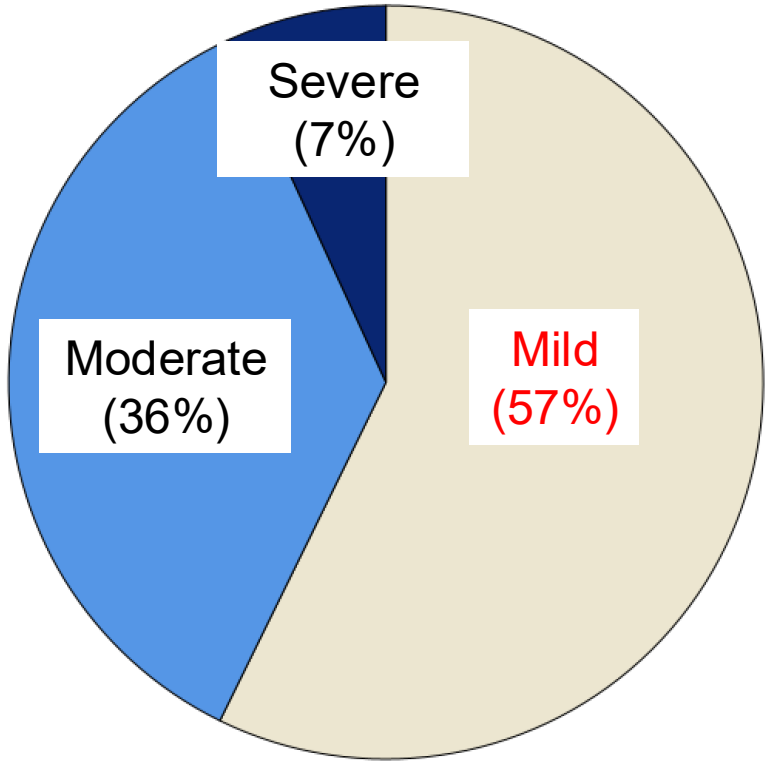
- Secondary analysis of the COOL-Trips database that collects prospective data from all neonates retrieved by London NTS
- 1 January 2022 to 31 December 2023
- Neurological assessment was made using the modified Sarnat Score, initially by referring unit, repeated by NTS clinicians on arrival (< 6 hours of age)

2022/2023 Results: HIE stage

- 159 babies were transferred for cooling over the 2 years study period
  – 131 (82%) neurological assessments by both referral and NTS



