This paper reviews the evidence surrounding tongue tie division (frenotomy) and reports on the findings of a national survey to map the provision of UK NHS tongue tie services. The study reports data from 86 of 167 NHS acute Trusts/boards across the UK, plus 20 community Trusts, looking at the availability of tongue tie services, referral numbers and criteria, and the nature of the service provided. The findings emphasise the variability of service provision across NHS Trusts, and the limitations within the evidence base relating to assessment tools and intervention. There is a need for equitable access to skilled assessment and services to prevent both under- and over-diagnosis, and a need for all women to receive appropriate and timely breastfeeding support.

Introduction

NCT is a parents’ charity, providing support and information to women and their partners in pregnancy and the first two years after birth. NCT has a long history of influencing maternity services and related areas of policy in order to improve the care and experiences of all women. From a service user perspective, it is clear that there are wide inconsistencies in access to NHS tongue tie division services. There is also clear concern and valid debate about the quality of the evidence base, and the potentially damaging issues of both over- and under-diagnosis. This report represents a service user initiated enquiry, and calls for further research and service development.
Tongue tie or ankyloglossia is a congenital condition where the lingual frenulum (mucous membrane under the tongue) is abnormally tight, short or thick and restricts tongue mobility. It is estimated to occur in between 2.8% and 10.7% of newborns (Edmunds et al 2011), with estimates of prevalence varying greatly, partly due to the lack of uniform diagnostic criteria (Burrows & Lanlehin 2015). Tongue function is considered more significant than appearance as this has an impact on whether the baby is able to feed effectively (Power & Murphy 2015).

Reports suggest that tongue tie can affect breastfeeding in numerous ways, including maternal nipple damage and pain, difficulty in the baby attaching to the breast, uncoordinated sucking and frequent or continuous feeds (Hall & Renfrew 2005, Edmunds et al 2011). A small proportion of babies are also reported to have difficulty maintaining suction when bottle feeding (Hogan et al 2005). In contrast, it is estimated that more than 50% of babies with observed tongue tie do not experience any feeding problems (Emond et al 2014).

The most commonly used clinical assessment tool is the Hazelbaker Assessment Tool for Lingual Frenulum Function (Hazelbaker 1993), although other researchers have not found all elements of the tool useful. Preliminary work on the simpler Bristol Tongue Assessment Tool shows promise, but it is not known whether it is predictive of a need for intervention (Ingram et al 2015).

Guidance by the National Institute for Health and Care Excellence (NICE 2005) indicates that babies assessed as having a tongue tie that impacts on breastfeeding after skilled support with positioning and attachment at the breast, may benefit from frenulum division. The procedure, known as frenotomy, involves dividing the lingual frenulum with sharp, blunt ended scissors. In infants it is usually carried out without anaesthetic and is seen as a simple, safe procedure with few reported side effects provided that it is carried out by a trained, skilled professional (NICE 2005, Emond et al 2014, Power & Murphy 2015).

However research evidence for the effectiveness of frenotomy is limited (O’Shea et al 2014). NICE (2005) guidance is over a decade old and there is a lack of published position statements from large professional bodies on the diagnosis and treatment of ankyloglossia (Burrows & Lanlehin 2015). This ambiguity and uncertainty is reflected in the uneven provision of services and conflicting advice given to mothers (Care Quality Commission 2015).

Concerns have been raised that tongue tie diagnosis and treatment are a current ‘fad’ or popular ‘quick fix’ for breastfeeding problems, and are not being considered carefully or critically enough. Critics claim that the medicalisation of feeding difficulties may be unhelpful, particularly in combination with an absence of skilled breastfeeding support, and over-diagnosis may damage maternal self-efficacy (Douglas 2013). Preoccupation with tongue tie may lead professionals to ignore other potential causes of breastfeeding difficulties and result in unnecessary surgical interventions (Power & Murphy 2015).

There is also a risk of repeat frenotomies where no improvement is seen following the procedure. Issues are further complicated by limited knowledge about posterior tongue tie (a less obvious frenulum located under folds of mucosa at the base of the tongue), which are thought to require deeper frenotomy with greater potential side effects (Douglas 2013).

