

**STARTING IN A FEW MINUTES AT 15:30**



## **Tongue Tie - it's not clear cut**



**#iHVInsights**

**15 August 2024**



## Tongue Tie - it's not clear cut



#iHVInsights

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# Welcome



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**The Institute of Health Visiting is a charity and academic body. Its core purpose is:**  
To improve outcomes for children and families and reduce health inequalities through strengthened health visiting services

# Agenda

## Welcome

- **Amanda Holland** - iHV Professional Services Lead
- **Helen Smith** - Infant Feeding Co-ordinator and BFI Project Lead, Swindon 0-19 Public Health Nursing Service

## Guest Speakers

- **Phyll Buchanan** - Breastfeeding Network Tutor and Supervisor. Patient and Public Involvement Representative and co-investigator of the FROSTTIE RCT
- **Sarah Winspear** - Infant feeding Lead, Redcar and Cleveland
- **Laura Paterson** - Specialist Midwife Infant Feeding Lead, South Teesside
- **Rosie Duck** - Parent with Lived Experience

## Q&A with Speakers

## Close and Evaluation

# What is tongue tie?

Helen Smith, Infant Feeding Coordinator

0-19 Public Health Nursing Service



# Tongue Tie

A tongue tie, or ankyloglossia, is caused by a short or tight lingual frenulum which can restrict tongue movement and function. It may not cause any feeding problems but in some cases, difficulties may be experienced.

Breastfed babies may experience:

- Difficulty attaching or staying attached to the breast
- Lengthy or very frequent feeds
- Seem unsettled/unsatisfied
- Making clicking noises when feeding
- Slow weight gain

Can lead to low milk supply, sore or cracked nipples, engorgement and mastitis.

Bottle fed babies may experience:

- Lengthy or very frequent feeds
- Seem unsettled/unsatisfied
- Excessive dribbling
- Choking
- Slow weight gain

[\(NHS Better Health Start for Life 2024\)](#)



Image: NHS, <https://www.nhs.uk/conditions/tongue-tie/>



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## Next: Phyll Buchanan

Breastfeeding Network Tutor and Supervisor. Patient and Public Involvement Representative of the FROSTTIE RCT



FROSTTIE – TRIAL OVERVIEW | IHV Webinar August 2024 | Trial registration number ISRCTN 10268851.



FROSTTIE

A randomised controlled trial of Frenotomy and breastfeeding support Or breastfeeding Support without frenotomy to investigate continuation of breastfeeding for babies with Tongue-TIE



## Trial overview

- Background
- Current Practice
- Rationale
- Objectives and outcomes
- Trial design
- Results
- Trial challenges and facilitators



# Background

- Tongue-tie can be diagnosed in 3 – 11% of babies
- Less than 50% of babies with tongue-tie are reported to have breastfeeding difficulties
- Breastfeeding support – very wide range of provision in type and availability throughout the UK



## Rationale

- A Cochrane review identified 5 previous trials - total 302 babies
- Mostly small trials, with short-term outcomes
- Many had almost all babies undergoing frenotomy in both groups [within days]
- Statistically under-powered
- Bottom line: Not enough evidence

<https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD011065.pub2/full>



## NICE guidelines (2005)

- allow for frenotomy procedure based on lack of safety concerns
- Limited evidence of efficacy

<https://www.nice.org.uk/guidance/ipg149>



## Objective

- To investigate whether frenotomy is clinically - and cost-effective to promote continuation of breastfeeding at 3 months in infants with breastfeeding difficulties diagnosed with tongue-tie.



## Primary Outcome

- To compare the rate of any breastfeeding at 3 months of age in infants with breastfeeding difficulties and diagnosed tongue-tie who undergo frenotomy and receive breastfeeding support versus those who receive breastfeeding support only.



## Study design and inclusion criteria

The FROSTTIE trial was a multicentre RCT in England.

