# **Ankyloglossia in Australia:** Are we making the cut or missing the mark?

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This is to certify that the thesis entitled "Ankyloglossia in Australia: Are we making the cut or missing the mark?" submitted by Donna Akbari Harris in fulfilment of the requirements for the degree of Doctor of Philosophy is in a form ready for examination.

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# Statement of Originality

*This is to certify that the content of this thesis is my own work. This thesis has not been submitted for any other degree or purpose.*

*I certify that the intellectual content of this thesis is the product of my own work, and that all assistance received in preparing this thesis and all sources have been acknowledged.*

Donna Akbari Harris

December 2025

# Generative AI Statement

No content produced by generative AI tools has been used in the preparation of this thesis.

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This research was supported by an Australian Government Research Training Program (RTP) Scholarship.

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Parts of the work presented in this thesis have been published and/or presented in the following forums:

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**Akbari, D.,** Bogaardt, H., & Docking, K. (2023). Ankyloglossia in Central Australia: Prevalence, identification and management in infants. *International journal of pediatric otorhinolaryngology*, *170*, 111604. https://doi.org/10.1016/j.ijporl.2023.111604

**Akbari, D.,** Bogaardt, H., Lau, T., & Docking, K. (2023). Ankyloglossia in Australia: Practices of health professionals. *International journal of pediatric otorhinolaryngology*, *171*, 111649. https://doi.org/10.1016/j.ijporl.2023.111649

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## Oral Presentations

**Akbari, D.,** Bogaardt, H., & Docking, K. Tied Tongues: Parents' Perspectives. Presented at: Australasian Society for Tethered Oral Tissues Conference; 2025 May 16; Melbourne, Australia [invited speaker]

**Akbari, D.,** Bogaardt, H., & Docking, K. Ankyloglossia in Australia: Practices of health professionals. Presented at: International Consortium of Ankyloglossia Professionals Conference; 2022 September 2; online [invited speaker]

**Akbari, D.,** Bogaardt, H., & Docking, K. Management of tongue tie in rural Australia. Presented at: Australasian Society for Tongue and Lip Ties Conference; 2022 September 1; Canberra, Australia [invited speaker]

**Akbari, D.,** Bogaardt, H., & Docking, K. Tongue tie in Central Australia: Prevalence and management – preliminary data results. Presented at: International Consortium of Ankyloglossia Professionals Conference; 2021 October 1; online (due to COVID-19) [invited speaker]

**Akbari, D.,** Bogaardt, H., & Docking, K. Tongue tie in Central Australia: Prevalence and management – preliminary data results. Presented at: Speech Pathology Australia National Conference; 2021 June 1; Darwin, Australia (presented via videoconference due to COVID-19)

**Akbari, D.,** Bogaardt, H., & Docking, K. Tongue tie in Central Australia: Prevalence, identification and management. Presented at: Sydney Swallowing Lab Symposium; 2019 October 3; Sydney, Australia (presented via videoconference)

# Abstract

Ankyloglossia can significantly disrupt infant feeding, yet its diagnosis and management in Australia remain inconsistent, fragmented, and poorly understood. Despite increasing global attention to ankyloglossia, Australian research remains sparse, with no previous comprehensive investigations examining how the condition is identified, managed, and experienced across metropolitan, rural, and remote settings. Existing studies are limited in scope, often focused on narrow clinical populations or specific professional groups, leaving substantial gaps in understanding the realities of care across the broader healthcare system. This lack of robust, context-specific evidence has contributed to wide variation in clinical practices, uncertainty among health professionals, and uneven access to timely assessment and intervention for families. In response to these gaps, this thesis provides the first integrated examination of ankyloglossia care in Australia, bringing together the perspectives of health professionals and parents, and examining the impact of geography, workforce variability, and the absence of national clinical guidelines on infant feeding outcomes and family experiences. Using a mixed-methods research design, this program of work investigates prevalence, clinical practice, and parental experience to build a holistic understanding of how ankyloglossia is identified, managed, and lived within diverse Australian contexts. Collectively, the findings illuminate the consequences of clinical variability, highlight barriers to accessing timely and evidence-informed care, and generate preliminary recommendations to support more consistent, equitable, and family-centred models of care.

Study One (Chapter Two) employed a retrospective clinical file audit to examine the prevalence, assessment practices, and management pathways for ankyloglossia among infants in Central Australia over a six-year period. This world-first investigation into ankyloglossia in a remote setting revealed significant variation in diagnostic approaches, highlighted gaps in care linked to staffing turnover and service constraints, and provided essential baseline evidence for understanding practice in rural and remote regions.

Study Two (Chapter Three) used an anonymous mixed-methods online survey to capture the diagnostic and management practices of health professionals across Australia.

Quantitative items documented patterns in clinical assessment, use of diagnostic tools, and confidence levels, while qualitative responses underwent thematic analysis to explore the reasoning behind practice variability. This study demonstrated substantial differences between professions, low confidence in diagnosis and management, and limited use of formal assessment tools, underscoring the need for clearer national guidance.

Studies Three and Four (Chapters Four and Five) used anonymous mixed-methods online surveys to investigate the experiences, perspectives, and decision-making of parents whose infants had been diagnosed with ankyloglossia anywhere in Australia. Chapter Four examined parents' interactions with a wide range of health professionals, the accessibility and clarity of information they received, their pathways to assessment and treatment, and their overall satisfaction with care. The findings revealed substantial variability in the quality and consistency of support offered to families, with many parents reporting delays in accessing knowledgeable clinicians, contradictory advice about breastfeeding and ankyloglossia, and uncertainty regarding the necessity or timing of intervention. These patterns underscored the emotional toll and logistical challenges families encounter when navigating a fragmented system of care.

Chapter Five built on these insights by exploring parental experiences of decision-making in greater depth, analysing the personal, practical, and informational factors that influence whether families pursue procedures such as frenotomy. Through thematic analysis of rich qualitative responses, this study highlighted how parents weigh conflicting professional recommendations, peer advice, perceived feeding difficulties, and their own confidence in interpreting clinical information. Many parents described feeling pressured to make rapid decisions, while others felt unsupported as they sought to reconcile differing views from lactation consultants, general practitioners, midwives, and specialists. Together, Studies Three and Four illuminate the human experience behind ankyloglossia management, demonstrate how professional variability directly translates into parental confusion and distress, and underscore the need for clearer communication, coordinated care pathways, and family-centred clinical guidance.

Finally, Chapter Six integrates findings across all studies, demonstrating the systemic and experiential gaps that shape ankyloglossia care in Australia. It proposes preliminary,

evidence-based recommendations for improving clinical consistency, strengthening workforce training, and informing the development of future national guidelines. Together, this thesis provides the first holistic account of ankyloglossia care in Australia, offering a foundation for policy development and future research aimed at improving outcomes for infants and families across metropolitan, rural, and remote settings.

# Dedication

This thesis is dedicated to the many infants across Australia diagnosed with ankyloglossia, and to their families, who continue to seek support, answers, and hope as they navigate this journey.

It is also dedicated to the health professionals and researchers who work tirelessly to ease the challenges faced by these infants and their loved ones in an often stressful and highly emotional time of their lives.

My hope is that this work will make a meaningful difference by deepening understanding, sparking reflection, and helping to light the way toward more compassionate and effective care for all infants with ankyloglossia facing feeding challenges.

# Acknowledgements

This journey has taught me that, although only one person is awarded the PhD certificate and the title of 'doctor,' completing a PhD is truly a team effort.

Firstly, to my amazing supervisors – I feel so fortunate to have shared this journey with you both over the years, and genuinely could not think of two better clinicians, academics and humans to have worked with on this project. Hans, thank you for being ever the optimist in every situation and believing wholeheartedly in me and this project. Thank you for the hours spent screen-sharing, and for your patience during statistics sessions. Kimberley, thank you for your constant encouragement, kindness and for always believing in me. You have been so generous with your time and expertise, and I can only hope and dream of one day being the calm force of wisdom that you are. Finally to Liz, thank you for your guidance and support in the 11th hour of this journey.

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This PhD isn't just mine, it's all of ours.

*Whatever you do, work at it with all your heart, as working for the Lord, not for human masters.*

Colossians 3:23.

# Authorship Attribution Statement

**Chapter Two** of this thesis has been published as: Akbari, D., Bogaardt, H., & Docking, K. (2023). Ankyloglossia in Central Australia: Prevalence, identification and management in infants. *International journal of pediatric otorhinolaryngology*, *170*, 111604. https://doi.org/10.1016/j.ijporl.2023.111604. I designed the study, analysed the data and wrote the drafts of the manuscript.

**Chapter Three** of this thesis has been published as: Akbari, D., Bogaardt, H., Lau, T., & Docking, K. (2023). Ankyloglossia in Australia: Practices of health professionals. *International journal of pediatric otorhinolaryngology*, *171*, 111649. https://doi.org/10.1016/j.ijporl.2023.111649. I designed the study, analysed the data and wrote the drafts of the manuscript.

**Chapter Four** of this thesis has been published as: Akbari, D., Bogaardt, H., & Docking, K. (2024). Ankyloglossia in Australia: Experiences and perspectives of parents and caregivers. *International journal of pediatric otorhinolaryngology*, *183*, 112046. https://doi.org/10.1016/j.ijporl.2024.112046. I designed the study, analysed the data and wrote the drafts of the manuscript.

**Chapter Five** of this thesis has been submitted for publication at *Advances in Communication and Swallowing* and is currently under peer review. I designed the study, analysed the data and wrote the drafts of the manuscript.

In addition to the authorship attribution statements above, in cases where I am not the corresponding author of a published item, permission to include the published material has been granted by the corresponding author.

Donna Akbari Harris

December 2025

As supervisor for the candidature upon which this thesis is based, I can confirm that the authorship attribution statements above are correct.

Kimberley Docking

December 2025

# Chapter 1

## Introduction

Although global awareness of ankyloglossia (tongue-tie) is increasing, critical gaps remain in our understanding of its prevalence, diagnosis, and management, particularly within an Australian context. These gaps are especially pronounced in rural and remote regions, where no studies have been conducted to date. Internationally, research into how health professionals identify and manage ankyloglossia is limited, and there is a complete absence of data focused on the clinical practices of health professionals managing this condition in Australia. Furthermore, no studies have explored how health professionals working in remote settings, either in Australia or abroad, approach this condition. Parental experiences are similarly underrepresented in the literature, with few studies examining how parents navigate the diagnostic and treatment process, and none within the Australian context. Despite increasing clinical and social attention, the management of ankyloglossia in Australia remains highly variable, with inconsistent approaches to both diagnosis and intervention. The voices of parents - those who must navigate this fragmented system on behalf of their children - are still largely unheard. Families living in rural and remote areas are particularly underrepresented in this narrative, despite facing additional challenges in accessing care, including high staff turnover, limited specialist availability, and a reliance on broadly trained generalist health professionals. These gaps carry significant implications for both families and clinicians, highlighting the importance of conducting research in the Australian context. Collectively, they point to an urgent need to understand ankyloglossia in Australia not only as a clinical issue, but as a lived experience shaped by access, geography, and the voices of families themselves.

## Ankyloglossia

### ***Definition***

Ankyloglossia, or tongue-tie, is traditionally defined as a congenital oral condition in which tongue movement is restricted by a shortened, thickened, or tightened lingual frenulum, or band, that connects the tongue to the floor of the mouth [1, 2]. Whilst the traditional definition of ankyloglossia remains the most common way of describing the condition in current literature, this understanding is gradually evolving. Anatomical and histological studies of cadavers have shown that the lingual frenulum is a midline fold

rather than a discrete band, as previously believed [3]. In addition to these anatomical definitions, a panel of ankyloglossia experts in the United States recently developed the Tongue-Tie Case Definition (TTCD) for infants, proposing that the condition be defined not only by anatomical features, but also by associated functional or behavioural impairments [4]. It is important to note that an observable or palpable lingual frenulum is considered normal and is common in infants and young children, so should not be considered ankyloglossia in the absence of functional impact [5].

In some literature, ankyloglossia has been described as either anterior or posterior, depending on the location of the frenulum's attachment to the ventral surface of the tongue. Anterior ankyloglossia generally refers to a visible frenulum that extends to, or near, the tip of the tongue and restricts tongue mobility [6]. In contrast, the definition and validity of posterior ankyloglossia remain the subject of considerable debate. Some authors describe it as a frenulum attaching to the posterior portion of the tongue, while others refer to a submucosal or less visible restriction. A number of experts, however, question whether posterior ankyloglossia represents a distinct anatomical entity at all, arguing that the term should be discontinued due to lack of consensus and anatomical clarity [7].

### *Prevalence*

Only one study to date has documented the prevalence and management of ankyloglossia in Australia [8], and no studies have been conducted in rural or remote regions. More broadly, there is also a complete absence of research on ankyloglossia in remote settings, both nationally and internationally.

The prevalence of ankyloglossia generally ranges in the international literature between 4.2% and 10.7% [9, 10], however, recent meta-analysis has found the range between 2% and 20%, with a prevalence of 7% for infants, 1% for children, and 2% for adolescents [11]. Ankyloglossia has consistently been reported to be more common in male infants by around 1.6 to 3-fold, based on international cohorts [12-14].

This large range exists due to the lack of consensus regarding diagnostic tools and practices, and likely reflects both under and over diagnosis of ankyloglossia [10]. It

should be noted that these figures are drawn from studies conducted outside of Australia, as national data on prevalence is currently limited.

### *Impacts*

The impacts of ankyloglossia in infants are most evident in the context of feeding, particularly breastfeeding. A systematic review and meta-analysis by Cordray et al [15] demonstrated strong associations between ankyloglossia and markers of breastfeeding difficulty. These included infant-related symptoms such as ineffective latch, rapid onset of feeding fatigue, inadequate weight gain, and even gastroesophageal reflux. Mothers were also found to experience a range of feeding-related difficulties, including nipple pain, engorgement, and tissue damage.

Beyond these physical challenges, the impacts of ankyloglossia extend into the emotional and psychological domains of maternal wellbeing. Difficulties with breastfeeding are frequently reported as sources of frustration and distress, with many mothers describing feelings of desperation, guilt, shame, or disappointment when feeding does not progress as hoped [16, 17]. Concerningly, these experiences are not only burdensome in the moment but may also undermine maternal confidence, strain the mother–infant bond, and have been linked to an increased risk of postpartum depression [16, 18, 19].

In addition to feeding difficulties in infants ankyloglossia has historically been linked to speech and oral development [20, 21]. However, recent literature shows no difference in tongue mobility or speech outcomes in young children regardless of intervention in infancy, and therefore does not support surgical treatment during this period solely to enhance later speech production [21, 22]. Ankyloglossia has additionally been linked to alterations in dental development, contributing to orthodontic issues such as malocclusion, open bite, and spacing between the mandibular incisors [23].

### *Diagnosis*

Although references to ankyloglossia appear in medical writings dating back centuries, ankyloglossia was generally diagnosed by sight alone [24, 25]. Only in recent decades

have clinicians shifted from basic anatomical descriptions to more structured, function-focused tools designed to capture the complexities of infant feeding. Despite this evolution, each diagnostic tool continues to present with a range of limitations, reflecting ongoing attempts to overcome long-standing challenges in achieving consistent and reliable assessment.

The Coryllos criteria is one of the earliest, widely cited systems for anatomical classification of ankyloglossia. This criteria categorises ankyloglossia anatomically based on the attachment site of the lingual frenulum, and provides classifications including anterior (types I and II) or posterior (types III and IV) [26]. Although this tool may be useful for anatomical description, its utility is limited in informing management decisions or predicting functional impairment or breastfeeding outcomes [5, 27, 28]. Similarly, Kotlow's classification was developed in response to a need for a simple, objective way to classify ankyloglossia based on anatomical characteristics [29]. This tool's primary focus is on the length of the 'free tongue', and classifies ankyloglossia into four grades of severity based on the distance from the tongue tip to the insertion of the lingual frenulum [29]. Whilst this tool is widely recognised and an objective measurement, similarly to the Coryllos criteria, it again focuses on anatomy rather than the function of the tongue's mobility within a feeding context [27].

The Bristol Tongue Assessment Tool (BTAT) was developed to provide a quick, simple and standardised method for assessing ankyloglossia in infants, particularly in the context of breastfeeding [30]. The BTAT evaluates four key items: tongue appearance, frenulum attachment to the lower gum ridge, tongue lift with the mouth open, and tongue protrusion [30]. Its pictorial adaptation, the Tongue-tie and Breastfed Babies Assessment Tool (TABBY), was created to make the BTAT assessment more visually intuitive, thereby improving inter-rater reliability and ease of use for healthcare professionals with varying levels of experience compared to the BTAT [31]. The BTAT and TABBY tools have been praised for their simplicity, speed and minimal training requirements, however, they do not include any functional assessment of feeding [31].

These anatomical tools – the Coryllos criteria, Kotlow's classification, and the BTAT and TABBY tools, primarily describe the frenulum itself without considering tongue function,

a key component of ankyloglossia diagnosis, and therefore results must be interpreted with caution.