**Evidence of efficacy**

Recent systematic reviews (Edmunds et al 2011, Finigan & Long 2013, Webb et al 2013, Francis et al 2015) have found limited evidence from a number of small scale short-term studies that frenotomy can be associated with mother-reported improvements in breastfeeding and a reduction in maternal nipple pain (Francis et al 2015), thus supporting breastfeeding continuation (Finigan & Long 2013).

Research studies include five randomised controlled trials (RCTs) (Hogan et al 2005, Dollberg et al 2006, Buryk et al 2011, Berry et al 2012, Emond et al 2014) and 29 observational studies (Francis et al 2015). There are significant limitations to the trials conducted, including small sample size (25–107 mother-infant dyads) and lack of complete blinding, leading to likelihood of placebo effect, especially where mothers or professionals perceive frenotomy as a ‘magic bullet’. Outcome measures are also variable, including mother-reported improvements in feeding (Hogan et al 2005, Berry et al 2012), improvements in LATCH score (Dollberg et al 2006, Emond et al 2014) and reduction in maternal pain scores (Dollberg et al 2006, Buryk et al 2011).

Selection criteria for breastfeeding dyads entering the trials is variable, therefore we cannot assume that they are representative of women being referred to services across the UK. There may be different levels of clinical, social and emotional breastfeeding support provided prior to considering frenotomy, and higher or lower thresholds for recommending frenotomy as a response to nipple pain or other feeding difficulties.

No studies have explored the long-term effects of division versus non-division on breastfeeding outcomes and maternal and infant health. All RCTs offered frenotomy to dyads in the control group too, either immediately after assessment (Hogan et al 2005, Dollberg et al 2006, Berry et al 2012) or in the following days/weeks (Buryk et al 2011, Emond et al 2014). The majority of the control groups chose to accept frenotomy, therefore longer-term comparisons between the control and intervention groups are not available. Whilst research design would be...
strengthened by *not* offering frenotomy to the control group, there are ethical and practical barriers to implementing this protocol. Qualitative studies have highlighted the pain, loss of self-confidence and emotional distress that ongoing breastfeeding problems can cause for mothers (Edmunds *et al* 2013, Webber & Webber 2016), and there are concerns over slow weight gain and potential dehydration in infants.

**NCT research**

Increasing awareness of tongue tie as a potential cause of breastfeeding problems has led to high demand for services in some areas of the UK, and concerns amongst parents and health professionals regarding the uneven availability of skilled support and service provision. Others are concerned about the provision of services without adequate evidence base. In response to this situation, in autumn 2014, NCT sent all UK infant feeding leads a survey to map the occurrence and characteristics of NHS tongue tie services. The specific objectives of the survey work were to:

1. Identify which maternity units/Trusts provide a tongue tie division service.
2. Identify gaps in provision of a tongue tie service.
3. Ascertain the proportion of tongue tie services that have staff with specialist breastfeeding knowledge.
4. Identify the main barriers to providing and referring to a tongue tie service.
5. Place the survey findings within a broader context of evidence of effectiveness and general breastfeeding support.

Out of 167 NHS acute Trusts/boards in the UK with a maternity service, 77 responded directly and a summary of nine services in the east of England brought the number of responses to 86 (a 51% response rate). A further 20 responses were received from community Trusts in England.

**Trusts/boards with a tongue tie service**

Eighty-three per cent of acute Trusts responding to the survey stated that they have a tongue tie service, whilst 17% do not, meaning that at least 43% of all UK acute Trusts are providing some form of tongue tie service, with some ongoing expansion of provision. Eleven of the 20 community Trusts responding provide a tongue tie service (55%). Responses and provision by UK nation and English region are shown in Tables 1 and 2 below:

The key finding was the variability — both in provision and set up of services:

- mainly hospital-based but some community-based
- some commissioned by the Clinical Commissioning Group or local authority, some not
- some providing a service for bottle-fed babies, some not
- some accepting referrals for posterior tongue ties, some not
- variability of service provider, with services run by midwives, ear, nose and throat (ENT) surgeons, maxillofacial surgeons, dentists or paediatricians
- variability in the quality of assessment
- breastfeeding support is not always available immediately after division and follow up is variable.