Aimed to recruit 870 babies over two years:

- Any infant aged less than 10 weeks referred to an infant feeding service with breastfeeding difficulties and judged to have tongue-tie, as diagnosed according to usual hospital practice plus the Bristol Tongue Assessment Tool (BTAT)
- 12 participating infant feeding services



# Trial design - BTAT

## BTAT – Bristol Tongue-tie Assessment Tool

	0	1	2	Score
Tongue tip appearance	Heart shaped	Slight cleft / notched	Rounded	
Attachment of frenulum to lower gum ridge	Attached at top of gum ridge	Attached to inner aspect of gum	Attached to floor of mouth	
Lift of tongue with mouth wide (crying)	Minimal tongue lift	Edges only to mid-mouth	Full tongue lift to mid-mouth	
Protrusion of tongue	Tip stays behind gum	Tip over gum	Tip can extend over lower lip	



# Summary of results - before trial stopped

- Trial ran from March 2019 to November 2020
- 169 infants were randomised, 80 to the frenotomy with breastfeeding support arm and 89 to the breastfeeding support arm from a planned sample size of 870 infants.
- The trial was stopped in the context of the ongoing COVID-19 pandemic due to withdrawal of breastfeeding support services, slow recruitment and crossover between arms.
- In the frenotomy with breastfeeding support arm 74/80 infants (93%) received their allocated intervention, compared to 23/89 (26%) in the breastfeeding support arm.
- Mothers reported a mean pain score of 4 out of 10 while feeding during the previous 24 hours
- Women reported high levels of anxiety and depression both at recruitment, and, to a lesser extent, at 3 months, indicating an important need for mental health support.
- Primary outcome data were available for 163/169 infants (96%).
- There was no evidence of a difference between the arms in the rate of breastmilk feeding at 3 months, which was high in both groups [67/76, 88% vs. 75/87, 86%; adjusted risk ratio (aRR) 1.02, 95% CI 0.90 to 1.16].



# Economic evaluation & Adverse events

- There were no statistically significant differences in health-care resource use, costs and benefits between the two groups.
- **Adverse events** occurred in three infants: one infant had bleeding, one infant had salivary duct damage, and the third infant had an accidental cut to the tongue and salivary duct damage.
- There were no other serious adverse events causally related to the intervention.



# Trial challenges and facilitators

- **Challenges:** The main challenge to the trial concerned equipoise, which was a barrier to recruitment both due to staff attitudes and parents' expectations. More than half of women recruited to the trial believed that frenotomy would help their baby and fewer than half were truly in equipoise.

## **Facilitators: maintaining equipoise by keeping options open**

- Clinics named 'feeding' or 'breastfeeding support' clinics rather than Frenotomy clinic
- Frequent clinics, some offering drop-in clinics up to 5 days per week.
- Time to work on attachment before referral for frenotomy [when appropriate]
- Recruited early. Babies were recruited at the point of first contact within the clinics prior to breastfeeding support.
- Cohesive teams - Clinics for support and frenotomy were held within the same department.
- **Equity:** 94% were of white ethnicity. Only 8% were resident in the most deprived quintile of areas.



# Study details

Chief Investigator: Prof. Marian Knight

Sponsor: University of Oxford

Funder: NIHR Health Technology Assessment programme (NIHR HTA)

**Reference:** Knight M, Ramakrishnan R, Ratushnyak S, Rivero-Arias O, Bell J, Bowler U, Buchanan P, Carter C, Cole C, Hwer O, Hurd M, King A, Juszczak E, Linsell L, Long AM, Mottram L, Murray D, Oddie S, Quigley M, Stalker V, Stanbury K, Welsh R, Hardy P; FROSTTIE Trial Collaborative Group. Frenotomy with breastfeeding support versus breastfeeding support alone for infants with tongue-tie and breastfeeding difficulties: the FROSTTIE RCT. Health Technol Assess. 2023 Jul;27(11):1-73. doi: 10.3310/WBBW2302. PMID: 37839892; PMCID: PMC10591207.