Functional assessment tools were subsequently developed to address the significant gaps in ankyloglossia diagnosis left by tools solely describing anatomical indicators [27]. Such tools aimed to evaluate tongue function and feeding, providing clinicians with a more meaningful foundation for informed clinical decision-making. These tools systematically evaluate tongue mobility, strength and effectiveness during clinically relevant tasks such as breastfeeding, sucking, or speech. Among the most currently used tools are the Hazelbaker Assessment Tool for Lingual Frenulum Function (HATLFF), and the Lingual Frenulum Protocol for Infants (LFPI). Each tool offers distinct advantages in terms of objectivity, ease of use, and relevance to clinical decision making, while also carrying limitations related to subjectivity, and scope of assessment.

The HATLFF was developed from a need to overcome the limitations of the anatomically focused Coryllos and Kotlow tools by providing a formal, standardised method to assess ankyloglossia in infants, incorporating items that assess function, particularly in the context of breastfeeding [27, 32]. The infant-specific tool combines appearance criteria (e.g. frenulum length, elasticity, attachment) with function criteria (e.g. lateralisation, tongue life, cupping), and provides a scoring system to support clinical decision making [33]. Whilst some items in this tool have demonstrated good inter-rater reliability, studies have also highlighted poor agreement on certain functional items, raising concerns about consistency of use amongst clinicians [32]. The HATLFF has further been critiqued as being challenging to use and unsuitable as a quick screening tool in fast-paced hospital environments [34].

The LFPI was developed to provide a standardised, comprehensive assessment of both anatomical and functional aspects of the lingual frenulum infants [35-37]. This tool has recently been recognised as the most reliable and valid tool for evaluating tongue structure and function in infants and is considered the most comprehensive instrument for diagnosing ankyloglossia [38]. It is specifically designed to assess tongue movements that are crucial for effective breastfeeding. The protocol incorporates distinct sections addressing breastfeeding parameters, including nutritive and non-nutritive sucking, alongside overall breastfeeding skills [35]. These components collectively produce a

score that aids in identifying alterations of the lingual frenulum and supports the clinical diagnosis of ankyloglossia. Whilst the LFPI is the most comprehensive tool for ankyloglossia diagnosis available at present, more research is needed to establish how assessment results translate into long-term management and intervention pathways [38].

In practice, the HATLFF and LFPI are often used alongside informal functional assessments, which can vary widely among health professionals [39]. Despite the availability of these tools, significant challenges remain. Globally, a standardised approach to diagnosing ankyloglossia has yet to be established, with ongoing disagreement over appropriate diagnostic tools [10]. None are considered fully reliable or standardised, and there is still no consensus on a preferred grading system or diagnostic tool for ankyloglossia [7]. This lack of consistency creates uncertainty for clinicians, and leaves families navigating unclear or conflicting advice, potentially affecting management decisions and care experiences. These gaps underscored a need for research as outlined in the proceeding thesis examining how inconsistent assessment practices influence both clinical outcomes and parental experiences.

### *Management*

The primary treatment types for ankyloglossia available can be classified into two approaches: non-surgical treatments and surgical treatments. To date, there have been no standardised management guidelines, either internationally or within Australia. This absence of clear, evidence-based guidance contributes to substantial variability in clinical practice, with clinicians differing in how they assess ankyloglossia, determine treatment eligibility, and provide follow-up care. For families, this inconsistency can create confusion, uncertainty, and conflicting advice, which may affect timely decision making and satisfaction with care. These gaps highlighted the urgent need for high-quality research that integrates the perspectives of both parents and health professionals, to inform the development of evidence-based treatment pathways and ultimately establish standardised guidelines that enhance clinical consistency and support positive family experiences of care.

### Non-surgical management

It has been widely reported in the existing literature that non-surgical treatment options should be considered prior to proceeding with or considering surgical treatment options [39, 40]. Non-surgical treatments for ankyloglossia are typically delivered by trained health professionals, including International Board-Certified Lactation Consultants, midwives, child health nurses, speech-language pathologists, and, in some cases, alternative practitioners such as chiropractors and osteopaths [39, 41]. These interventions commonly focus on supporting effective feeding, through strategies such as positional adjustments, optimisation of the infant's latch, and the use of external aids like nipple shields or supplementary nursing systems. In addition to these conventional approaches, some families also explore complementary therapies, including bodywork and craniosacral therapy, to address feeding difficulties associated with tongue-tie [39, 41, 42].

### Surgical management

Surgical management of ankyloglossia can be divided into two modalities – frenotomy and frenuloplasty. The most commonly provided surgical management for ankyloglossia involves a conventional frenotomy, in which the lingual frenulum is divided using scissors or a scalpel [43-49]. This procedure is generally considered to be conservative and simple [50]. More recently, there has been an increase in the use of frenotomy procedures using lasers [51]. The use of laser frenotomy in the surgical management of infants with ankyloglossia has been acknowledged by the American Academy of Pediatric Dentistry [52]. Within the available literature, diode, neodymium, carbon dioxide, and erbium lasers have been used for the procedure, with diode lasers being the preferred tool for the surgery of oral soft tissues, as well as for their relative costs [47, 49, 53, 54]. Frenuloplasty is considered to be more complex than frenotomy, and generally refers to rearranging tissue or adding grafts after making incisions and closing the resultant wound in a specific pattern to lengthen the anterior tongue. Specific types of frenuloplasty include Z-frenuloplasty, horizontal-to-vertical frenuloplasty, and horizontal frenuloplasty. Frenuloplasty is most commonly performed under a general anaesthetic and used in older infants and children or in more complex repairs [43].

In Australia, common practice is for surgical management of ankyloglossia to be carried out by paediatricians, otolaryngologists, and midwives. However, in recent years with the rise of laser frenotomy procedures, there has been an increase in frenotomy procedures conducted by paediatric dentists in private clinics. The literature demonstrates considerable variation in surgical management of ankyloglossia both between and within professional groups [55, 56]. For example, notable differences have been reported in frenotomy rates, as well as in preferences for clinic-based versus operating room procedures among otolaryngologists [55]. Similarly, a recent survey of paediatric dentists, otolaryngologists and surgeons identified variations within and across specialities regarding the age at which awake frenotomy is performed, choice of analgesia, and selection of surgical technique [56].

Pre- and post-operative care for ankyloglossia, including active wound management through stretching and strengthening exercises, has been reported to support healing, reduce re-attachment, and improve tongue function and mobility [57]. Active wound management typically involves stretching the diamond-shaped wound under the tongue to promote vertical, rather than horizontal healing, and thus avoiding reattachment [58]. Strengthening exercises commonly include encouraging tongue lateralisation by running a finger along the infants lower gum line to guide side to side movement, as well as allowing the infant to suck on a finger while gently applying resistance and slowly withdrawing it, prompting the tongue to engage and strengthen [58, 59]. It should be noted that there is no overall consistency in the active wound management of ankyloglossia [40].

A recent scoping review highlighted that when frenotomy is performed in conjunction with pre- and post-operative care, improvements have been reported across a range of outcomes such as breastfeeding, speech or articulation, sleep, tongue structure and function, weight gain, reflux, wound healing and posture [51]. Importantly, this body of evidence relates primarily to minor post-operative issues, as the review found that frenotomy combined with supportive care was associated with low recurrence of ankyloglossia and only minor post-operative complications [51]. Despite these relatively positive outcomes, no universally accepted guidelines exist, and care protocols are inconsistently described in the literature, with limited high-quality evidence to determine

the most effective approaches [40, 57, 60]. Consequently, a variety of practices are employed by health professionals, and there is a significant gap in knowledge and consensus regarding which regimens are most effective and how confident clinicians are in their application.

When frenotomy is considered more broadly, outside the context of specific pre- or post-operative care protocols, complications have been documented throughout the literature. Overall, frenotomy procedures have been generally considered a safe and effective procedure for the management of ankyloglossia-related breastfeeding challenges, however, complications such as bleeding, airway obstruction, scarring and oral aversions do appear across studies [7, 61-65].

### *Rural and remote health*

Understanding the role geography plays in determining how families access and experience healthcare is essential when examining the diagnosis and management of ankyloglossia across Australia. This is particularly relevant for families in rural and remote areas, where high staff turnover, limited access to specialist services, and reliance on generalist practitioners can affect continuity of care and restrict timely, coordinated multidisciplinary management of many medical conditions [8, 66, 67].

Central Australia represents a distinctive rural context, home to almost 40,000 people across an expansive catchment of 827,861 square kilometres, encompassing the key townships - Alice Springs and Tennant Creek - as well as numerous surrounding communities and outstations [68, 69]. As a geographically vast, sparsely populated region with complex service delivery challenges, Central Australia offers an important and representative lens through which to understand ankyloglossia care in rural and remote areas more broadly. Despite its size and diversity, this region is notably underrepresented in the literature, leaving the prevalence of ankyloglossia in Central Australia unknown. Kapoor and colleagues [8] reported 22 surgically managed cases of ankyloglossia in the Northern Territory in 2016 [8]; however, as this figure was drawn from Medicare records, it likely does not accurately reflect Central Australia, where reliance on the public health system means Medicare rebates are often not applied [70]. The small

sample size further limits the generalisability of these findings, making them insufficient for drawing broader conclusions about ankyloglossia management in the region.

The Modified Monash Model (MMM) is used to classify locations across Australia based on both geographic remoteness and population size, on a scale of Modified Monash (MM) categories MM 1 to MM 7, where MM 1 is a major city and MM 7 is very remote. These remoteness classifications are based on the Australian Statistical Geography Standard – Remoteness Areas framework [71]. Central Australia is categorised as MM6 (Remote) for much of its population, with some areas designated as MM7 (Very Remote), classifications that are highly relevant to understanding the health care contexts within this catchment.

In the context of ankyloglossia, the MMM provides a useful framework for examining how the geographic location of families and health professionals influences access to assessment, diagnosis and treatment [72]. This framework is particularly relevant, as families living in areas classified as rural and remote face unique workforce challenges. These services often experience high rates of staff turnover, limited access to specialist physicians, and a greater reliance on generalist health professionals to meet diverse community needs [73-76]. These factors can disrupt continuity of care and restrict access to specialised assessment and management, particularly for conditions like ankyloglossia that often require coordinated, timely multidisciplinary input [73, 75, 76]. Applying the MMM therefore enables a clearer understanding of how geographic context shapes parents' experiences when seeking care for their infants, and helps to contextualise the geographical inequities that contribute to variability in ankyloglossia management across Australia.

### *The controversy*

A key point of contention in the diagnosis and management of tongue-tie lies in the intersection between rapidly proliferating social-media discourse and divergent professional opinion. On one hand, online parent forums and social-media platforms have amplified anecdotal accounts of dramatic improvement following frenotomy, creating heightened awareness, and at times, pressure, for intervention. A qualitative

study of X posts (formerly known as Twitter) found that from 2009 to 2018 tweets about ankyloglossia and frenotomy increased by 2395%, and among provider posts, 94.4% expressed a pro-frenotomy sentiment [77]. Simultaneously, research analysing social-media content found that only 11.3% of posts on Instagram contained no misinformation, raising concerns about the quality and veracity of information families receive online [66]. On the other hand, as previously established, within the clinical domain there remains a lack of consensus around the definition, classification, functional significance and management of ankyloglossia - no universally validated diagnostic system exists, and treatment indications vary considerably.

The controversy is further fuelled by marked increases in reported surgical interventions, such as the documented 420% rise in frenotomy claims in Australia over a decade, despite limited high-quality evidence for long-term outcomes [8]. Thus, the social-media narrative tends to emphasise “quick fix” surgical solutions and dramatic outcomes, while the scientific and clinical narrative emphasises careful functional assessment, conservative management, and consideration of over-diagnosis and overtreatment. The resulting disjunction means parents and health professionals navigate not only a complex evidence base but also emotionally charged and sometimes commercially amplified messaging, making informed shared decision-making especially challenging in this field.

## Overarching aims

Ankyloglossia can profoundly disrupt infant feeding, yet its identification and management in Australia remain inconsistent and poorly understood. Addressing these gaps is critical for improving the quality and consistency of care, reducing unwarranted practice variation, and ensuring families receive timely, evidence-informed support. The studies that have been conducted within this thesis bring together the perspectives of both health professionals and parents to build a clearer understanding of current practice, lived experience, and service accessibility. This thesis therefore aims to provide the first comprehensive exploration of how ankyloglossia is identified, managed, and experienced within the Australian healthcare context.

Specifically, this research explores how Australian health professionals assess and manage ankyloglossia - highlighting variations in practice, professional training, and approaches to parent education. Gaining insight into these clinical perspectives is essential, as variability in assessment and management of ankyloglossia can contribute to health inequity, delays in appropriate treatment and uncertainty for parents seeking support.

These studies also explore the experiences of parents and caregivers whose infants have been diagnosed or treated for ankyloglossia, examining their interactions with health professionals, access to treatment options, perceptions of care outcomes, and the factors influencing their decision-making around treatment. Understanding these experiences is essential, as parental perceptions and the quality of support they receive directly shape feeding outcomes, influence treatment uptake, and highlight gaps in communication and service provision. These insights are critical for informing more responsive, family-centred models of care and reducing the uncertainty many parents face when navigating ankyloglossia for their infant.

Finally, this thesis presents a world-first report on the prevalence and management of ankyloglossia among infants in Central Australia, providing important insights into the realities of care in rural and remote regions. This evidence is vital, as it highlights how geographical context shapes service delivery, clinical decision-making and equity of access – factors that must be understood to improve outcomes for families outside major metropolitan centres.

Collectively, the findings of this thesis aim to inform the development of consistent, evidence-based, and equitable models of care for infants and their families affected by ankyloglossia across Australia.

The overarching aims of this thesis can be summarised as follows:

1. To determine the prevalence of ankyloglossia in infants over time in a rural Australian setting

2. To describe the patterns of clinical assessment and management practices for ankyloglossia across Australia

3. To explore Australian parents' experiences and satisfaction with the care their infant received, including treatment, access to information, and interactions with health professionals
4. To formulate preliminary, evidence-based recommendations for Australian health professionals, parents and policy makers to assist with ankyloglossia diagnosis and management decisions, pending the development of formalised guidelines

## Methodological approach

As previously outlined, the identification and management of ankyloglossia in Australia is complex, influenced by factors such as geography, the absence of clinical guidelines, workforce variability, and differences in professional training and practice. Addressing these challenges required drawing on diverse sources of information, and multiple approaches, as the lack of standardised guidance places significant pressure on parents seeking answers and on health professionals striving to deliver safe, consistent care.

This complexity underscored the need for rigorous, multifaceted research into ankyloglossia care in Australia. In response, this program of work examined several critical areas: the prevalence of ankyloglossia and the practices surrounding its diagnosis and management in a rural and remote region of Australia, the practices and decision-making of health professionals involved in diagnosing and managing ankyloglossia, and the perspectives of parents and carers whose infants received a diagnosis. Together, these lines of inquiry were designed to build a comprehensive understanding of how ankyloglossia is identified and managed across diverse contexts, and to illuminate the systemic and experiential gaps that currently shape the care journey for Australian families.

To meet this gap in knowledge, this thesis employs a combination of methods, including a retrospective file audit, and anonymous online surveys incorporating multiple choice items, Likert scales and open- ended questions. These tools captured both quantitative and qualitative data from health professionals across Australia, as well as from parents whose infants have been diagnosed with ankyloglossia and have navigated the diagnostic and management process on their behalf.

In Chapter Two, a retrospective file audit explored and analysed real-world clinical practice in the assessment and management of ankyloglossia, using existing records to capture patterns in diagnosis and treatment. This method was essential to capture infants diagnosed with ankyloglossia over a six-year period and consider changes in staffing, particularly given the high turnover of health professionals in rural and remote settings. This approach was particularly valuable for studying infants in rural and remote settings, where prospective recruitment is challenging due to the geographically dispersed population. It also allowed for identification of gaps in care, variability between clinicians, and opportunities for quality improvement, all while maintaining the confidentiality of a vulnerable infant population through de-identified data [67].

A mixed-methods approach using surveys was employed throughout this body of work, in Chapters 3 to 5. A quantitative survey was deemed an appropriate method for gathering information about the practices of health professionals working with infants diagnosed with ankyloglossia as it allowed for the systematic collection of data from a large and geographically dispersed sample. Given that health professionals are located across metropolitan, rural, and remote areas, the survey format facilitated efficient participation without the logistical constraints of face-to-face or telephone interviews. The anonymous survey also included open ended questions, which encouraged honest responses about clinical practice, professional knowledge, and decision-making, reducing social desirability bias and concerns about professional scrutiny [78, 79]. Incorporating both quantitative and qualitative components enabled the collection of structured data for statistical analysis, while also capturing contextual insights into practice patterns and reasoning that could not be conveyed through numerical data alone [80]. The qualitative survey responses were analysed using thematic analysis, which provided a flexible and rigorous method for constructing, examining, and reporting patterns and themes within the data [81]. This approach enabled the systematic organisation of complex and unique insights from health professionals, the exploration of both shared experiences and divergent perspectives, and the integration of these insights with quantitative findings to provide a comprehensive understanding of current professional practice [81].