### Table 1. UK nations: responses and provision

<table>
<thead>
<tr>
<th>Nation</th>
<th>Number of Trusts with maternity</th>
<th>Number of Trusts responding</th>
<th>Number of Trusts with tongue tie service</th>
</tr>
</thead>
<tbody>
<tr>
<td>England</td>
<td>141</td>
<td>71</td>
<td>58</td>
</tr>
<tr>
<td>Scotland</td>
<td>14</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Wales</td>
<td>7</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Northern Ireland</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
</tbody>
</table>

### Table 2. Regions of England: responses and provision

<table>
<thead>
<tr>
<th>Strategic health authority</th>
<th>Number of Trusts with maternity</th>
<th>Number of Trusts responding</th>
<th>Number of Trusts with tongue tie service</th>
</tr>
</thead>
<tbody>
<tr>
<td>North East</td>
<td>8</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>North West</td>
<td>20</td>
<td>9</td>
<td>6</td>
</tr>
<tr>
<td>Yorkshire and the Humber</td>
<td>13</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>East Midlands</td>
<td>8</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>West Midlands</td>
<td>15</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>East of England</td>
<td>17</td>
<td>15</td>
<td>14</td>
</tr>
<tr>
<td>London</td>
<td>22</td>
<td>13</td>
<td>11</td>
</tr>
<tr>
<td>South East Coast</td>
<td>11</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>South Central</td>
<td>9</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>South West</td>
<td>16</td>
<td>12</td>
<td>12</td>
</tr>
</tbody>
</table>

**Commissioning of services**

In England and Wales 17 respondents stated that the service was commissioned, and 17 that it was not. In Northern Ireland, the service is provided by ENT surgeons in two Trusts and by dentists/oral surgeons in the other three, seeing babies as part of their regular clinics.

**Referrals for bottle-fed babies**

Of the 71 hospital Trusts/Boards providing a tongue tie service, 38 (54%) accept referrals for bottle-fed babies, whilst 13 (18%) do not. A further five did not know, and 15 did not answer the question.
Referral criteria

Altogether, 60 Trusts provided information regarding referral criteria, with 53 (88%) using oral assessment, indicating that the baby’s mouth is usually checked. All respondents used the criterion “difficulty with breastfeeding not improved sufficiently by skilled help with positioning and attachment”, whilst 36 (60%) also selected “breastfeeding difficulty only”, suggesting a potential lack of breastfeeding support prior to diagnosis.

Referrals for posterior tongue ties

There are variations in opinion as to the benefits and risks of intervention for posterior tongue tie (Douglas 2013), and there is currently no validated diagnostic tool. One survey respondent commented that ‘most of the consultants tell me there is no such thing’ and that they ‘use clinical judgement and do not like to use any assessment tool’, whilst another explained ‘personally I don’t find these terms [anterior and posterior] to be relevant… it is the function of the tongue and effect that matters’.

Despite ongoing controversy, of 71 hospital Trusts with a tongue tie service, 36 (51%) divide posterior tongue ties, as do five of the 11 community Trusts with a service. Fifteen stated they do not divide posterior ties, although two of these refer elsewhere, possibly due to lack of in-house training in the procedure.

Numbers of referrals and divisions

Sixteen Trusts which accept out-of-area referrals provided data on numbers of referrals and divisions. This varied from 110 referrals with 93 divisions in the past year, an average of just under two divisions per week, to a maximum of around 1500 for King’s College Hospital in London, an average of 29 divisions per week.

Some Trusts and Boards which do not accept out-of-area referrals provided figures on divisions which could be calculated as a percentage of the Trust’s birth rate. Table 3 shows the variation, up to a maximum of 7% of births.

Waiting time between referral and appointment for division

Of 55 responses from hospital Trusts in England, Wales and Scotland, 67% were usually given an appointment for division within two weeks of referral, whilst 10% had a waiting time of more than three weeks. In Northern Ireland waiting times were shorter, at 1–2 weeks or less. Prompt division is considered important as mothers may experience significant pain and breastfeeding problems during this period. Long waiting times may prompt them to seek alternative help from private practitioners, at significant financial cost. In areas where no NHS tongue tie service exists, private practitioners are often the first port of call for tongue tie assessment and treatment, presenting a conflict of interest for those who charge to carry out procedures.