Accessed 22 July 2024 <https://pubmed.ncbi.nlm.nih.gov/37839892/>





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**Next:**

**Sarah Winspear**

Infant feeding Lead Redcar and Cleveland

**Laura Paterson**

Specialist Midwife Infant Feeding Lead,  
South Teesside

**#iHVInsights**



South Tees Hospitals  
NHS Foundation Trust

# South Tees Tongue-tie Service

Sarah Winspear – Infant feeding lead for Redcar & Cleveland Health Visiting & Family Hubs

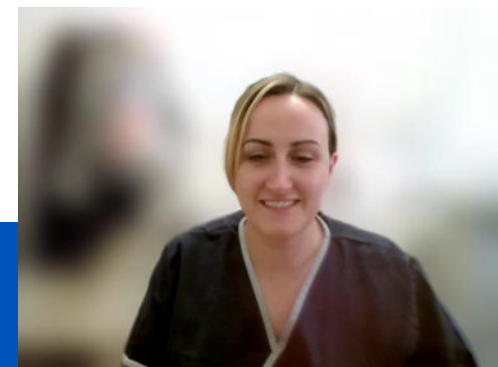
Laura Paterson - Specialist Midwife for Infant Feeding South Tees



# Service need

- Developed in response to service user demand
- Joint support and financial backing from Middlesbrough and Redcar & Cleveland Family Hubs Transformation Project (DfE funding)
- In 2023, 100 babies referred from South Tees to NHS tongue-tie services
- Only 10% of the babies referred would attend appointments\* (others accessed private services at cost of ~£200 or stopped breastfeeding due to lengthy wait)
- Actual number accessing tongue-tie services was unknown due to ease of accessing private services. Parents very aware of historical lack of provision within the area (no NHS tongue-tie services within 50-mile radius)
- Previously we relied on referral to neighbouring Trust with ~6-10 week wait
- Last business case for local service submitted and declined in 2013
- Feedback regarding wait times and lack of service was a recurring theme

\*during audit period of Apr-Sep 2023

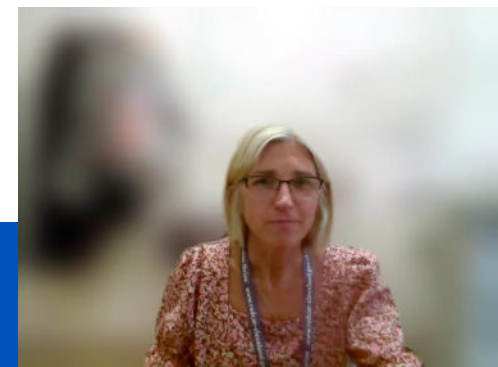


# Service user survey results

- Online survey circulated via Trust social media to gain insight into experiences of families experiencing tongue tie between 2018-2023
- 117 responses
- 83% were either dissatisfied or very dissatisfied with current service availability
- 96% felt a local service would be extremely valuable
- 92% said they would preferred to be seen within 1-3 weeks
- Just 10% reported they were referred and seen by within an NHS service in a timely manner.

Findings were consistent with the service-user feedback via

South Tees Maternity Voices Partnership group



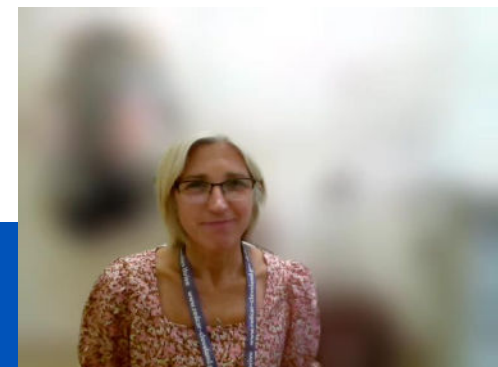
# Collaboration

- Joint venture between Health Visiting and Maternity Services
- Training access via Wolverhampton University
- Funded placements secured with York Hospitals NHS Trust
- Honorary contract for external staff
- Business case – presented to Trust Board
- Development and governance of operational policy, consent, LocSSIP, bleeding guidelines and pathway, parent information, referral process, administration procedures (clinic bookings, GP/HV letters etc.)
- ENT involvement
- Purchasing of equipment