To complement this approach, a mixed-methods survey with both quantitative and qualitative analysis was used to gather information from parents about their perspectives and experiences of ankyloglossia. Recognising that parents are often time poor, an anonymous online survey provided a flexible and accessible way for this population to participate at their convenience. This approach also enabled the inclusion of parents from diverse backgrounds and across all geographical areas of Australia, ensuring representation from a wide range of experiences and contexts. The combination of multiple choice questions and open-text responses allowed the study to capture both measurable trends and the nuanced, personal experiences of parents navigating the diagnostic and management process for their infants with ankyloglossia. The open text responses from parents were analysed using thematic analysis, which facilitated the construction of recurring themes, highlighted important patterns in parental experiences, and provided rich context to complement and deepen the understanding gained from the quantitative data [81].

Overall, using a combination of the above approaches strengthened this body of work by capturing the perspectives of diverse stakeholders involved in ankyloglossia care in Australia. Surveys enabled broad geographic reach and the inclusion of diverse experiences and viewpoints, while also accommodating the limited time availability of both health professionals and parents – many of whom may have been unable to participate in interviews or focus groups [82, 83]. This approach also enabled the capture of a broader range of perspectives, providing breadth of understanding that would have been difficult to obtain through interview-based methods alone. Together, these methods facilitated a comprehensive understanding of current practice, parental experiences, and the factors influencing decision-making, thereby enhancing the relevance, validity, and applicability of the study findings.

## The Studies & Thesis Structure

This body of work addresses a debated and poorly understood area of infant care – management of ankyloglossia [41, 84]. This thesis represents a comprehensive program of research designed to address the urgent need for evidence-based approaches to

ankyloglossia care in Australia. Through a series of interconnected studies, it systematically explores prevalence, professional practices, and parental experiences, culminating in recommendations for improving clinical consistency and equity. By integrating insights from both health professionals and families, this research identifies the practical implications of current gaps in care, and the real-world consequences these have for infant feeding and family wellbeing. The findings in this thesis underscore the pressing need for coordinated multidisciplinary efforts to support clearer assessment pathways and more accessible care. Ultimately, this body of work provides a foundation for future policy development, workforce training, and research that can meaningfully improve outcomes for infants and families in Australia.

The first study in this thesis, Chapter Two, establishes the prevalence and management practices in a remote region of Australia, highlighting systemic gaps. Building on these findings, the second study, Chapter Three, investigates professional practices nationally, providing context for these gaps and revealing variability in clinical confidence. The third and fourth studies, Chapters Four and Five, shift focus to parents, exploring their experiences and decision-making, offering insight into the impact of clinical variability on families within a fragmented system. This is the first research to examine ankyloglossia in remote Australian settings and the first to integrate both professional and parental perspectives into a unified analysis. Collectively, these studies provide the first holistic understanding of ankyloglossia care in Australia, demonstrating the necessity of evidence-based, coordinated approaches to assessment and management. By generating actionable insights for policy development, workforce training and clinical practice, this body of work lays the foundation for more consistent, equitable, and family-centred care for infants affected by ankyloglossia across diverse Australian contexts.

The first study (**Chapter Two)** delivers a world-first report on the prevalence and management of ankyloglossia for infants in Central Australia – a region previously absent from research literature. Only a limited number of studies have examined how health professionals diagnose and manage ankyloglossia internationally [27, 85], and none have focused specifically on practices within Australia. Moreover, no research has

investigated how ankyloglossia is identified and managed by clinicians working in remote settings, either in Australia or abroad. Developing a clearer picture of diagnostic and management practices across diverse healthcare contexts in Australia is essential for creating clinical guidelines that are responsive to the realities and resource constraints of all practice settings, including rural and remote areas.

The foundational work in Chapter Two highlights systematic challenges in remote healthcare and sets the stage for exploring broader national patterns and policy development and aims to inform future health care and the development of policies to meet the needs of rural health care settings in Australia. Given its vast geography, sparse population and complex service delivery environment, Central Australia constitutes an instructive setting from which to examine ankyloglossia care in rural and remote contexts. Its geographic isolation and dependence on public health services render it a valuable catchment for producing insights applicable to comparable regions across Australia. Thus, the initial investigation into the diagnosis and management of ankyloglossia in the remote region of Central Australia serves as a foundational step in revealing broader gaps within the national evidence base. In particular, it highlights the need for further research into the specific health professionals involved in the identification and management of ankyloglossia across Australia, as well as the diverse clinical practices they employ in the absence of consistent national guidelines.

Building on these insights, **Chapter Three**, examines the practices and perspectives of health professionals across Australia, revealing variability in diagnostic approaches, confidence levels, and management strategies.  It was hypothesised that (i) opinions about ankyloglossia varied between professions, (ii) the diversity of professions involved in the diagnosis and management of infants with ankyloglossia was numerous, (iii) the majority of clinicians do not use established tools to guide management of babies with suspected ankyloglossia and (iv) clinicians would have low confidence in their skills due to a lack of standardised diagnostic and management guidelines. Reporting on the current ankyloglossia diagnostic, management, and educational practices of health professionals in Australia informs the future development of policies to standardise processes nationally.

While investigating the clinical practices of health professionals involved in the diagnosis and management of ankyloglossia revealed significant variability and a lack of standardised approaches, important questions were raised regarding how such inconsistencies impact the care families navigating this condition receive for their infants. In particular, when health professionals offered differing assessments, recommendations, and treatment pathways, parents were often left to interpret conflicting information and make complex decisions on behalf of their children, frequently without clear guidance. The absence of clearly defined diagnostic criteria and treatment guidelines for ankyloglossia raised critical concerns for informed consent, and may have shaped parents' perceptions of treatment outcomes. Parents reported frustration with barriers to assessment, diagnosis, and management, as well as inconsistencies in healthcare provider knowledge and recognition of ankyloglossia's impact on breastfeeding [16, 86]. This highlighted a critical gap in the literature: the need to understand how parents experience and respond to the diagnostic and treatment process within this fragmented clinical landscape. As such, exploring parental perspectives emerged as a necessary next step in developing a more holistic understanding of ankyloglossia care in Australia, particularly in terms of how the professional practices of health professionals influence parental decision-making, confidence, and satisfaction with care.

The next phase of this program of research shifts the focus to families. **Chapter Four** explores parental experiences of navigating the diagnostic and treatment process, providing rich insight into how clinical variability impacts decision-making and satisfaction with care. This chapter contributes valuable knowledge about the perspectives of Australian parents and caregivers whose infants have been diagnosed with ankyloglossia, offering evidence that can inform more consistent, supportive and family-centred care. Given the significance of obtaining informed consent and providing patient-centred healthcare, this study investigated the viewpoints and experiences of parents whose infants were diagnosed with ankyloglossia in Australia. The study posited the following hypotheses: (i) parental experiences would exhibit regional variations throughout Australia; (ii) a wide array of professions would be involved in diagnosing and

managing infants with ankyloglossia; and (iii) parents would express dissatisfaction with the care their infant received.

Findings from the study of parental perspectives revealed not only the emotional and logistical challenges families face, but also the critical role parents play in treatment decision-making, often in the absence of clear and consistent clinical guidance. Parents described feeling uncertain, conflicted, and in some cases pressured, as they navigated varying professional opinions, anecdotal information, and social influences when deciding whether to pursue treatment, such as frenotomy, for their child. These insights underscored the need to explore, in greater depth, how parents make treatment decisions, what factors shape their choices, and how they weigh risks, benefits, and professional advice in the context of inconsistent care pathways. As a result, a focused examination of parental decision-making processes became a necessary progression in understanding the broader impact of clinical variability on family experiences and outcomes.

Through the previous chapters, it became increasingly evident that in Australia, the clinical management of ankyloglossia is highly variable, with healthcare providers employing diverse approaches to both diagnosis and treatment (Chapters Three and Four) [42, 87]. Although the condition has received growing clinical attention, little research has explored how parents experience navigating this process on behalf of their children. Understanding these parental perspectives is crucial for refining care pathways, improving communication between providers and families, and strengthening support for parents [86]. While international studies have examined parental views on ankyloglossia management, often through social media platforms [77], no Australian research had directly investigated the lived experiences of parents managing their child's diagnosis and treatment.

**Chapter Five** deepens this exploration by examining parental decision-making in detail, uncovering the personal, practical, and informational factors that shape choices about interventions such as frenotomy. Together, Chapters Four and Five illuminate the human

dimension of ankyloglossia care and highlight the consequences of fragmented clinical pathways. As there have been no Australian studies directly exploring the lived experiences of parents managing the process of ankyloglossia management, this final study addresses this gap by examining the experiences of Australian parents whose infants have undergone treatment for ankyloglossia, with particular attention to: (i) their interactions with healthcare providers, (ii) their access to different treatment options, (iii) their perceptions of treatment outcomes, and (iv) their personal experiences throughout the care pathway and beyond.

Finally, **Chapter Six** synthesises findings across all studies, drawing out implications for clinical practice, workforce training, policy development, and future research. It proposes preliminary recommendations for improving consistency and equity in care, laying the groundwork for future national guidelines. Collectively, this program of research not only fills critical evidence gaps but also provides a roadmap for transforming ankyloglossia management in Australia – empowering health professionals with greater confidence and creating a more reassuring, compassionate experience for parents, caregivers and their infants.

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# Chapter 2

## Ankyloglossia in Central Australia: prevalence, identification and management in infants

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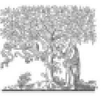

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### Ankyloglossia in Central Australia: Prevalence, identification and management in infants

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A R T I C L E  I N F O

*Keywords:*
Infant
Ankyloglossia
Feeding
Tongue tie
Lingual frenulum
Breastfeeding
Prevalence

A B S T R A C T

*Purpose:* To investigate the prevalence and management of ankyloglossia for infants in Central Australia.
*Method:* Retrospective chart review consisting of a medical file audit of infants (n = 493) <2 years old diagnosed with ankyloglossia from January 2013 to December 2018 in the primary hospital in Central Australia. Patient characteristics, reason for diagnosis, reason for procedure and outcomes of procedures routinely recorded in the patient clinical files were recorded.
*Results:* The overall prevalence of ankyloglossia in this population was 10.2%. Frenotomy was performed in 97.9% of infants diagnosed with ankyloglossia. Infants with ankyloglossia were more likely to be male (58% vs 42%), diagnosed and managed with a frenotomy on the third day of life. Most ankyloglossia diagnoses were identified by a midwife (>92%). Most frenotomy procedures were completed by lactation consultants who were also midwives (99%) using blunt-ended scissors. More infants were classified with posterior ankyloglossia than anterior ankyloglossia (23% vs 15%). A frenotomy procedure resolved feeding issues in 54% of infants with ankyloglossia.
*Conclusions:* The prevalence of ankyloglossia and rate of frenotomy procedures were high when compared to previous reports in the general population. Frenotomy for ankyloglossia in infants with breastfeeding difficulties was found to be effective in more than half of the reported sample, improving breastfeeding and decreasing maternal nipple pain. A standardised approach and validated screening or comprehensive assessment tool for the identification of ankyloglossia is indicated. Guidelines and training for relevant health professionals on non-surgical management of the functional limitations of ankyloglossia are also recommended.

#### 1. Introduction

Ankyloglossia (also known as tongue-tie) refers to the limited movement of the tongue causing functional limitations, as well as a visually restricted lingual frenulum [1]. The anatomy of the lingual frenulum has recently been described as a structure formed by the dynamic elevation of a midline fold in the floor of mouth fascia; not a band or cord, as it has previously been described [2]. Whilst these definitions are used most frequently, there are no established universal criteria. The cause of ankyloglossia is unknown and requires further investigation, however, literature has reported hypotheses of an association between higher frequencies of pre-conception folic acid intake, as well as a genetic link [3,4].

The role of the health professionals in ankyloglossia assessment and management has not been well-defined through published position papers or clinical guidelines by professional bodies internationally. The Academy of Breastfeeding Medicine, American Academy of Otolaryngology and the Canadian Paediatric Society's publications on ankyloglossia and breastfeeding highlight the feeding difficulties that can arise as a result of ankyloglossia, and outline the importance of a multidisciplinary approach to diagnosis and management, however, do not specify the specific roles of health professionals [5–7]. As ankyloglossia can impact an infant's feeding ability, many health professionals provide vital contributions to ankyloglossia assessment and management.

Prevalence rates of ankyloglossia have been reported to range between 0.02% and 11% [8–10]. Various tools have been established to identify, rate the severity of and determine the need for management of ankyloglossia. These tools lack reliability and standardisation and are

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I, Donna Akbari Harris, made the following contributions:

- Designed the study with support from the supervisory team.
- Extracted the data
- Conducted the analysis
- Drafted and completed the manuscript with critical feedback and revision from the supervisory team.

The International Journal of Pediatric Otorhinolaryngology requires that the lead author must be the corresponding author.

As primary supervisor for the candidature upon which this thesis is based, I can confirm that the authorship attribution statements above are correct.

Associate Professor Kimberley Docking

Faculty of Medicine and Health

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I, Donna Akbari Harris, as the candidature student, confirm that the authorship attribution statements above are correct.

Donna Akbari Harris

December 2025

**Ankyloglossia in Central Australia: Prevalence, Identification and Management in Infants**

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**Running head:** Ankyloglossia in Central Australia

**Abstract**

*Purpose*: To investigate the prevalence and management of ankyloglossia for infants in Central Australia.
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**Keywords**

Infant, ankyloglossia, feeding, tongue tie, lingual frenulum, breastfeeding, prevalence

## Introduction

Ankyloglossia (also known as tongue-tie) refers to the limited movement of the tongue causing functional limitations, as well as a visually restricted lingual frenulum[1]. The anatomy of the lingual frenulum has recently been described as a structure formed by the dynamic elevation of a midline fold in the floor of mouth fascia; not a band or cord, as it has previously been described[2]. Whilst these definitions are used most frequently, there are no established universal criteria. The cause of ankyloglossia is unknown and requires further investigation, however, literature has reported hypotheses of an association between higher frequencies of pre-conception folic acid intake, as well as a genetic link[3, 4].

The role of the health professionals in ankyloglossia assessment and management has not been well-defined through published position papers or clinical guidelines by professional bodies internationally. The Academy of Breastfeeding Medicine, American Academy of Otolaryngology and the Canadian Paediatric Society's publications on ankyloglossia and breastfeeding highlight the feeding difficulties that can arise as a result of ankyloglossia, and outline the importance of a multidisciplinary approach to diagnosis and management, however, do not specify the specific roles of health professionals[5-7]. As ankyloglossia can impact an infant's feeding ability, many health professionals provide vital contributions to ankyloglossia assessment and management.

Prevalence rates of ankyloglossia have been reported to range between 0.02% to 11%[8-10]. Various tools have been established to identify, rate the severity of and determine the need for management of ankyloglossia. These tools lack reliability and standardisation and are therefore a likely contributor to the broad prevalence rates reported.

Ankyloglossia can be classified as anterior or posterior, based on where the frenulum is attached on the ventral surface of the tongue[11]. Anterior ankyloglossia encompasses two types: Type I where the insertion of the lingual frenulum is on the top of tongue; and Type II, where the insertion of the lingual frenulum is slightly behind the tongue tip[12]. Posterior ankyloglossia also encompasses two types: Type III where the lingual frenulum is located inferiorly at the mid-tongue; and Type IV where the lingual frenulum is not visible, referred to as a submucosal frenulum[12]. The severity of ankyloglossia has also been classified using measurements of the lingual frenulum, as outlined byKotlow [13], who suggested that lingual frenulum lengths between 0 and 16mm be given severity ratings of mild, moderate, severe and complete, in increments of 4 mm. These tools were designed to describe the lingual frenulum appearance but do not assess tongue function.

The Hazelbaker Assessment Tool for Lingual Frenulum Function (ATLFF) assesses infants with ankyloglossia through five appearance items and seven function items[14]. The ATLFF was designed to determine the severity and extent of ankyloglossia[15]. The tool has been found to have a high inter-rater reliability within the appearance component and in providing

a recommendations for frenotomy, however, the researchers reported a lack of agreement on the function items related to infant sucking, and suggested that the function items should be altered[15]. Similarly to the ATLFF, the Lingual Frenulum Protocol for Infants consists of a two-part protocol designed to evaluate the lingual frenulum in infants[16]. The first section contains a clinical history with specific questions about breastfeeding, and the second part includes a clinical examination of the tongue, and sucking evaluations. This tool was established to assess and diagnose anatomical differences of the lingual frenulum, and identify the possible impacts of these on breastfeeding.

The Bristol Tongue Assessment Tool (BTAT) was developed using principles from the ATLFF to rate severity of ankyloglossia[17]. The BTAT is a four item, eight-point assessment tool which measures tongue tip appearance, attachment of the frenulum to the lower gum ridge, lift of tongue with mouth wide and protrusion of tongue[17]. An adjunct to the BTAT is The Tongue-tie and Breastfed Babies (TABBY) assessment tool, that was developed to provide a pictorial representation of the BTAT[18].

Ankyloglossia is asymptomatic in most infants, however, it has been recognised as a condition that results in breastfeeding difficulties in 12 to 44% of infants with ankyloglossia[19]. Ankyloglossia may restrict the movement of the tongue, causing significant functional impairments in infants, including poor latch, sucking mechanics, breastmilk transfer and maternal nipple pain and trauma while breastfeeding[5, 6, 20].