Referral hospital assessment

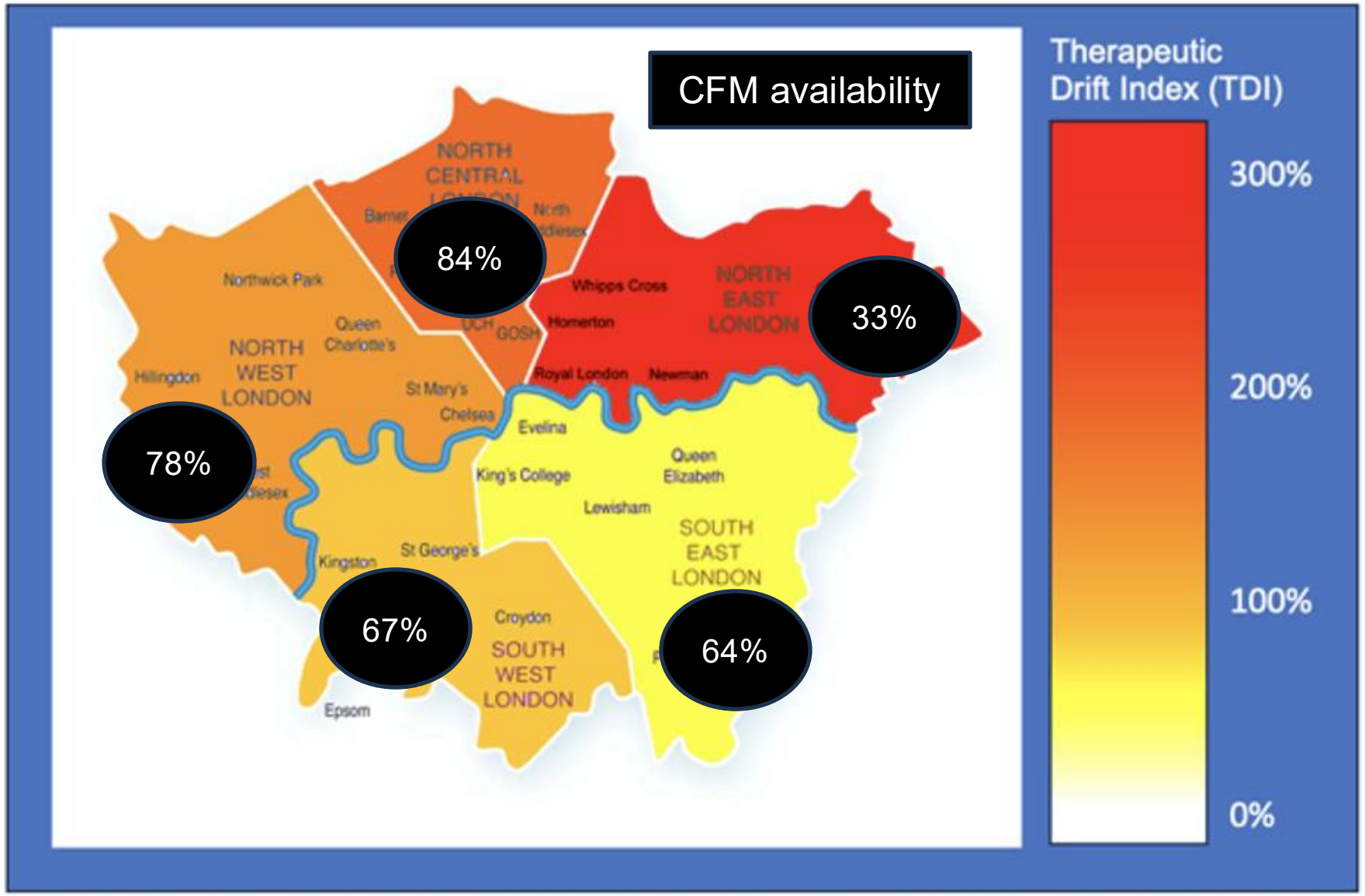


NTS assessment

**Referral team assessments were before sedation and NTS was after sedation*

Results: Practice variations

Therapeutic Drift Index (TDI) = $\frac{\text{Mild HIE}}{\text{moderate + severe HIE}} \times 100$



British Association of Perinatal Medicine

Therapeutic Hypothermia for Neonatal Encephalopathy

A Framework for Practice
November 2020

1) Babies with moderate or severe HIE should receive induced hypothermia within six hours birth.

2) Babies with mild HIE should not be treated with induced hypothermia outside clinical trials.

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Findings

- More than half the babies transferred by NTS had mild encephalopathy
- Extensive variations in cooling practices with London ODN
- Poor agreement between neurological assessment of referring hospital clinicians and NTS teams. Sedation confounder
- None of the examiners were trained and certified on neurological assessment

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Conclusions

- Training and certification on modified Sarnat stage may improve clinical care of babies with HIE and reduce practice variations, deliver cost effectiveness & avoid unnecessary parental separation

- Clinical trials of induced hypothermia could provide clearer guidance on treating babies with mild HIE

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Parent experience of HIE and hypothermia: A call for trauma informed care

- Department of Pediatrics, Barbara Bush Children's Hospital at Maine Medical Center, Portland, ME, USA
- A 29-question anonymous survey posted on a parent support website sent to members via e-mail responses from open-ended questions analysed using thematic analysis
- 165 respondents completed the survey and 108 (66%) infants were treated with TH

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Explaining therapeutic drift to parents

- Setting for communication: Parents preferred face to face meetings with clinicians
- Content and clarity of language: Parents valued clear language (use of layman's terms) and being explicitly told the medical diagnosis of HIE
- Emotional Support: Parents required support from clinicians to process the trauma of the birth experience and TH treatment
- Clinician time and scheduling: Parents valued the ability to join rounds and other major conversations about infant care
- Physical Presence and Touch: Parents valued being physically present and touching their baby

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Am J Perinatol. 2022 Jan 13;41(5):586–593

- “I want to explain why we are offering cooling. Cooling can protect the brain if there has been significant injury, and it’s standard for moderate/severe cases. In your baby’s situation we think there is a risk of brain injury because [brief clinical reason]. Some babies like yours were not included in the earliest trials, so there’s a bit more uncertainty about the benefit. Because this is time-sensitive, we recommend starting cooling now while we keep watching and doing tests. We will explain everything step-by-step, write down the reasons, and follow up with imaging and a neurology plan. Do you have any questions right now? If it helps, I can give this note to read and come back in 10–20 minutes to answer anything.”