# Clinic set-up

- Weekly clinics (9am-5pm)
- Maternity support worker present in clinic to hold baby and compliment specialist feeding support
- Clinic rota – covered alternate weeks by tongue-tie practitioners to ensure service sustainability (3<sup>rd</sup> practitioner from Middlesbrough HV team to join in 2024-25 to further strengthen service)
- 6-7 x 1 hour appointments
- Waiting times ~1-2 weeks
- Treatment offered up to 12 weeks
- Follow-up telephone call to audit outcomes 1 week post division
- Outcomes recorded for audit and monitoring



# Clinic outcomes Jan-Jun 2024

- 129 babies seen in clinic

- 95 divisions performed

- 8 lost to follow-up

- **Self-reported improvement in feeding**

• significant improvement	54/87	62.1%	}	<b>Improvement</b> 95.4%
• significant-slight improvement	5/87	5.7%		
• slight improvement	24/87	27.6%		
• no change	5/87	5.7%		

- **Self-reported improvement in pain (of the 68 who experienced nipple pain)**

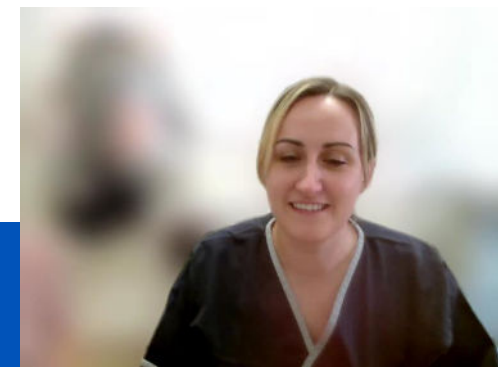
• significant improvement	45/68	66.2%	}	<b>Improvement</b> 80.2%
• slight improvement	14/68	20.6%		
• no change	8/68	11.8%		
• Worse	1/68	1.5%		

- **Service satisfaction**

• Extremely satisfied	81/87	93.1%	}	<b>Satisfied</b> 100%
• Satisfied	6/87	6.9%		
• Dissatisfied	0/87	0%		

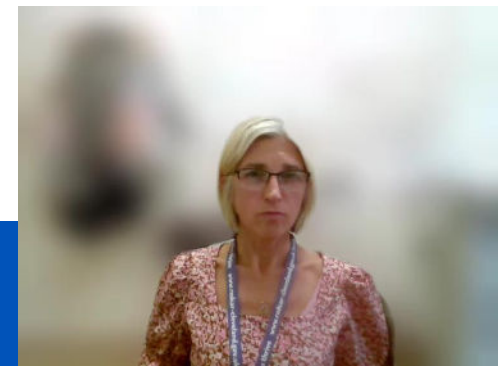
- 1 baby required 10mins pressure to resolve bleeding

- No other adverse outcomes



# Overcoming challenges

- Honorary contract (DBS, Occupational Health etc.)
- Securing practice placements
- Clinic space
- Multiple layers of governance
- Backlog – initial long waiting list due to sudden closure of neighbouring service
- Stream-lining of follow-up support & feedback to services
- Sustainability



# What mothers said...

“For the first time, you all made me feel heard”

“It wasn't just a tongue-tie snip. The support, advice and reassurance that went with the service was great”

“From the initial phone call after being referred and in the clinic - you were all amazing”

“You truly have changed and improved his life”

“Amazing service, It saved my breastfeeding journey”

“My supply was much improved post division”



South Tees Health Watch STAR Awards 2024 – Special Recognition Award



South Tees International Day of the Midwife Awards – South Tees Service Improvement of the year 2024







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- **Brief question**
- **Your name** (if you wish to do so)

**Next:**

**Rosie Duck**

Parent with lived experience

# Q&A



We will aim to answer as many questions as possible during the live session.