There is a vast disparity of opinions among health professionals regarding management of ankyloglossia[21]. Currently, frenotomy is the primary intervention used to manage ankyloglossia. Frenotomy for ankyloglossia is a procedure where the lingual frenulum is divided either in the midline or at the underside of the tongue, using sharp blunt-ended scissors[21]. Other less common surgical procedures to manage ankyloglossia include frenuloplasty - releasing and suturing the lingual frenulum, Z-plasty – releasing the frenulum and creating flaps and suturing these, and laser interventions – used by dentists to ablate and separate the frenulum tissue[22, 23]. Further research is required to support claims regarding the superiority of frenotomy techniques[7]. Surgical management should be undertaken by appropriately trained health professionals within appropriate clinical settings. These settings must be equipped to manage possible complications[1].

Non-surgical interventions can be provided by relevant, trained health professionals such as International Board Certified Lactation Consultants (IBCLCs), midwives, child health nurses and speech-language pathologists[1, 24]. Non-surgical managements of breastfeeding difficulties arising from ankyloglossia include strategies such as positional changes, the alteration of feeding frequency, providing support to mothers to maintain a milk supply, latch optimisation and the use of external tools such as nipple shields or supplementary nursing systems[1].

An increase of 420% in the rate of frenotomy procedures was reported in Australia between 2006 to 2016[25]. These increasing rates of frenotomy have also been mirrored internationally

in Canada and the United States, at rates of increase as high as 400% and 866% respectively[8, 26]. A lack of standardised indications for the procedure have also been highlighted in recent literature, with more research required to develop diagnostic standards and examine long term outcomes of frenotomy procedures[1, 6, 25, 27]. Messner and colleagues reached consensus that the potential benefits of frenotomy include relief of maternal pain, however, also reached consensus that frenotomy is not always effective in relieving maternal pain and breastfeeding difficulty[7]. O'Shea et al. [28]reported a lack of consistent positive breastfeeding outcomes associated with frenotomy, despite a reduction in short-term nipple pain. This Cochrane review examined the efficacy of frenotomy procedures in 2017, and found that frenotomy reduced breastfeeding mothers' nipple pain in the short term, however, the efficacy of frenotomy procedures was questioned as there were no consistent positive effects on infant breastfeeding[28].

There are only a few reports documenting the prevalence and management of ankyloglossia in Australia[25], with a complete lack of studies conducted in rural and remote areas of Australia. Further, there is also a complete lack of studies investigating ankyloglossia in remote settings both in Australia and internationally. Central Australia is a unique rural environment that is home to an estimated 38,737 people, and encapsulates an expansive catchment area of 827,861 square kilometres covering Alice Springs, Tennant Creek and numerous communities and outstations[29, 30]. Underrepresentation of this large population in current literature means that the prevalence of ankyloglossia in Central Australia is currently unknown. Kapoor and colleagues reported 22 cases of ankyloglossia that were surgically managed in the Northern Territory in 2016[25]. As this data was obtained from Medicare records, these cases are not a true representation of the Central Australian region; an area which relies heavily on the public health care system where Medicare rebates are not applied[31]. The small sample size does not make this paper suitable for more general conclusions about the management of ankyloglossia in Central Australia.

This study therefore aimed to examine and provide a world-first report on the prevalence and management of ankyloglossia for infants in Central Australia. Reporting on ankyloglossia management in remote areas such as Central Australia will inform future health care and the development of policies to meet the needs of rural health care settings in Australia.

**Methods**

Ethical approval for this retrospective medical file audit was granted by the Central Australian Human Research Ethics Committee (CA19-3338).

Data were collected from Central Australian Health System database which contains the medical files of all live born infants and children under two years of age in Central Australia between January 2013 and December 2018. This database includes all births occurring in a hospital (majority of births in Central Australia) within Central Australia[32]. Diagnoses in the database were coded using the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification (ICD-10-AM), and procedures were

coded using the Australian Classification of Health Interventions (ACHI). Ankyloglossia (Q381) and frenotomy (3027802) were identified using appropriate codes.

Within the health system targeted in this study, ICD-10-AM codes are allocated through manual medical coding by medical coding staff members reviewing paper charts to identify key diagnostic words (e.g., tongue-tie/ankyloglossia/frenotomy/tongue-tie cut). These target diagnostic words are then correlated to a relevant diagnostic code. This data were then extracted from medical files and entered into Statistical Package for Social Sciences (SPSS) (version 25). The proforma was prescriptive with a combination of variables including free text (e.g., description of feeding difficulty) and numerical coding (e.g., type of ankyloglossia). Participants in the study were infants born in the maternity unit of a large regional hospital in Central Australia. This hospital services a rural and remote community, with approximately 800 births annually. It has received baby-friendly designation, indicating that its policies promote and support breastfeeding in the early postpartum period[33, 34]. Eligible participants were <24 months of age, male or female, with a diagnosis of ankyloglossia. Demographic data collected from hospital records are outlined in Table 1.

**Table 1**

*Overview of analysed data.*

| | |
|---|---|
| Human record number<br>Date of birth<br>Gender<br>Date of admission<br>Date of discharge<br>Type of ankyloglossia identified<br>Method of identification of ankyloglossia<br>Patient age at identification of ankyloglossia<br>Discipline of health professional who identified ankyloglossia<br>Feeding issue leading to identification of ankyloglossia | Other issue leading to identification of ankyloglossia (description of issue as stated in medical file)<br>Documented type of management<br>Reason for frenotomy (as listed on procedure consent form in medical file)<br>Patient age at frenotomy (days of life)<br>Documented outcome post procedure |

Data variables were entered into SPSS for analysis. Summary measures were calculated, and chi-squared tests were used to compare target years. All p-values were calculated with a two-sided significance level of .05.

## Results

### *Study Sample*

From 2013 to 2018, 4,728 live births were reported in Central Australia (Table 2). Birth numbers ranged from 759 to 825 across the target six years with a mean of 788 births per year.

**Table 2**

*Prevalence of ankyloglossia and frenotomy rates within target years of 2013-2018. Percentages are calculated out of all births for diagnoses, and out of all diagnoses for procedures.*

| | *2013 n (%)* | *2014 n (%)* | *2015 n (%)* | *2016 n (%)* | *2017 n (%)* | *2018 n (%)* |
|---|---|---|---|---|---|---|
| *Births* | *797* | *769* | *793* | *825* | *759* | *785* |
| *Ankyloglossia diagnoses* | *34 (4.3)* | *75 (9.8)* | *110 (13.9)* | *112 (13.6)* | *87 (11.5)* | *64 (8.2)* |
| *Frenotomy procedures* | *33 (97.1)* | *73 (97)* | *106 (96.4)* | *112 (100)* | *86 (98.9)* | *64 (100)* |

### *Ankyloglossia Diagnosis and Management*

Of the 4,728 births in Central Australia across 2013 to 2018, there were 478 cases of ankyloglossia reported, yielding an overall prevalence of 10.2%.

Of the 797 births in 2013, 34 infants (4.3%) were diagnosed with ankyloglossia, and 33 infants (4.1%) underwent frenotomy, representing a frenotomy rate of 97.1%. Of the 785 births in 2018, 64 infants (8.2%) were diagnosed with ankyloglossia, demonstrating a significant increase from 2013 (p=0.002). Sixty-four infants (8.2%) underwent frenotomy, representing a frenotomy rate of 100%. Across the data collection period, ankyloglossia was diagnosed by midwives (45%), midwives who were also lactation consultants (49%), nurses (2%), physicians (1%) and other sources such as speech-language pathologists and parents (3%).

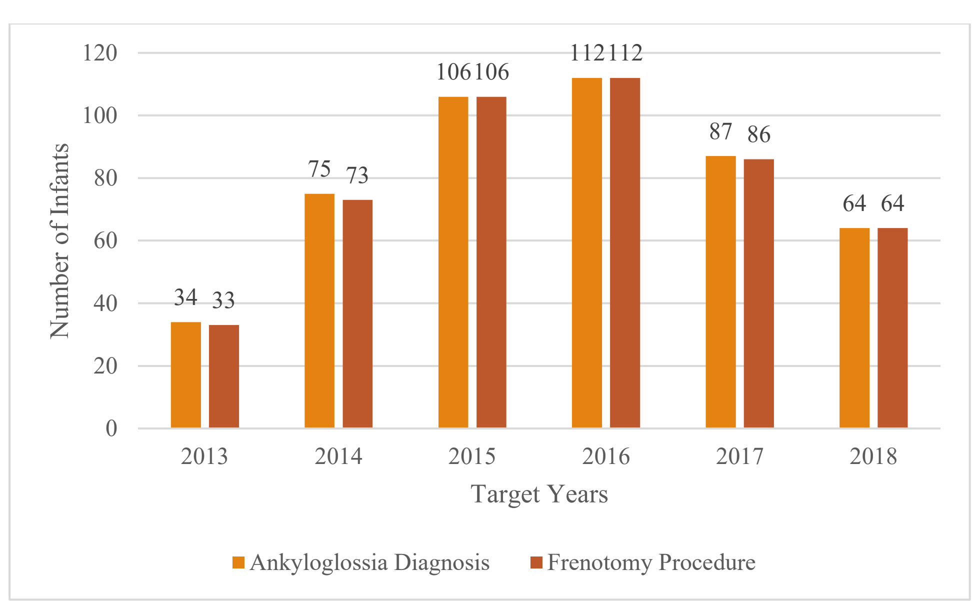
In total, there were 474 infants who were managed surgically with frenotomy, representing 97.9% of cases diagnosed with ankyloglossia. No significant differences between the rates of frenotomy were found over time, when comparing 2013 and 2018 (p=0.553). Frenotomies were completed by lactation consultants who were also midwives using the cold steel method with blunt-ended scissors in 471 infants (99%). The procedures were completed during the infants' newborn (birth) admission in hospital.

Throughout the retrospective data collection period, non-surgical management involving positional changes were provided by the midwife or lactation consultant to 41 infants with ankyloglossia (8.3%). Following this, 40 (98%) of these infants also received a frenotomy procedure. Non-surgical management was not offered to 452 infants (92%) with ankyloglossia.

The highest prevalence of ankyloglossia was reported in 2015 with 13.9% of infants diagnosed. The highest rates of frenotomy procedures were in in 2016 and 2018, with 100% of infants diagnosed with ankyloglossia receiving a frenotomy procedure. The lowest rate of ankyloglossia was in 2013, with 4.3% of all births receiving a diagnosis of ankyloglossia. The lowest rate of frenotomy was in 2015, with 96.4% of infants with ankyloglossia receiving a frenotomy procedure. (Figure 1).

**Figure 1**

*Trends in ankyloglossia diagnosis and frenotomy rates in Central Australia within target years of 2013 to 2018.*




A trend indicating higher prevalence of ankyloglossia was reported for males with an average of 58% compared to 42% in females across the target years. This result, however, was not statistically significant (p=0.388). A significantly higher proportion of infants were classified with posterior ankyloglossia (23% vs 15%) (p<0.01). Prior to 2016, a significant difference was noted between anterior and posterior ankyloglossia diagnoses in 2013 to 2015 (p<0.01). In 2017 and 2018, classifications of anterior and posterior ankyloglossia were comparable.

On average, ankyloglossia was diagnosed on the third day of life across all years in the reporting period. Frenotomy procedures were completed on the same day as diagnosis in all years except 2018, where frenotomy procedures were completed two days post diagnosis on average.

Across 2014 to 2018, more than 92% of infants with ankyloglossia were identified by a midwife, or a lactation consultant (Table 3). Prior to this period, in 2013, there was greater variability in the discipline of the health professional diagnosing ankyloglossia.

There was a significant increase in infants diagnosed with ankyloglossia, with 4.3% diagnosed in 2013 to 8.2% diagnosed in 2018 (p<0.01). The rate of frenotomy did not increase significantly during that period (p=0.553) (Table 2; Figure 1).

**Table 3**

*Demographic and diagnostic data of infants diagnosed with ankyloglossia within target years of 2013 to 2018. Percentages are calculated out of all diagnoses.*

| | *2013 n (%)* | *2014 n (%)* | *2015 n (%)* | *2016 n (%)* | *2017 n (%)* | *2018 n (%)* |
|---|---|---|---|---|---|---|
| *Gender* | | | | | | |
| *Male* | *20 (59)* | *40 (53)* | *70 (66)* | *69 (62)* | *47 (54)* | *34 (53)* |
| *Female* | *14 (41)* | *35 (47)* | *36 (34)* | *43 (38)* | *40 (46)* | *30 (47)* |
| *Mean age at diagnosis (days)* | *4* | *3* | *4* | *3* | *3* | *3* |

| *Mean age at procedure (days)* | *4* | *3* | *4* | *3* | *3* | *5* |
|---|---|---|---|---|---|---|
| *Type of tongue tie* | | | | | | |
| *Anterior* | *5 (15)* | *4 (5)* | *8 (7.5)* | *16 (14)* | *20 (23)* | *16 (25)* |
| *Posterior* | *5 (15)* | *23 (31)* | *40 (38)* | *27 (24)* | *9 (10)* | *14 (22)* |
| *Anterior + Posterior* | *1 (3)* | *1 (1)* | *0* | *2 (2)* | *0* | *0* |
| *Other* | *0* | *0* | *0* | *2 (2)* | *1 (1)* | *8 (13)* |
| *Not specified* | *23 (68)* | *47 (63)* | *58 (55)* | *67 (60)* | *57 (66)* | *26 (41)* |
| *Discipline identified* | | | | | | |
| *Midwife/Lactation* | *20 (59)* | *73 (97)* | *100 (94)* | *111 (99)* | *84 (97)* | *59 (92)* |
| *Consultant* | *9 (27)* | *0* | *1 (1)* | *0* | *0* | *1 (2)* |
| *Nurse* | *1 (3)* | *0* | *0* | *0* | *3 (3)* | *2 (3)* |
| *Physician* | *4 (12)* | *2 (3)* | *5 (5)* | *1 (1)* | *0* | *2 (3)* |
| *Other* | | | | | | |

***Clinical Outcomes***

Table 4 highlights the reported rationale and outcomes of frenotomy procedures, which included poor latch, sucking issues and maternal nipple pain.

Latching issues and maternal nipple pain were reported as the primary reason for frenotomy procedures across all target years, at a rate of 70% and 39% respectively. Following a frenotomy procedure, 60% of infants demonstrated an improved latch, 79% had decreased nipple pain, and 57% had improved sucking ability across the target years. The mean length of admission for infants with ankyloglossia was 5 days. These improvements were noted by the lactation consultant who performed the frenotomy, as well as midwives and nursing staff during the admission period. Once discharged from hospital, follow up was not documented in the clinical files.

Overall, in 54% of infants, a frenotomy procedure was effective in the resolution of feeding issues.

A total of eighty-seven infants (18%) underwent a frenotomy procedure with no feeding difficulty identified prior to procedure. The rates of these cases ranged from as low as 3% (in 2018) up to 27% (in 2015). These infants presented with a structural defect only and had no functional deficits, and therefore were not indicated for surgical intervention.

***Adverse Events***

Adverse events were reported in the data. Bleeding, ulcers and swelling were the primary issues reported post frenotomy throughout the study (Figure 2; Table 4).

Five infants were re-admitted to hospital for ongoing feeding difficulties throughout the target years. The primary reasons for readmission were difficulties with feeding, poor weight gain, and maternal challenges such as bleeding nipples. In one of these infants, ankyloglossia was identified during the birth admission on day 3 of life, and the infant was discharged without any surgical intervention. The infant was readmitted on day 7 of life and had a frenotomy procedure on day 8 of life (Table 4).