Table 3. Regions of the UK: numbers of referrals and divisions

<table>
<thead>
<tr>
<th>Region/country in which Trust/board situated</th>
<th>Number of referrals in recent 12 month period</th>
<th>Number of divisions</th>
<th>Divisions as percentage of all births in Trust</th>
</tr>
</thead>
<tbody>
<tr>
<td>West Midlands</td>
<td>38</td>
<td>38</td>
<td>0.8%</td>
</tr>
<tr>
<td>London</td>
<td>356</td>
<td>340</td>
<td>5%</td>
</tr>
<tr>
<td>London</td>
<td>179</td>
<td>155</td>
<td>4%</td>
</tr>
<tr>
<td>London</td>
<td>55 in 3 months</td>
<td>20</td>
<td>0.4% (but new service)</td>
</tr>
<tr>
<td>London</td>
<td>625</td>
<td>330</td>
<td>3.5%</td>
</tr>
<tr>
<td>South East Coast</td>
<td>260</td>
<td>230</td>
<td>6%</td>
</tr>
<tr>
<td>South West</td>
<td>90</td>
<td>51</td>
<td>0.5%</td>
</tr>
<tr>
<td>South West</td>
<td>400–500</td>
<td>6–7%</td>
<td></td>
</tr>
<tr>
<td>Wales</td>
<td>77</td>
<td>1%</td>
<td></td>
</tr>
<tr>
<td>Wales</td>
<td>60</td>
<td>63</td>
<td>1%</td>
</tr>
<tr>
<td>Wales</td>
<td>c200</td>
<td>c100</td>
<td>2.8%</td>
</tr>
<tr>
<td>Wales</td>
<td>13</td>
<td>13</td>
<td>0.4%</td>
</tr>
<tr>
<td>Scotland</td>
<td>280</td>
<td>7%</td>
<td></td>
</tr>
</tbody>
</table>

Maximum age for referrals

There is considerable variation in the maximum age for referrals for tongue tie division. Of 55 hospital Trusts responding, 33% had no age limit, a further 33% had a limit of 3–4 months, 16% a limit of 2–3 months and 13% a limit of 1–2 months.

Availability of skilled help immediately after division

Once the division procedure has been carried out, skilled help may be needed to enable the baby to attach effectively to the breast. The majority of Trusts responding (79%) provide such help, but 21% do not. In three of the cases where such help is not available, the tongue tie division service is provided by the hospital ENT department, rather than maternity services.

Follow up as part of the service

Ongoing skilled breastfeeding support is an important component of tongue tie services as babies may take several days to learn how to breastfeed effectively following division, or this may not solve breastfeeding issues. Thirty-seven Trusts (61%) do provide follow up, although 24 (39%) do not.

Referrals from outside the Trust

Twenty-six Trusts accept referrals from outside the Trust/board (42%), whilst 30 (48%) do not and in a further six Trusts this was not known. The distances travelled for referrals were usually between 20–60 miles, but some families have travelled 200 miles to obtain the service in Lancashire and Cornwall.
Referrals to another service

Of the fourteen responses from hospital Trusts, seven were able to give a figure, which varied between 10 and 150 per year. Community Trust referral figures varied from 12 to 50 per year.

Barriers to setting up a service or to referring elsewhere

Respondents who stated that their Trust did not have a tongue tie service were asked what the barriers were. Several barriers were listed — funding, availability of staff, training, venue, governance/safety issues, those with the power to set up a service not seeing a need, service not commissioned, differences in opinion between different professions, lack of referral routes, lack of skilled support for breastfeeding, and unsatisfactory referral criteria.

Even where a service is provided this may be unsatisfactory. An example was given of an ENT consultant who uses poor or no weight gain in a breastfed baby as the sole referral criterion. A respondent from a community Trust commented: ‘This is a specialist service which should sit with maternity provision’.

Where there is no service in the Trust, 23 out of 24 respondents stated there is a referral pathway elsewhere. Barriers to referral are similar to those in setting up a service: costs and paediatricians and commissioners not understanding the value of such a service.

Comments from respondents

Additional comments provided by respondents show a clear recognition of the need for more equitable, evidence-based support.

Two comments mentioned the inequitable service:

‘It is very frustrating for... women who I feel don’t get an equitable service in relation to breastfeeding support and tongue tie support due to the barriers indicated earlier.’

Eight responses mentioned the service having insufficient capacity, which leads to long waiting times:

‘I feel that the amount of appointments for the service themselves are not adequate for the demand. The services are excellent but the mothers have to wait too long for an appointment at a time when they are really struggling.’