Use the Q&A function:

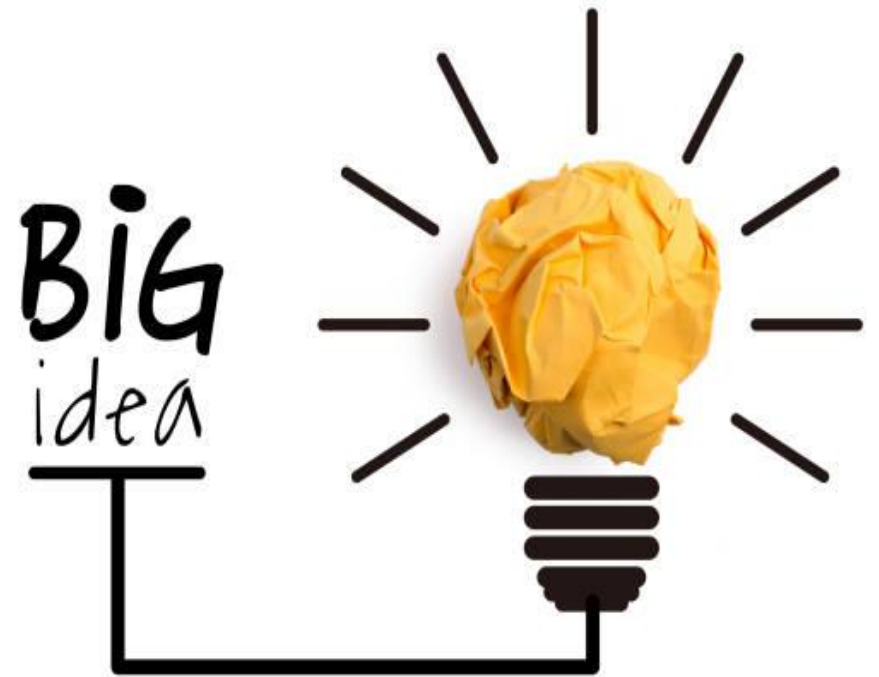
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# Thank you so much for joining us



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# Future iHV Member Benefit Event Dates

- **26<sup>th</sup> Sep** | iHV Insights - Introducing the iHV Preceptorship Framework for Health Visitors
- **16<sup>th</sup> Oct** | SCPHN Student Networking Event
- **22<sup>nd</sup> Oct** | Practice Education Networking: Meeting the NMC standards of proficiency for SCPHN-HV – with special focus on Genomics
- **24<sup>th</sup> Oct** | iHV Insights - Health visiting supporting families experiencing poverty

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## **Introducing the iHV Preceptorship Framework for Health Visitors**

**Join us for our iHV Insights webinar event on  
Thursday 26 September 2024**



# iHV In Focus PIMH Conference 2024

## Thursday 19<sup>th</sup> September 2024 – Virtual Half-Day Conference



### Dismantling the Barriers:

collaborative approaches to perinatal mental health care



iHV Perinatal and Infant Mental Health Conference



Virtual Conference

- **Young Parents**
- **Gypsy Roma Traveller Families**
- **Mothers in Prison**
- **Asylum Seeking Families**
- **Putting Recommendations Into Practice**



Find out more and book on our  
conference website

<https://events.ihv.org.uk/in-focus-pimh-2024>

Our conference programme brings together experts and speakers who are focused on raising awareness of families whose perinatal mental health needs are less well met and understood.

By considering recommendations from recent research, reflections on best practice examples and powerful accounts from parents, we'll think about how we can work together to improve experiences and dismantle barriers for these families in receiving equitable, high quality perinatal mental health care.

### Standard Pricing

Standard pricing starts on 19/07/2024 at 17:00

iHV Members &  
Mental Health Champions

£53

iHV Student &  
Retired Members

£40

Non-members

£64

All ticket prices are exempt from VAT and the student rates apply to SCPHN Students only.