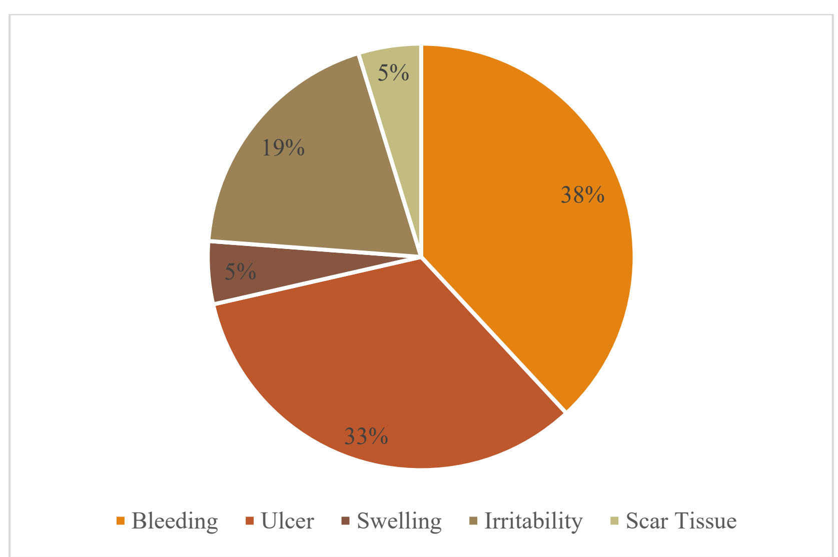
**Table 4**

*Outcomes of infants who underwent frenotomy procedures within target years of 2013-2018. Percentages are calculated out of all infants who underwent frenotomy procedures.*

| | 2013 (n=33) | | 2014 (n=73) | | 2015 (n=106) | | 2016 (n=112) | | 2017 (n=86) | | 2018 (n=64) | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Yes | No | Yes | No | Yes | No | Yes | No | Yes | No | Yes | No |
| Latching issues resolved (total number of latching issues n=334) | 15 (68%) | 7 (32%) | 15 (36%) | 27 (64%) | 40 (58%) | 27 (40%) | 47 (64%) | 26 (36%) *1 with nil issues developed latching issues post procedure (total 27 (36%)) | 45 (67%) | 21 (32%) *1 with nil issues developed latching issues post procedure (total 22 (33%)) | 39 (67%) | 19 (33%) |
| Maternal pain resolved (total n=187) | 5 (56%) | 4 (44%) | 13 (62%) | 8 (38%) | 16 (80%) | 4 (20%) *2 with nil pain prior to procedure with more pain post total 6 (27.3%) | 36 (82%) | 8 (18%) *1 with nil pain prior to procedure with more pain post total 9 (20%) | 35 (81%) | 8 (19%) | 43 (92%) | 4 (9%) |
| Sucking issues resolved (total n=138) | 15 (79%) | 4 (21%) | 12 (57%) | 9 (43%) | 21 (55%) | 17 (45%) *2 with nil issues prior to procedure deteriorated (total 19 (48%)) | 15 (65%) | 8 (35%) *1 with nil issues prior to procedure deteriorated (total 9 (38%) | 11 (46%) | 13 (54%) | 4 (40%) | 6 (60%) |
| No feeding issues (total n=87) | 4 (12%) | | 18 (25%) | | 29 (27%) | | 27 (24%) | | 7 (8%) | | 2 (3%) | |
| Adverse events (total n=21) | 8 | 25 | 2 | 71 | 7 | 99 | 0 | 112 | 3 | 83 | 1 | 63 |
| Readmissions to hospital (total n=5) | 1 | | 3 | | 1 | | 0 | | 0 | | 0 | |

**Figure 2**

*Characteristics of adverse events following frenotomy recorded throughout 2013 to 2018*



## Discussion

This study aimed to examine the prevalence and management of ankyloglossia for infants in Central Australia. The demographics of infants diagnosed with ankyloglossia in this study were consistent with prevalence literature, which reported that ankyloglossia is more common in male patients by around 1.6 to 3-fold[8, 35, 36]. The significantly higher proportion of posterior ankyloglossia are reported among infants in this study compared to anterior ankyloglossia (23% vs 15%) has not been previously reported. Previous studies have reported a higher proportion of anterior ankyloglossia[12, 37]. This discrepancy with findings in the present study may have been due to a lack of consistent or standardised criteria used by health professionals tasked with diagnosing ankyloglossia in this population.

An average prevalence rate of 10.2% of all infants born in Central Australia diagnosed with ankyloglossia in this study reflects the upper end of the previously range reported for children in other studies and locations[9]. The baby-friendly hospital status of the major hospital in Central Australia may be a contributing factor to an increased awareness of ankyloglossia compared to other sites. The identification and management of ankyloglossia during newborn admissions in the literature showcase sporadic and symptom-prompted identification such as poor feeding or maternal pain[35]. This was also reflected in the current study in the Central Australian population, with ankyloglossia being identified in infants the third day of life, and frenotomy procedures occurring on the day of identification in majority of cases. Buryk, Bloom [38]in their randomized controlled trial cited the mean age at frenotomy as 6.7 days, however, the optimal age of infants at the time of frenotomy has not yet been examined[39]. Factors including the length of time that the infant has practiced feeding and the mothers' prior breastfeeding experience play a significant role in infant feeding, and should be considered in ankyloglossia management guidelines.

The rate of frenotomy reported in Central Australia (97.9%) in the current study was higher than previously reported rates ranging from 85 to 94%[40]. The Canadian Paediatric Society [6] published a position statement on ankyloglossia and breastfeeding in 2015 and reaffirmed their position in 2018, outlining that based on available evidence, frenotomy cannot be recommended for all infants with ankyloglossia. They also concluded that whilst frenotomy cannot be recommended in all cases, it should be conducted by an experienced clinician if ankyloglossia is contributing to substantial breastfeeding difficulties[6]. This was mirrored in both the Australian Dental Association and the American Academy of Otolaryngology's Clinical Consensus Statement, stating that a frenotomy should only be performed in the presence of a functional deficit[1, 7]. In this study, a frenotomy procedure was performed on a total of 87 infants (18%) who had no reported feeding difficulties prior to the procedure. This highlights uncertainty about why these infants received a diagnosis of ankyloglossia, and further, why they then received a surgical procedure. The significant number of unnecessary frenotomy procedures has been highlighted in recent literature, and requires further investigation within all health services[7]. In light of the recommendations around frenotomy in the literature and reports stating that most ankyloglossia cases may be asymptomatic, the rate of frenotomy procedures in Central Australia should be rigorously examined[36].

The nature of remote health services may be reflected in the prevalence of ankyloglossia and rates of frenotomy in Central Australia. In Central Australia, frenotomy was performed exclusively by IBCLCs who are also midwives, whereas in metropolitan health settings, frenotomy is generally performed by dentists, general practitioners, lactation consultants, otolaryngology surgeons, paediatricians and paediatric surgeons[41]. Remote health services often lack specialist physicians, and therefore rely on health professionals developing generalist skills to cover these areas[42]. The development of these skills is reliant on balanced education programs and professional development courses that can provide education on tools to accurately diagnose ankyloglossia as well as conduct frenotomy. Such programs are often difficult to access due to staffing pressures and budgeting restrictions in remote settings. These factors may have led to an overdiagnosis of ankyloglossia and a high frenotomy rate, due to limited education and training on ankyloglossia, and limited specialist services to provide advice or follow-up.

The current study revealed that frenotomy procedures led to adverse effects in an average of 6.5% of infants in the Central Australian population, similar to the rates found in previous studies[19, 43, 44]. Adverse events found in the current study such as irritability, bleeding, ulceration, scar tissue formation and oral aversion have also been previously documented[45, 46]. Further to these recorded adverse events, there is also evidence that infants experience prolonged pain and stress[45]. These findings highlight the importance of ongoing education for health professionals on the potential complications of frenotomy procedures. Further, awareness of potential complications and accurate success rates of the procedure are imperative for parents consenting to frenotomy procedures to facilitate informed consent.

Frenotomy for ankyloglossia in infants with breastfeeding difficulties was found to be effective 54% of the reported sample, improving breastfeeding and decreasing maternal nipple pain. These results are consistent with available literature examining the effectiveness of frenotomy procedures, however, the retrospective nature of this study does not allow for follow-up data and the exploration of consistent and long term frenotomy effectiveness[21, 28, 47]. Variability in the success rate of frenotomy was also examined in our study; although more than half of the sample experienced an improvement in symptoms, 46% of infants who underwent a frenotomy procedure did not demonstrate discernible benefits following the procedure.

The 46% rate of infants-mother dyads who did not benefit from frenotomy examined in this study highlight that further consideration should be given to non-surgical management strategies in clinical practice. As an alternative to frenotomy, these strategies can be an effective first-line therapy for the management of functional limitations associated with ankyloglossia[7, 48]. Breastfeeding difficulty can often improve with time or non-surgical intervention by a lactation consultant or speech-language pathologist who specialises in breastfeeding issues[49, 50]. Non-surgical strategies for management of ankyloglossia include advice on positioning, latch optimisation, feed frequency, supporting mothers to maintain milk supply, and the use of external tools such as nipple shields or supplementary nursing systems[1]. Non-surgical management was provided by midwives and lactation consultants to only 41% of infants with ankyloglossia in this study, highlighting the importance of education and training in these strategies. Speech-language pathologists were not involved in the non-surgical management of

ankyloglossia within this study, highlighting a lack of multi-disciplinary collaboration. It is important for both health professionals and caregivers to understand that there are alternative and non-surgical treatment options that may eliminate the need for frenotomy procedures. Future studies investigating the effectiveness of multidisciplinary non-surgical interventions are warranted.

Previous researchers have emphasised the value of clinical judgement and establishing the cause of the breastfeeding difficulty for each infant-mother pair before intervening[51]. This highlights the role of a multidisciplinary team in implementing screening and holistic decision-making for ankyloglossia in infants. These principles should be at the forefront of rural and remote health services for infants with ankyloglossia to ensure the most appropriate management is provided.

The lack of formal accreditation for health professionals performing frenotomy procedures in Australia[52], as well as the lack of standardised screening tools [8] may also be responsible for the higher prevalence rates of ankyloglossia in the current study. Further, the lack of involvement of speech-language pathologists, as health professionals trained in the assessment and management of infant feeding difficulties, in the assessment and management of ankyloglossia in this study is notable. These factors may also contribute to the high frenotomy rate for infants with ankyloglossia.

The development of a formal accreditation package for health professionals involved in ankyloglossia and frenotomy procedures may improve the accuracy of diagnosis of ankyloglossia and may reduce the high rates of invasive surgical management reported in our study. Similar publications, such as the guideline for the educational and ongoing competency requirements for midwives, medical practitioners and dental surgeons to perform frenotomy, from the New Zealand Government's Ministry of Health [46] should be considered for implementation across all health services. Further, clinical guidelines clearly defining the roles of health professionals in the assessment and management of ankyloglossia should be considered to establish roles and responsibilities within the multidisciplinary team.

Limitations reporting retrospective file data were evident in this study. The methods and tools used to diagnose ankyloglossia were not outlined in the clinical files. Inconsistent terminology and reporting in medical notes across professions may have impacted accurate and complete reporting of data points, including the severity and type of ankyloglossia.

The low rate of adverse events following frenotomy reported in this study will assist healthcare professionals in decision-making processes and inform consent discussions. Future prospective cohort studies following long-term outcomes of infants in remote settings who both underwent frenotomy and were untreated would be beneficial in further identifying the efficacy of frenotomy procedures that occur in this Central Australian healthcare setting. Additionally, studies gathering the perspectives of health professionals on their role in the assessment and management of ankyloglossia would be beneficial.

## Conclusion

The prevalence of ankyloglossia in infants was 10.2% between 2013 and 2018. The frenotomy rate of 97.9% in this study setting was higher than rates previously reported in the literature. The 46% of infants who had a frenotomy procedure with no improvement in feeding difficulties, and the high proportion of infants who received a frenotomy in the absence of functional deficits highlight the importance of establishing a standardised and multidisciplinary approach, involving relevant professionals such as speech-language pathologists, lactation consultants, midwives and nurses. This study also reiterated the need for a validated screening or comprehensive diagnostic tool for the identification of ankyloglossia and clear clinical guidelines outlining the indications for frenotomy, as well as the requirement for health professionals to receive education and training in non-surgical strategies for the management of ankyloglossia.

These recommendations, in combination with future data from metropolitan regions, may provide the necessary information for the development of clinical guidelines for the identification and management of ankyloglossia in rural and remote health services in Australia.

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# Chapter 3

## Ankyloglossia in Australia: Practices of health professionals

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### Ankyloglossia in Australia: Practices of health professionals

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ABSTRACT

*Objectives:* To investigate the opinions and practices of health professionals involved in ankyloglossia diagnosis and management in Australia.
*Method:* Two hundred and thirty-seven health professionals across Australia responded to an online survey including their diagnostic and management practice of ankyloglossia. Descriptive statistics, content analysis and thematic analysis were used to analyse quantitative data and open-ended responses, respectively.
*Results:* Most (91.6%) respondents reported they are responsible for the assessment and diagnosis of ankyloglossia in their clinical practice. A majority (56.7%) reported using more than one assessment tool in clinical practice. Less than half (46.4%) reported providing treatment to manage ankyloglossia. Surgical management was used by 44.5%, and 56.4% used non-surgical management as their primary treatment of ankyloglossia. Of the total sample, 26.6% had completed no further training or professional development in the field. 46% of respondents stated they always educate parents about ankyloglossia diagnoses, whereas 29.5% reported they always educate parents about management of ankyloglossia. Of respondents, a high level of confidence was reported by 62.6% of health professionals in the assessment of infants with ankyloglossia. Of those who perform surgical management, 53.7% reported feeling extremely confident in their skills. Fifty-two percent of respondents reported they were dissatisfied with the current service delivery for infants with ankyloglossia.
*Conclusions:* The diagnosis, management and education practices varied greatly amongst health professionals in Australia. Clinical guidelines for all relevant health professionals are needed to ensure standardised diagnosis and management processes. In future, this will help guide evidence-based diagnosis and intervention for infants with ankyloglossia.

#### 1. Introduction

Ankyloglossia refers to the limited movement of the tongue causing functional limitations, as well as a visually restricted lingual frenulum [1]. The anatomy of the lingual frenulum has recently been described as a structure formed by the dynamic elevation of a midline fold in the floor of mouth fascia; not a band or cord, as it has previously been described [2]. Whilst these definitions are used most frequently, there are no established universal criteria [3]. Internationally and within Australia, a broad range of health professionals are involved in the diagnosis and management of ankyloglossia [1]. With a lack of clinical guidelines, the diagnostic criteria, diagnostic tools and management pathways for ankyloglossia likely vary greatly amongst these health professionals [3, 4].

Tools that have been developed to classify ankyloglossia diagnoses include the Coryllos criteria, which classifies ankyloglossia into two types – anterior (types I and II), and posterior (types III and IV) [5]. Classification systems to describe the severity of ankyloglossia based on the length of the lingual frenulum have also been developed [6]. The tools were designed to describe the lingual frenula but do not address the functionality of the tongue, and should be used with caution. Several tools have been developed to examine the impact of ankyloglossia on function. The Hazelbaker Assessment Tool for Lingual Frenulum Function (HATLFF) was developed to determine the severity and functional impact of ankyloglossia [7]. The Lingual Frenulum Protocol for Infants [8] was established to assess and diagnose anatomical differences of the lingual frenulum, and identify the possible impacts of these on breast-feeding. The Bristol Tongue Assessment Tool (BTAT) was developed using principles from the HATLFF to rate severity of ankyloglossia by measuring the tongue tip appearance, attachment of the frenulum to the

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I, Donna Akbari Harris, made the following contributions:

- Designed the study with support from the supervisory team.
- Extracted the data
- Conducted the analysis
- Drafted and completed the manuscript with critical feedback and revision from the supervisory team.

The International Journal of Pediatric Otorhinolaryngology requires that the lead author must be the corresponding author.

As primary supervisor for the candidature upon which this thesis is based, I can confirm that the authorship attribution statements above are correct.

Associate Professor Kimberley Docking

Faculty of Medicine and Health

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I, Donna Akbari Harris, as the candidature student, confirm that the authorship attribution statements above are correct.

Donna Akbari Harris

December 2025

**Ankyloglossia in Australia: Practices of Health Professionals**

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**Running head:** Ankyloglossia practices in Australia

**Abstract**

*Objectives*: To investigate the opinions and practices of health professionals involved in ankyloglossia diagnosis and management in Australia.

*Method*: Two hundred and thirty-seven health professionals across Australia responded to an online survey including their diagnostic and management practice of ankyloglossia. Descriptive statistics, content analysis and thematic analysis were used to analyse quantitative data and open-ended responses, respectively.

*Results*: Most (91.6%) respondents reported they are responsible for the assessment and diagnosis of ankyloglossia in their clinical practice. A majority (56.7%) reported using more than one assessment tool in clinical practice. Less than half (46.4%) reported providing treatment to manage ankyloglossia. Surgical management was used by 44.5%, and 56.4% used non-surgical management as their primary treatment of ankyloglossia. Of the total sample, 26.6% had completed no further training or professional development in the field. 46% of respondents stated they always educate parents about ankyloglossia diagnoses, whereas 29.5% reported they always educate parents about management of ankyloglossia. Of respondents, a high level of confidence was reported by 62.6% of health professionals in the assessment of infants with ankyloglossia. Of those who perform surgical management, 53.7% reported feeling extremely confident in their skills. Fifty-two percent of respondents reported they were dissatisfied with the current service delivery for infants with ankyloglossia.

*Conclusions*: The diagnosis, management and education practices varied greatly amongst health professionals in Australia. Clinical guidelines for all relevant health professionals are needed to ensure standardised diagnosis and management processes. In future, this will help guide evidence-based diagnosis and intervention for infants with ankyloglossia.

**Keywords**

Infant, ankyloglossia, feeding

## 1. Introduction

Ankyloglossia refers to the limited movement of the tongue causing functional limitations, as well as a visually restricted lingual frenulum[1]. The anatomy of the lingual frenulum has recently been described as a structure formed by the dynamic elevation of a midline fold in the floor of mouth fascia; not a band or cord, as it has previously been described[2]. Whilst these definitions are used most frequently, there are no established universal criteria[3]. Internationally and within Australia, a broad range of health professionals are involved in the diagnosis and management of ankyloglossia[1]. With a lack of clinical guidelines, the diagnostic criteria, diagnostic tools and management pathways for ankyloglossia likely vary greatly amongst these health professionals[3, 4].