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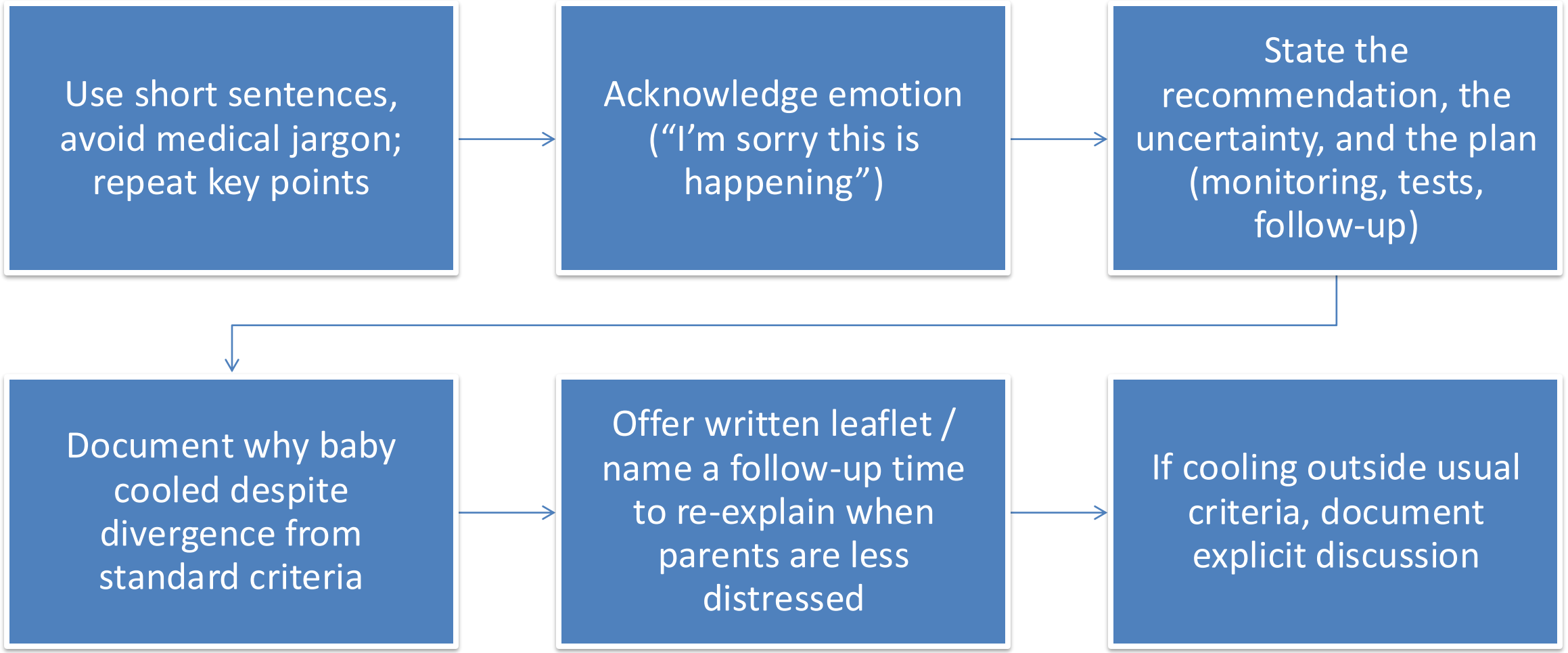
Practical tips to make the conversation easier



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Support for parents, families & friends of those who have experienced an H.I.E. event

(Hypoxic-Ischaemic Encephalopathy)

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From awareness & fundraising events to community drop-ins & support sessions - check out our upcoming events related to H.I.E.

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Family Stories

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Jargon Buster

Being in hospital can sometimes be an overwhelming experience. Our jargon buster can help you make sense of commonly used terms that come with H.I.E.

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