Lack of capacity can also apply to follow up:

‘I try to provide follow up support when I am able to [as Infant Feeding Lead Midwife], but it is not always possible due to workload.’

Three were concerned about inadequate assessment and the consequence of tongue ties being divided unnecessarily:

‘There is not enough help in assessing a breastfeed first. The message we are giving at times to parents is that tongue tied babies cannot feed.’

Two responses expressed concern about the service not being properly commissioned leading to lack of data collection:

‘There is currently no way to properly record on the hospital PAS system that a baby has attended for assessment and treatment.’

Three mentioned lack of management support:

‘I have been trying to set up a local tongue tie service for the past two years... but to date management are not willing to support the proposal.’

‘We really need our own provision and it’s quite a battle to convince the decision makers of its importance.’

Two respondents pointed out the variation between services:

‘We have three different paediatric surgeons who do tongue tie referral, with no agreed referral process or guidelines for practice, and no data collection. Most, but not all, are referred to the infant feeding team for support post-procedure.’

Two respondents expressed concern about the increase in numbers of tongue ties diagnosed:

‘Whilst tongue tie is clearly an issue for many babies I am concerned at the huge surge in numbers of babies now being identified as having this condition.’

Hopes were expressed by three respondents:

‘I would like to see tongue tie as a national priority for NHS, and acknowledging that tongue tie is a real problem, not a concept! No mothers and babies should suffer...’

‘It would be great to have an approved accredited training programme for tongue tie division...’

‘I would like to see more robust evidence re incidence, efficacy of different methods of division, and guidelines around management to inform development of effective, evidence-based services.’

Conclusions

Tongue tie remains the subject of much controversy with a lack of high-quality evidence or guidance regarding diagnosis and treatment. Whilst some see it as a latest ‘fad’ which medicalises breastfeeding relationships and leads to loss of maternal self-efficacy and unnecessary surgical intervention, others are concerned regarding the very real experiences of women suffering from painful feeding and lack of adequate support.

Unsurprisingly, current service provision in the UK is variable and unevenly distributed, with a lack of consistent skilled assessment and referral criteria.
NICE (2005) guidance on the subject is limited and more than ten years out of date. Further research is urgently needed to establish guidelines for practice and to minimise both under- and over-diagnosis. There is also the broader challenge of providing a consistent level of skilled breastfeeding support, with some Trusts not even working towards achieving Baby Friendly status.

Further research should address the need to conduct RCTs in an environment where many consider it unethical to withhold frenotomy from babies affected by tongue ties, yet others consider it an ineffective procedure. Research is also required to develop evidence-based diagnostic criteria for tongue tie, to understand the variability between practitioners and establish best practice guidelines.

Recommendations
As a parents’ charity, to help address the variability and improve care for families, we recommend:

1. All Trusts/boards have an infant feeding coordinator/team and are working towards achieving or maintaining Baby Friendly status, to provide at least the minimum level of skilled support with breastfeeding.

2. Identifying priorities and securing funding from the National Institute for Health Research for further research on tongue tie, including longer term follow up, research into women’s experiences and identifying standardised diagnostic criteria and assessment tools.

3. Development of evidence-based good practice protocols by NICE or as part of the Baby Friendly Initiative to include:
   - commissioning of services to ensure routine monitoring
   - skilled assessment of feeding prior to referral for possible division
   - clear criteria for referral for division
   - skilled support with feeding immediately after division
   - follow up, with ongoing support readily available
   - regular audit of the service
   - reviewing the training process, particularly for quality control – consistency, availability and the feasibility of certification.

4. Easy access for all parents to a tongue tie service, if needed, preferably provided by the local NHS Trust/board but, if not, with a clear referral route to a neighbouring Trust/board.

5. Services to have sufficient capacity, in order to minimise waiting times.

6. Recognition that mothers may have painful and upsetting experiences of tongue tie and should have their concerns taken seriously.

Acknowledgements
NCT is very grateful to Francesca Entwistle, who coordinates the National Infant Feeding Network, linked to the UNICEF Baby Friendly Initiative, and to Infant Feeding leads in Scotland, Wales and Northern Ireland, for distributing the survey link and reminders to infant feeding coordinators.

References