Tools that have been developed to classify ankyloglossia diagnoses include the Coryllos criteria, which classifies ankyloglossia into two types – anterior (types I and II), and posterior (types III and IV)[5]. Classification systems to describe the severity of ankyloglossia based on the length of the lingual frenulum have also been developed[6]. The tools were designed to describe the lingual frenula but do not address the functionality of the tongue, and should be used with caution. Several tools have been developed to examine the impact of ankyloglossia on function. The Hazelbaker Assessment Tool for Lingual Frenulum Function (HATLFF) was developed to determine the severity and functional impact of ankyloglossia[7]. The Lingual Frenulum Protocol for Infants [8] was established to assess and diagnose anatomical differences of the lingual frenulum, and identify the possible impacts of these on breastfeeding. The Bristol Tongue Assessment Tool (BTAT) was developed using principles from the HATLFF to rate severity of ankyloglossia by measuring the tongue tip appearance, attachment of the frenulum to the lower gum ridge, lift of tongue with mouth wide and protrusion of tongue[9]. An adjunct to the BTAT is The Tongue-tie and Breastfed Babies (TABBY) assessment, which was developed to provide a pictorial representation of the BTAT[10]. Despite a variety of tools to classify and assess the impact of ankyloglossia, these tools lack reliability and standardisation, and consensus regarding a preferred ankyloglossia grading system has not been established[3]. The tools are often used in conjunction with informal functional assessments which are likely to be variable amongst health professionals[1].

Non-surgical management of ankyloglossia can include strategies such as positional changes, the alteration of feeding frequency, providing support to mothers to maintain a milk supply, latch optimisation and the use of external tools such as nipple shields or supplementary nursing systems[1, 11]. These strategies are recommended to be implemented by relevant, trained health professionals such as International Board Certified Lactation Consultants (IBCLCs), midwives, child health nurses and/or speech-language pathologists[1]. Currently, frenotomy is the primary surgical intervention used to manage ankyloglossia. Frenotomy for ankyloglossia is a procedure where the lingual frenulum is divided either in the midline or at the underside of the tongue, using sharp blunt-ended scissors[12]. Increases in the rate of frenotomy in Australia have been reported as high as 420%[13], and reiterated internationally[14]. Other less common surgical procedures to manage ankyloglossia include frenuloplasty - releasing and suturing the lingual frenulum, Z-plasty – releasing the frenulum and creating flaps and suturing these, and

laser interventions – used by dentists to remove and separate the frenulum tissue. These surgical procedures have been recommended to be performed by suitably trained health professionals, and to be considered only following unsuccessful non-surgical management[1].

There are only a few reports documenting the practices of health professionals in the diagnosis and management of ankyloglossia internationally[4, 15], with no literature investigating practices in Australia. There is also a complete lack of studies investigating the identification and management practices of health professionals in the field of ankyloglossia in remote settings, both in Australia and internationally. Reports of a lack of professional education in the field of ankyloglossia, and a lack of consensus amongst health professionals on assessment and diagnostic tools has led to inconsistencies in clinical practice amongst clinicians[15]. These inconsistencies, as well as the increase in frenotomy rates has led to greater interest in the clinical practices and thoughts of health professionals managing ankyloglossia. Awareness of the clinical practices in ankyloglossia diagnosis and management across all health care settings in Australia will allow for clinical guidelines that are sensitive to the resources available in all areas of Australia.

This study, therefore, aimed to examine the opinions and practices of Australian health professionals in the assessment and management of ankyloglossia. It was hypothesised that (i) opinions about ankyloglossia will vary between professions, (ii) the diversity of professions involved in the diagnosis and management of infants with ankyloglossia will be numerous, (iii) the majority of clinicians do not use established tools to guide management of babies with suspected ankyloglossia and (iv) clinicians would have low confidence in their skills due to a lack of standardised diagnostic and management guidelines. Reporting on the current ankyloglossia diagnostic, management, and educational practices of health professionals in Australia will inform the future development of policies to standardise processes nationally.

## 2. Method

Ethical approval for this cross-sectional questionnaire study was granted by the Central Australian Human Research Ethics Committee (CA20-3629).

### *2.1 Survey design*

A survey was developed using Qualtrics software to evaluate the opinions and practices of Australian health professionals working with ankyloglossia. All questions in the survey were categorised into four blocks that included multiple choice and open response question formats. The four blocks explored health professionals' background and clinical experience, assessment practices, management practices and the provision of education. Open response questions were included.

The first block surveyed health professionals on their qualifications, geographical location based on Modified Monash Model classifications[16], clinical setting and years of experience. Participants were asked whether they have completed any professional development in the area of ankyloglossia or frenotomy and were provided with an open response text box to describe the training. The assessment practices section contained questions about factors leading to

assessment of infants for ankyloglossia, the assessment/screening tools used, and revisions made to these assessment tools. A 5-point Likert scale ranging from 1 – 'Not confident' to 5 – 'Extremely confident' was used to identify the health professionals' self-reported confidence level in assessing ankyloglossia. Fixed anchor points were used as they have been recommended as more reliable when making quantitative comparison[17]. The management of ankyloglossia was explored using multiple choice questions for the type of treatment provided, number of treatments provided per month, timeframes for intervention and improvements in management. Where applicable, multiple responses were allowed for questions relating to assessment and management practices. Likert scales were used to ascertain the self-reported confidence levels in the surgical management of ankyloglossia and non-surgical management of ankyloglossia, and satisfaction levels with the current service delivery for infants with ankyloglossia. The frequency of education provided about ankyloglossia and frenotomy was explored through two 5-point Likert scales.

### *2.2 Data collection*

Data was collected from a survey developed and published using Qualtrics software (www.qualtrics.com). Australian health professionals who practiced in the area of ankyloglossia were invited to complete an online survey through the Qualtrics web link. Health professionals were recruited via email, professional body newsletters, interest groups and through social media groups for paediatric feeding, ankyloglossia, and related topics, as well as via managers of speech pathology, midwifery and nursing departments throughout a number of hospitals and community health centres across Australia. The survey was disseminated through a link generated by the online survey tool. This link was not personalised to any one participant and an email outlining the study and survey was sent to moderators of the interest groups and managers of health services asking them to disseminate to staff and/or colleagues, as well as posted on relevant social media pages and professional body websites. Eligible participants for this study included English speaking health professionals with clinical experience in the diagnosis and/or management of ankyloglossia in Australia.

### *2.3 Data analysis*

Responses were downloaded into IBM SPSS Statistics For Windows (version 26) [18] for further analysis. Descriptive statistics were used to describe general trends. Additionally, chi-squared and Mann-Whitney U tests were used to explore differences between groups of respondents. All p-values were calculated with a two-sided significance level of .05 and power was set at 0.80. For multiple-choice questions where respondents could select more than one option, responses were analysed descriptively, with frequencies reported for each response option; as such, totals may exceed 100%.

Responses to open-ended questions were transferred to Microsoft Excel for content analysis. Content analysis was completed to determine practices of health professionals in the areas of assessment and management of ankyloglossia. A thematic analysis was used to identify key themes. The qualitative data were analysed using Braun and Clarke's six-phase thematic analysis [19]. Initially, two researchers (D.A. and T.L.) independently familiarised themselves with the data through repeated reading, noting patterns, commonalities, and unusual or

unexpected responses. Initial codes were then systematically generated across the dataset and collated into preliminary categories. These codes were compared and discussed between the two researchers to enhance analytic rigour. Further analysis was undertaken primarily by the lead researcher (D.A.) to collate codes into potential themes. Themes were subsequently reviewed in relation to both the coded extracts and the full dataset by all authors, refined and clearly defined, with any discrepancies resolved through discussion or by consensus, or by the lead researcher where required. Finally, the themes were organised by D.A. into a coherent analytic narrative, supported by illustrative data extracts, to address the research questions.

## 3. Results

### *3.1 Study Sample*

A total of 357 responses were collated, of which 120 responses were removed due to incomplete survey data or lack of consent to participate in the study. Responses received from 237 health professionals are reported.

Demographic information about the respondents is represented in Table 1. Speech pathologists were the largest participant group (40.1%), followed by lactation consultants (20.7%) and paediatricians (7.6%). Several health professionals, including midwives, dentists, nurses, chiropractors, general practitioners, osteopaths and other professionals, responded to the questionnaire in fewer numbers.

Participants responded from all eight Australian states and territories, with most health professionals practicing in New South Wales (31.6%) and Queensland (29.1%). Based on workplace location, 177 respondents (74.7%) worked in metropolitan or regional cities, whereas 60 respondents (25.3%) worked in rural and remote areas. The highest proportion of health professionals working in rural and remote areas was in Northern Territory.

Majority of participants worked in a hospital setting (41.4%), followed by private practices (36.7%). Participants also worked in settings including community-based government health services, other settings and non-profit organisations. Most health professionals reported working in the field of ankyloglossia for over 10 years (34.6%), with over 90% of the respondents working in the field for longer than two years.

**Table 1.** Demographic information of participants

| | N | % |
|---|---|---|
| Profession | | |
| *Speech Pathologist* | 95 | 40.1 |
| *Lactation Consultant* | 49 | 20.7 |
| *Midwife* | 14 | 5.9 |
| *Nurse (RN)* | 12 | 5.1 |
| *Paediatrician* | 18 | 7.6 |
| *Chiropractor* | 11 | 4.6 |
| *Osteopath* | 6 | 2.5 |
| *Dentist* | 13 | 5.5 |
| *GP* | 11 | 4.6 |
| *Other* | 8 | 3.4 |
| Work setting | | |

| | | |
|---|---|---|
| *Hospital* | 98 | 41.4 |
| *Community-based government health* | 44 | 18.6 |
| *Private practice* | 87 | 36.7 |
| *Non-profit organisation* | 3 | 1.3 |
| *Other* | 5 | 2.1 |
| State or Territory | | |
| *ACT* | 6 | 2.5 |
| *NSW* | 75 | 31.6 |
| *NT* | 19 | 8.0 |
| *QLD* | 52 | 21.9 |
| *SA* | 11 | 4.6 |
| *TAS* | 2 | .8 |
| *VIC* | 46 | 19.4 |
| *WA* | 26 | 11.0 |
| Workplace location | | |
| *Major city* | 136 | 57.4 |
| *Inner regional* | 41 | 17.3 |
| *Outer regional* | 35 | 14.8 |
| *Remote* | 22 | 9.3 |
| *Very remote* | 3 | 1.3 |
| Years of clinical experience | | |
| *0* | 1 | 0.4 |
| *1-2* | 21 | 8.9 |
| *3-4* | 40 | 16.9 |
| *5-6* | 42 | 17.7 |
| *7-8* | 28 | 11.8 |
| *9-10* | 23 | 9.7 |
| *10+* | 82 | 34.6 |

### *3.2 Ankyloglossia Diagnosis*

Of the health professionals who responded to the survey, 217 (91.6%) respondents reported that they assess and diagnose ankyloglossia in their clinical practice.

#### *3.2.1 Factors that led to assessment*

When health professionals were asked what led them to assess for ankyloglossia in infants, it was revealed that the factors preceding ankyloglossia assessment were often multifactorial. Over half of the respondents reported that they assess all infants (56.7%). Health professionals also reported that they assessed for ankyloglossia due to the infant demonstrating a poor latch (56.2%), the appearance of the tongue (55.3%), poor suck (52.1%), and due to maternal nipple pain (4.5%).

#### *3.2.2 Assessment tools*

Most health professionals reported using more than one assessment tool in their clinical practice. The most frequently used tools were observation (72.2%), an informal screening tool (44.3%) and the HATLFF (41.4%).

The responses of health professionals to the question of why this was their assessment tool of choice were analysed through both content and thematic analysis and overall themes of a preference for a functional assessment, and limitations in training, availability of tools and time emerged. These themes and subthemes are depicted in Table 2.

**Table 2.** Assessment practice of health professionals

| Assessment tool | N | % |
|---|---|---|
| *Observation* | 171 | 72.2 |
| *Informal screening / tool* | 105 | 44.3 |
| *Hazelbaker Assessment Tool for Lingual Frenulum Function* | 98 | 41.4 |
| *(HATLFF)* | 31 | 13.1 |
| *Bristol Tongue-Tie Assessment Tool* | 20 | 8.4 |
| *Unspecified* | 18 | 7.6 |
| *Lingual Frenulum Protocol (Martinelli)* | 9 | 3.8 |
| *Frenotomy Decision Tool for Breastfeeding Dyads (Dobrich)* | 9 | 3.8 |
| *Functional assessment* | 4 | 1.7 |
| *Neurological exam* | 2 | 0.8 |
| *Kotlow classification protocol* | 2 | 0.8 |
| *Referral* | 1 | 0.4 |
| *Coryllos classification system* | | |
| **Factors that led to assessment** | **N** | **%** |
| *All infants are assessed* | 123 | 56.7 |
| *Poor latch* | 122 | 56.2 |
| *Poor suck* | 113 | 52.1 |
| *Maternal nipple pain* | 118 | 54.4 |
| *Poor weight gain* | 98 | 45.2 |
| *Appearance of tongue* | 120 | 55.3 |
| *Other* | 43 | 19.8 |
| **Other factors that led to assessment** | **N** | **%** |
| *General feeding difficulties* | 13 | 30.2 |
| *Routine screening* | 9 | 20.9 |
| *Request for an assessment* | 5 | 11.6 |
| **Reasons for assessment tool selection** | **N** | **%** |
| *Preference for a combination of assessments* | 26 | 12 |
| *Dissatisfaction with other tools* | 14 | 6.4 |
| *Preference for a tool that is easy to use* | 37 | 17 |
| *Evidence base behind the tool* | 10 | 4.6 |
| *Preference for a functional assessment* | 53 | 24.4 |
| *Limitation of time* | 5 | 2.3 |
| *Limitation in tool availability* | 19 | 8.8 |
| *Limitation in training* | 33 | 15.2 |
| *Referral to other services for assessment* | 20 | 9.2 |

Thirty-three participants reported that they had a “no formal training” in the tools they were using (P39; P92) and that they “haven't heard of the others” (P91). As a result, their clinical practice was impacted by their level of expertise.

> “I do not have confidence I have the skills or tools to complete a formal Ax [assessment], nor feel it is within my scope of practice.” (P81)

Conversely, health professionals that were more familiar with diagnostic tools believed using "a combination of assessment/screening tools" (P77) achieves "a thorough assessment of the mobility and function of the tongue" (P187).

Health professionals were asked why they use the assessment tools they use in their clinical setting (Q3.3). A variety of limitations were reported by 57 health professionals to be a contributing factor as to why they used the assessment tools selected. For example, limitations in time were reported by 5 health professionals, who commented that they had "no time to complete formalised assessment tools" (P15), highlighting the fast-paced nature of many health care settings.

> "I run a drop-in for breastfeeding mothers so I haven't got time to do a lengthy assessment." (P175)

The availability of tools was a limitation for 19 health professionals, who reported that they use their current tool as it "is what the health service uses" (P78). A health professional in a regional setting had additional availability constraints due to the logistics of their health service.

> "I work in remote [supplied] region and am unable to bring all of my assessments with me due to weight limits on planes and large caseloads." (P237)

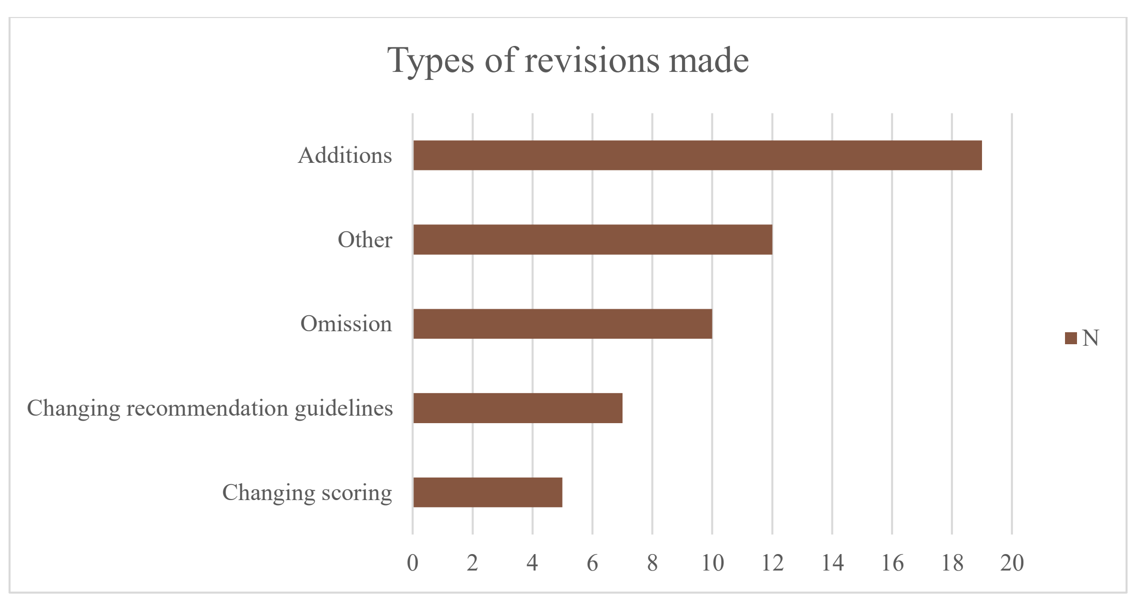
Functional assessments were a priority when selecting assessment tools for 53 health professionals, who reported that they "take a very function-based approach to the assessment" (HP90).

> "Not aware of any screening tool with strong evidence to support its use over functional assessment and clinical observation of feeding" (P140)

***3.2.3 Revision of assessment tools***

A total of 37 health professionals (15.6%) reported that they have made revisions to existing ankyloglossia assessment tools. Revisions were made to the HATLFF by 19 health professionals, the BTAT by 5 health professionals, and 13 respondents indicated that they had revised another existing informal screening tool. Further, 10 health professionals reported combining tools and adding test items, as well as revising tools which were not listed, including informal assessment tools developed specifically for their organisation. Some health professionals (40.5%) reported that they had made more than one type of revision to the above tools. The types of revisions made to these assessments are depicted in Figure 1.

**Figure 1**. Revisions made to assessment tools




***3.3 Ankyloglossia Management***

Of the health professionals who responded to the survey, 110 (46.4%) respondents reported that they provide treatment for and manage ankyloglossia. Of these, surgical procedures were performed by 49 health professionals (44.5%) as primary treatment for ankyloglossia. These procedures included frenotomy (29%), frenuloplasty/z-plasty (5.5%) and laser surgery (10%). Non-surgical management was provided by 62 health professionals who treat or manage ankyloglossia (56.4%). Health professionals were asked to specify the non-surgical treatments that they provide, which can be seen in Table 3.

Other treatments were reported by 60 health professionals (54.5%). Content analysis of these treatments found common themes, included using a multidisciplinary approach to treatment (8.5%), non-invasive treatments such as feeding therapy, oral therapies and compensatory feeding treatments such as positioning changes (64.8%), and referring to other providers for management (27.8%).

The frequency of surgical procedures for the management of ankyloglossia was examined (Figure 2). Over half of the health professionals performed less than five surgical treatments per month, with 11.6% providing over 30 surgical procedures per month. Of the 15 health professionals performing more than ten procedures per month, 11 were dentists, 1 was a surgeon, 1 was a general practitioner, and 2 were midwives. Ten of these health professionals used lasers as their surgical tool.

A Mann-Whitney U-test revealed that there was no significant difference in the number of procedures performed by health professionals when comparing metropolitan/regional locations and rural/remote locations ($p=0.220$).

The Australian health professionals who responded to this survey were asked about their preferred timeframe from diagnosis to intervention in Q4.7. Responses varied among the health professionals, with 24 (10.4%) reporting intervention should occur immediately, 32 (13.9%) preferred 1-3 day time frame, 30 (13%) preferred 3-7 days, 38 (16.5%) preferred over 7 days, and 107 (46.3%) reported that they would prefer a different time frame. The responses of health

professionals were analysed through content and thematic analysis. The themes and subthemes are depicted in Table 3.

In Q4.7.5, health professionals were asked to give details about their preferred timeframe from diagnosis to intervention, as they had selected ‘other’ in Q4.7. Various timeframes and ideas were reported by health professionals.

Individualised timeframes were preferred by 44 health professionals, who reported that the management timeframe “Depends on the presenting patient in every case” (P207).

> “Optimal timing of release is imperative for good outcomes. There is no one size fits all approach as each infant is different in relation to function. Each dyad is treated individually. I feel release of restricted oral tissue is vital for all dyads but the timing is also very important for good outcomes.” (P48)

Intervention for ankyloglossia as soon as possible was a priority for seven health professionals, who reported that a procedure should occur “As soon as diagnosis is made” (P153).

> “Ideally if impacting feeding they would be seen and given intervention ASAP.” (P158)

When asked what should be improved in the field of ankyloglossia management, multiple areas for improvement were identified by health professionals. Improved education for staff and clinicians was an area identified by 88.2% of health professionals. Improved education for parents was highlighted by 74.3%, regular training by 55.7% and different screening tools by 26.2%. Other areas of improvement were identified by 24.9% of health professionals, and included themes such as the creation of clinical guidelines, equitable access to ankyloglossia services, and further research.

**Figure 2.** Average number of surgical procedures performed per month

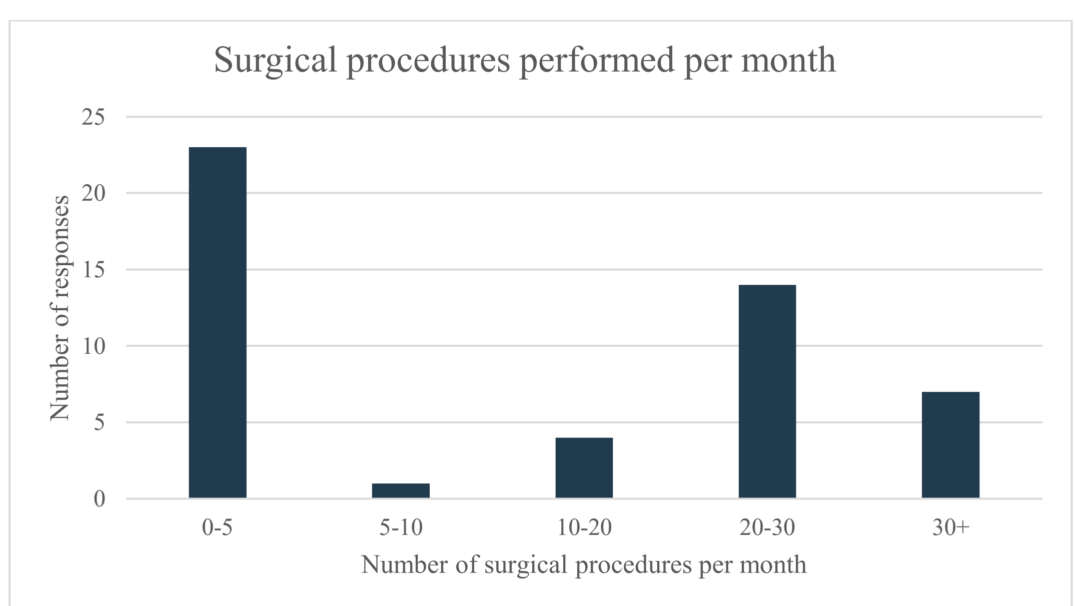



**Table 3.** Management practices of health professionals

| | N | % |
|---|---|---|
| Treatment | 110 | 46.4 |
| *Non-surgical* | 62 | 56.4 |
| *Frenotomy* | 32 | 29.1 |
| *Laser surgery* | 11 | 10 |
| *Frenuloplasty / Z-plasty* | 6 | 5.5 |
| *Other treatment* | 60 | 54.5 |
| Number of surgical treatments provided (per month) | | |
| *0 - 5* | 23 | 46.9 |
| *5 - 10* | 1 | 2.0 |
| *10 - 20* | 4 | 8.2 |
| *20 - 30* | 14 | 28.6 |
| *30+* | 7 | 14.3 |
| Non-surgical treatments provided | | |
| *Positioning changes* | 25 | 24 |
| *External tools e.g. nipple shield, dummy* | 11 | 10.6 |
| *Oral exercises* | 11 | 10.6 |
| *Latch optimisation* | 9 | 8.7 |
| *Osteopathic treatment* | 9 | 8.7 |
| *Myofunctional therapy* | 8 | 7.7 |
| *Chiropractic treatment* | 7 | 6.7 |
| *Referral to other providers* | 7 | 6.7 |
| *Feeding therapy e.g. sucking therapy* | 6 | 5.8 |
| *Education* | 5 | 4.8 |
| *Other* | 3 | 2.9 |
| *Speech therapy* | 2 | 1.9 |
| *Sensorimotor exercises* | 1 | 1 |
| Preferred time frame for intervention | | |
| *Immediately* | 24 | 10.4 |
| *1-3 days* | 32 | 13.9 |
| *3-7 days* | 30 | 13 |
| *7+ days* | 38 | 16.5 |
| *Other* | 107 | 46.3 |
| Preferred time frame for intervention (other) | | |
| *Individualised* | 44 | 62.9 |
| *Age-dependent* | 9 | 12.9 |
| *As soon as possible* | 7 | 10 |
| *Following assessment and non-surgical management* | 6 | 8.6 |
| *At the discretion of the health professional* | 4 | 5.7 |

### *3.4 Education to parents*

When surveyed, less than half (46%) of health professionals reported that they always educate parents about ankyloglossia, and 72% of health professionals provided education to parents about ankyloglossia in over half of their clinical interactions. A smaller proportion (27.5%) of health professionals provide education to parents on ankyloglossia half of the time or less.

Education to parents on frenotomy procedures was completed in all clinical interactions for 29.5% of health professionals. Over half of health professionals (57%) practicing frenotomy procedures reported that they educate parents on frenotomy in more than half of their clinical interactions. Frenotomy education was provided to parents half of the time or less by 36.2% of

health professionals. One participant stated that they never provide education on ankyloglossia, and 15 (6.3%) participants stated they never provide education on frenotomy.

Health professionals in Australia used a variety of tools, and often used more than one modality to educate parents and caregivers on ankyloglossia and frenotomy procedures. Health professionals primarily used verbal explanations when providing education to parents and caregivers (94.5%). Written education was provided by 44.7% of health professionals, as well as the use of web-based education materials (31.6%) and video resources (12.2%). Australian health professionals also reported providing education to parents and caregivers through other methods

### *3.5 Professional development*

Professional development was completed by 174 (73.4%) of health professionals, with 26.6% of respondents having completed no further training in the field. There was no significant difference in the rates of professional development among health professionals working in metropolitan and rural/remote regions (Chi-square; p=0.171).

The types of professional development completed by Australian health professionals were grouped following content analysis and fell into three categories. These included formal training (e.g., specialist training in paediatric dentistry) completed by 36 (20.8%) of respondents, informal training (e.g., attendance at conferences and workshops) completed by 122 (70.5%) of respondents, and self-directed professional development (e.g., reading of published literature) completed by 15 (8.7%) of health professionals.

### *3.6 Confidence and satisfaction of health professionals*

Health professionals were asked to rate their confidence on a Likert scale from 0 to 5 in the areas of assessment, non-surgical management, and surgical management of ankyloglossia. On this scale 0 indicated ‘no confidence’ and a 5 indicated ‘extremely confident’. The responses of health professionals are outlined below and in Table 4.

Of the 203 health professionals who conducted assessment of ankyloglossia, 62.6% reported a high level of confidence about their assessment skills, rating themselves as confident or extremely confident. More than one-third (37.5%) of health professionals rated their confidence as moderately confident or less. No health professionals rated themselves as having no confidence in the assessment of ankyloglossia.

A majority (74.1%) of health professionals performing non-surgical management reported they are moderately to extremely confident in their skills. Average to minimal confidence in their non-surgical management skills was reported by 24.7% of health professionals. One health professional reported no confidence in their non-surgical management skills.

Over half of respondents (53.7%) who perform surgical management of ankyloglossia reported that they feel extremely confident in their skills. Most participants (90.3%) rated moderate to extreme confidence in their surgical management of ankyloglossia. Four health professionals (9.8%) who perform surgical management reported no confidence in their skills. Of the 15 health professionals providing more than 10 surgical procedures per month, 14 reported they were 5/5 confident in their surgical skills.

Further analysis using a Mann-Whitney U-test revealed that there was a significant difference found in the confidence of health professionals when asked about their assessment skills. The confidence of health professionals practicing in metropolitan areas was rated higher than in rural areas (mean 3.9; SD=0.83 vs mean 3.3; SD=1.18; p=0.001). There was no significant difference in the confidence of health professionals practicing in metropolitan and rural areas when it came to non-surgical or surgical management of ankyloglossia (p=0.973 and p=-0.628 respectively). This can be seen in Table 5.

Over half (52%) of the health professionals involved in this study reported that they were dissatisfied with the current service delivery for infants with ankyloglossia, compared to 29.9% who reported that they were satisfied with the current service delivery.

**Table 4.** Confidence of health professionals

| | Assessment | | Non-surgical management | | Surgical management | |
|---|---|---|---|---|---|---|
| | **N** | **%** | **N** | **%** | **N** | **%** |
| 0 (no confidence) | 0 | 0.0 | 1 | 1.3 | 4 | 9.8 |
| 1 | 4 | 2.0 | 1 | 1.3 | 0 | 0.0 |
| 2 | 17 | 8.4 | 3 | 3.9 | 0 | 0.0 |
| 3 | 55 | 27.1 | 15 | 19.5 | 5 | 12.2 |
| 4 | 81 | 39.9 | 35 | 45.5 | 10 | 24.4 |
| 5 (extremely confident) | 46 | 22.7 | 22 | 28.6 | 22 | 53.7 |
| | 203 | | 77 | | 41 | |

**Table 5**. Confidence of health professionals in metro vs rural settings

| | Assessment | | | Non-surgical management | | | Surgical management | | |
|---|---|---|---|---|---|---|---|---|---|
| | All | Metro | Rural | All | Metro | Rural | All | Metro | Rural |
| N | 203 | 152 | 51 | 77 | 62 | 15 | 41 | 32 | 9 |
| *Mean* | 3.7 | **3.9*** | **3.3*** | 3.9 | 3.9 | 4.0 | 4.0 | 3.9 | 4.4 |
| *SD* | 0.97 | **0.83** | **1.18** | 0.98 | 1.02 | 0.85 | 1.51 | 1.65 | 0.73 |
| *Median* | 4.0 | 4.0 | 3.0 | 4.0 | 4 | 4 | 5 | 5 | 5 |
| *Variance* | 0.94 | 0.69 | 1.39 | 0.96 | 1.04 | 0.71 | 2.27 | 2.73 | 0.52 |
| *Min-Max* | 1-5 | 2-5 | 1-5 | 0-5 | 0-5 | 3-5 | 0-5 | 0-5 | 3-5 |

*= Mann-Whitney U-test; p=0.001

### 4. Discussion

This study aimed to explore the diversity and practices of health professionals working in the field of ankyloglossia assessment and management in Australia. The Australian health professionals working in the field of ankyloglossia were diverse regarding disciplines. The cohort included speech pathologists, lactation consultants, midwives, nurses, paediatricians, chiropractors, osteopaths, dentists, general practitioners and other health professionals such as craniosacral therapists, dietitians and oro-facial myologists. The type of health professionals who responded to our questionnaire were largely consistent with those listed as key relevant professionals in the field in Australia[1].

The spread of locations in which these health professionals practice reinforced that ankyloglossia assessment and management is occurring across all areas of Australia. In addition, the health professionals working in this field are incredibly varied in their training backgrounds. The variance in location and discipline highlights the importance of health professionals involved in ankyloglossia assessment and management being unified in diagnostic and management pathways. The experience levels of the health professionals working with infants with ankyloglossia were high, with one third of professionals having worked with infants with ankyloglossia for over ten years.

Professional development that is relevant to the scope of practice of a health professional is vital in maintaining, improving and broadening knowledge, expertise and competency[20]. Continuing professional development is a legal requirement for health professionals in Australia since the establishment of the National Registration and Accreditation Scheme (National Scheme) in 2010. The National Scheme is enacted in each state and territory of Australia since 2009 and 2010 and is regulated by a corresponding National Board for each discipline of health professional. This ensures that Australian health professionals are competent in the areas that they provide care. The professional development rate of 73.4% in our study showcases that over one quarter of health professionals working in the field of ankyloglossia have not completed further training in this area of practice. There was no significant difference in the rates of professional development among health professionals working in metropolitan and rural/remote areas, highlighting that access to professional development did not appear to be the challenging factor. Of the health professionals who had completed professional development in the area of ankyloglossia, 79.2% reported that they had completed informal and self-directed professional development, including reading literature and attending workshops and conferences.

The AHPRA 2021/2022 annual report reported that following routine audits which encompass professional development and recency of practice, 0.23% of health professionals were non-compliant with the registration requirements of their profession[21]. This rate contrasts with the professional development rate of health professionals in our study. This may be due to the lack of training courses in Australia that allow health professionals to register as specialists or experts in the identification or treatment of ankyloglossia[1]. This is likely compounded by the diversity in health professionals involved in the assessment and management of ankyloglossia, with no clear guidelines on the requirements of health professionals working in this field.

In this current study, observations and informal screenings were the most common tools used by health professionals to identify ankyloglossia, with 72.2% and 44.3% using these methods respectively. This is reflected in the comments of health professionals in this study reporting a preference for tools that include functional assessment methods that are individualized to the infant breastfeeding dyad. The health professionals in our study also highlighted a lack of access and training in other ankyloglossia assessment tools. These findings are consistent internationally, with only 33% of Canadian health professionals reporting the use of a framework or policy such as the HATLFF or Frenotomy Decision Tool for Breastfeeding Dyads

(FDTBD) to assess ankyloglossia in their clinical practice[22]. Additionally, over 50% of health professionals in this study reported that every infant is assessed for ankyloglossia. This is a higher proportion of respondents compared to available literature from Canada stating 11% of health professionals suggested that every infant regardless of their symptoms should be assessed for ankyloglossia[22]. The consensus statement released by the Australian Dental Association [1] outlines that the key pre-requisites for qualified health professionals making a suspected ankyloglossia diagnosis are a thorough case history, an objective functional assessment of tongue function using a diagnostic system and a complete assessment of functional issues impacted by the suspected ankyloglossia. This discrepancy between published literature and clinical practice may be contributing factors to the high rates of tongue-tie seen in Australia[13].

The Australian Dental Association's states "Surgical management should only be undertaken by appropriately trained health professionals"[1]. However, further detail outlining what is 'appropriately trained' is not provided, which may have contributed to the diversity of health professionals who performed surgical procedures to management ankyloglossia in this study. This lack of clarity around the necessary training required to perform frenotomy procedures may also be reflected in the low confidence self-ratings in some health professionals conducting these surgical procedures.

The frequency of frenotomy procedures per month was not consistent with the rising rates of frenotomy reported as high as 400% in Canada, and 866% in the United States[23, 24]. In our study, most providers of surgical procedures for the management of ankyloglossia performed less than five procedures per month.

The current study revealed that dentists performed the highest frequency of surgical procedures for ankyloglossia, using laser as their primary tool. This is consistent with reports of increased laser use in frenotomy procedures, with dentists performing 88% of frenotomies by laser[25-27]. A recent study has found that use of the lasers to perform frenotomy was significantly associated with oral aversion and feeding refusal as a complication, however, was associated with less reported bleeding than use of scissors/scalpel for frenotomy[26]. Further studies and protocols should be established to ensure the efficacy of these procedures in Australia, given the insufficient evidence to support laser as a superior technique for frenotomy[3].

Amongst the 237 health professionals who completed the survey and were involved in ankyloglossia assessment and management, satisfaction levels were reported as low regarding the current service delivery for infants with ankyloglossia. These health professionals reported that they are revising assessment and diagnostic tools, and using a combination of tools to assess infants, which highlights the likelihood that these health professionals are not satisfied with the tools currently available to them[15, 26].

The confidence ratings among the workforce in remote areas was lower than that of the workforce in metropolitan areas. It is likely that the reason for this difference is multifactorial. Remote health services are often characterized by high staff turnover, limited numbers of

specialist physicians and a reliance on more generalist health professionals[28, 29]. Additionally, the current study highlighted that there was no significant difference in the rates of professional development amongst health professionals working in remote settings and metropolitan areas. These considerations may imply that the lower confidence ratings of health professionals in rural and remote areas is unlikely to be due to a lack of training, but perhaps the pressure of diagnosing and managing ankyloglossia without clear published diagnostic criteria, and without specialist physicians, in an isolated setting[15, 30].

The rates of education provided to parents by health professionals on frenotomy and associated procedures were considered low. Whilst frenotomy is generally considered a low-risk procedure regardless of the instrument used to perform the division, risks such as bleeding, ulceration, oral aversion and swelling should be considered[1, 3, 31]. These risks should be discussed with parents prior to all frenotomy procedures, as part of the informed consent process[3]. Concerningly, the 15% of health professionals providing frenotomy procedures in this study reported that they only ‘sometimes’ educate parents on the procedure. Health professionals should ensure that they are adherent to the codes of conduct and ethical standards outlined by their professional governing bodies[32].

Potential sample bias was considered to be a limitation of the current study, in that Australian health professional survey participants were recruited based on their own perception of previous experience with infants with ankyloglossia. Incomplete survey responses reduced the effective sample size and may have introduced response bias, as participants who completed the survey in full may differ systematically from those who did not. This should be considered when interpreting the findings, as the results may not fully reflect the experiences of all respondents. A further limitation is the use of Likert scales, as may be considered a subjective method of evaluation. Evidence suggests that responses to a question on a Likert scale may vary across people from different cultures and countries[33]. More broadly, the use of closed-ended survey questions may have constrained the range and depth of responses, limiting participants’ ability to fully elaborate on the complexity of their clinical reasoning and practice. This limitation was managed through the integration of open-ended questions, which offered participants the opportunity to provide detail about their current clinical practice.

Future directions in extending the current study may include examination of parental experiences with current diagnostic and management practices for ankyloglossia. This may lead to a clearer idea of the impact of clinical practice on parental experiences and informed consent. Future studies may explore the professional development opportunities for health professionals when expanding their scope of practice to ankyloglossia diagnosis and management.

**5. Conclusion**

This study was designed to explore the practices of Australian health professionals identifying and managing ankyloglossia in infants, and is the largest survey conducted to date regarding clinical practice in the field of ankyloglossia. At present, ankyloglossia diagnosis and management is occurring across Australia, by a broad range of health professionals including

speech-language pathologists, lactation consultants, midwives, nurses, dentists, as well as medical professionals. The diagnosis, management and education practices varied greatly amongst health professionals in this study. Rates of professional development among health professionals were low. The health professionals performing over 30 frenotomy procedures per month reported high levels of confidence in their skills. Over half of the health professionals involved in this study were dissatisfied with the current service delivery for infants with ankyloglossia. Clinical guidelines for all relevant health professionals are needed to ensure standardised diagnosis and management processes, and to improve clinical confidence and satisfaction. Emphasis on a multidisciplinary approach is essential. These guidelines will help facilitate evidence-based diagnosis and intervention for infants with ankyloglossia.

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**Declaration of interest**
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# Chapter 4

## Ankyloglossia in Australia: Experiences and perspectives of parents and caregivers

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### Ankyloglossia in Australia: Experiences and perspectives of parents and caregivers

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A R T I C L E I N F O

*Keywords:*
Infant
Ankyloglossia
Feeding

A B S T R A C T

*Objectives:* To investigate the perspectives and experiences of parents of infants with ankyloglossia in Australia.
*Method:* Two hundred and sixty-seven parents across Australia responded to an online survey including their experiences of having a child with ankyloglossia. Descriptive statistics were used to analyse quantitative data.
*Results:* Participants were from all Australian states and territories, with the majority residing in New South Wales and Victoria. Ankyloglossia diagnoses typically occurred within the first two weeks of life, driven mainly by difficulties with feeding. Lactation consultants played a prominent role in diagnosis, particularly in rural areas. Surgical interventions were common, with frenotomy using scissors or scalpel being the primary treatment. Aftercare recommendations, including stretching the frenotomy wound, were prevalent. Most parents received education about ankyloglossia, primarily through verbal and written information. Parents generally reported high satisfaction with the effectiveness of treatments, favouring surgical interventions. However, satisfaction with health professionals' support did not consistently correlate with the likelihood of consenting to the treatment again, and those who conducted their own research on ankyloglossia expressed lower satisfaction with health professionals' support.
*Conclusions:* The experiences of Australian parents in their infant's diagnosis, management and education of ankyloglossia varied greatly. Clinical guidelines for all relevant health professionals are needed to ensure standardised diagnosis and management processes. In future, this will help guide evidence-based diagnosis and intervention for infants with ankyloglossia.

#### 1. Introduction

Ankyloglossia, more commonly known as tongue-tie, refers to the limited movement of the tongue causing functional limitations, as well as a visually restricted lingual frenulum [1,2]. Ankyloglossia can result in a range of effects on both newborns and older children, and particularly significant is its connection to feeding difficulties in infants, with half of mothers with infants diagnosed with ankyloglossia experiencing breastfeeding challenges [3]. Ankyloglossia can result in ineffective infant latching, maternal pain during breastfeeding, and ultimately inadequate weight gain and irritability. Whilst these symptoms are the most commonly reported complaints in infants with ankyloglossia, they lack specificity and may be present due to other reasons [4].

A lack of clinical guidelines, diagnostic criteria and tools, pathways for the diagnosis and management of ankyloglossia, and lack of clear outcome measures has resulted in great diversity of practice among health professionals in Australia and internationally [2,5–7]. Our previous study, which explored the practices of Australian health professionals working in the field of ankyloglossia highlighted the variances in clinical practice amongst the cohort [8]. We hypothesised that these variances in clinical practice were likely a direct reflection of a lack of clinical guidelines [8]. This wide range of approaches is expected to lead to significantly varied experiences in the diagnosis and treatment of infants with ankyloglossia among parents in Australia. It has been previously established that an uncoordinated approach to ankyloglossia diagnosis and management creates health care system distrust among mothers, and parents broadly who experience breastfeeding challenges [9].

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Chapter Four of this thesis has been published as:

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I, Donna Akbari Harris, made the following contributions:

- Designed the study with support from the supervisory team.
- Extracted the data
- Conducted the analysis
- Drafted and completed the manuscript with critical feedback and revision from the supervisory team.

The International Journal of Pediatric Otorhinolaryngology requires that the lead author must be the corresponding author.

As primary supervisor for the candidature upon which this thesis is based, I can confirm that the authorship attribution statements above are correct.

Associate Professor Kimberley Docking

Faculty of Medicine and Health

The University of Sydney

I, Donna Akbari Harris, as the candidature student, confirm that the authorship attribution statements above are correct.

Donna Akbari Harris

December 2025

**Ankyloglossia in Australia: Experiences and perspectives of parents and caregivers**

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**Running head:** Ankyloglossia in Australia – parental experiences

**Abstract**

*Objectives*: To investigate the perspectives and experiences of parents of infants with ankyloglossia in Australia.

*Method*: Two hundred and sixty-seven parents across Australia responded to an online survey including their experiences of having a child with ankyloglossia. Descriptive statistics were used to analyse quantitative data.

*Results*: Participants were from all Australian states and territories, with the majority residing in New South Wales and Victoria. Ankyloglossia diagnoses typically occurred within the first two weeks of life, driven mainly by difficulties with feeding. Lactation consultants played a prominent role in diagnosis, particularly in rural areas. Surgical interventions were common, with frenotomy using scissors or scalpel being the primary treatment. Aftercare recommendations, including stretching the frenotomy wound, were prevalent. Most parents received education about ankyloglossia, primarily through verbal and written information. Parents generally reported high satisfaction with the effectiveness of treatments, favouring surgical interventions. However, satisfaction with health professionals' support did not consistently correlate with the likelihood of consenting to the treatment again, and those who conducted their own research on ankyloglossia expressed lower satisfaction with health professionals' support.

*Conclusions*: The experiences of Australian parents in their infant's diagnosis, management and education of ankyloglossia varied greatly. Clinical guidelines for all relevant health professionals are needed to ensure standardised diagnosis and management processes. In future, this will help guide evidence-based diagnosis and intervention for infants with ankyloglossia.

**Keywords**

Infant, ankyloglossia, feeding

## 1. Introduction

Ankyloglossia, more commonly known as tongue-tie, refers to the limited movement of the tongue causing functional limitations, as well as a visually restricted lingual frenulum[1, 2]. Ankyloglossia can result in a range of effects on both newborns and older children, and particularly significant is its connection to feeding difficulties in infants, with half of mothers with infants diagnosed with ankyloglossia experiencing breastfeeding challenges[3]. Ankyloglossia can result in ineffective infant latching, maternal pain during breastfeeding, and ultimately inadequate weight gain and irritability. Whilst these symptoms are the most commonly reported complaints in infants with ankyloglossia, they lack specificity and may be present due to other reasons[4].

A lack of clinical guidelines, diagnostic criteria and tools, pathways for the diagnosis and management of ankyloglossia, and lack of clear outcome measures has resulted in great diversity of practice among health professionals in Australia and internationally[2, 5-7]. Our previous study, which explored the practices of Australian health professionals working in the field of ankyloglossia highlighted the variances in clinical practice amongst the cohort[8]. We hypothesised that these variances in clinical practice were likely a direct reflection of a lack of clinical guidelines[8]. While that study delineated the services and approaches reported by health professionals, the current investigation builds on this work by examining how parents access these services and their satisfaction with the care provided to their infants. Such diversity in practice is likely to translate into markedly different parental experiences of diagnosis and treatment across Australia. Previous research has demonstrated that uncoordinated approaches to ankyloglossia diagnosis and management are associated with health care system distrust among mothers, and parents broadly who experience breastfeeding challenges [9].

Few studies have explored the perspectives of parents with children with ankyloglossia to date, with nil studies of this nature being conducted in Australia. Literature has highlighted the challenges faced by breastfeeding mothers of infants with ankyloglossia, including negative effects on maternal emotional and physical wellbeing[10]. In a study by Waterman et al. (2021), these negative effects were induced by physical pain during breastfeeding, and desperation, guilt and disappointment in their breastfeeding journey[9]. Despite the challenges, the women surveyed in the study demonstrated resilience by advocating and educating themselves, and persevering in their breastfeeding relationship. The Feeding Infants in Newfoundland and Labrador (FiNaL) study conducted in Canada delved into the elements contributing to difficulties in breastfeeding and the early discontinuation of breastfeeding[9]. The findings revealed that mothers who encountered breastfeeding hurdles due to ankyloglossia expressed significant frustration due to the limited availability of evaluation, diagnosis, and treatment options [4]. Additionally, the study underscored the absence of comprehensive assistance for families dealing with ankyloglossia in Canada, and an overall frustration with the health care they received. As a result of this lack of support, parents questioned the expertise of healthcare practitioners working with them and reported receiving inconsistent information from their providers[9].

A consensus statement in 2020 outlined the importance of breastfeeding parents receiving adequate support, education, counselling, and being involved in shared-decision making discussions[2]. Parents are provided with limited education on ankyloglossia the benefits and risks of frenotomy procedures, likely due to the scarcity of literature and standardised guidelines accessible to healthcare professionals[8]. Due to the current absence of defined diagnostic criteria and treatment indications for ankyloglossia, there are implications for informed consent which may impact the post-intervention perceptions of parents. Previous reports of parents of infants with ankyloglossia have described high levels of frustration with access to assessment, diagnosis and management, as well as significant inconsistencies in health care provider knowledge and acceptance of ankyloglossia, and its effect on breastfeeding[9, 11].

The likelihood of a disparity or lack of alignment between the best evidence and practice recommendations of healthcare professionals, and the information that the general public may encounter on non-peer-reviewed social media platforms is consistently highlighted[12]. Whilst health professionals have been reported to use social media to share information[12], professional advertising may not always reflect current best medical evidence, and this vulnerable patient population needs to be fully informed about the options available to them. A study by Grond, Kalllies and McCormick (2021) investigated the social media posts on Twitter of parents with infants with ankyloglossia. These researchers reported that of the parents who tweeted about a previous frenotomy procedure, 92% expressed satisfaction and 8% dissatisfaction post-operatively. In addition, amongst the healthcare providers who stated an opinion on frenotomy, 94.4% were judged to have a pro-frenotomy sentiment[13]. This highlights a need to explore the self-education practices of parents to understand what information is being disseminated online by parents and healthcare providers, as the sentiments expressed may be shaping patient decision making. [13]

The current study, therefore, aims to contribute important information to the limited body of literature on the experiences of Australian parents and caregivers who have had an infant diagnosed with ankyloglossia. Previous Australian research has documented the range of services provided by health professionals working in the area of ankyloglossia, outlining the diversity of assessment and management approaches currently offered [14]. Building on this professional perspective, this study shifts the focus to parents, examining how families access these services and evaluating their satisfaction with the care received. Given the significance of obtaining informed consent and providing patient-centred healthcare, this study set out to investigate the viewpoints and encounters of parents whose infants were diagnosed with ankyloglossia in Australia. The study posited the following hypotheses: (i) parental experiences would exhibit regional variations throughout Australia; (ii) a wide array of professions would be involved in diagnosing and managing infants with ankyloglossia; and (iii) parents would express dissatisfaction with the care their infant received.

## 2. Method

Ethical approval for this cross-sectional questionnaire study was granted by the University of Adelaide Human Research Ethics Committee (H-2023-010).

***2.1 Survey design***

A survey was developed to explore the experiences and perspectives of Australian parents and caregivers who have had a child under the age of two years diagnosed with ankyloglossia. All questions in the survey were categorised into four blocks that included multiple choice question formats. The four blocks explored parents' demographic information, experiences with assessment practices, management practices and the education they were provided.

The first block surveyed parents on their geographical location within Australia based on Modified Monash (MM) Model classifications[14]. The second block contained questions about factors leading to assessment of infants for ankyloglossia, the age of the infant at diagnosis and the health professionals involved in this process. The management of ankyloglossia was explored in block three using multiple choice questions for the type of treatment provided, the health professionals involved in the process, and the post-operative care their child received. A 5-point Likert scale ranging from 1 – 'Not at all to 5 – 'Extremely' was used to identify the parents' perception of the effectiveness of the treatment for ankyloglossia. Fixed anchor points were used as they have been recommended as more reliable when making quantitative comparison[15]. Likert scales were used to ascertain the satisfaction of parents, and the likelihood of parents to consent to the treatment again. Information regarding the types and quality of education provided about ankyloglossia and frenotomy was explored through multiple choice questions and two 5-point Likert scales in block four.

***2.2 Data collection***

Data was collected from a survey developed and published using Qualtrics software (Qualtrics, Provo, UT). Australian parents who have had an infant under the age of two with ankyloglossia were invited to complete the online survey. Parents were recruited via email, professional body newsletters, interest groups and through social media groups for paediatric feeding, ankyloglossia, and related topics. The survey was disseminated through a link generated by the online survey tool. This link was not personalised to any one participant and an email outlining the study and survey was sent to moderators of the interest groups asking them to disseminate to their networks, as well as posted on relevant social media pages and professional body websites. The survey was open for responses from January 2023 until March 2023. Eligible participants for this study included Australian, English-speaking parents who have had a child under the age of two diagnosed with ankyloglossia.

***2.3 Data analysis***

Survey responses were downloaded into IBM SPSS Statistics For Windows (version 26) [16]for further analysis. Descriptive statistics were used to describe general trends. Additionally, Chi-squared and Mann-Whitney U tests were used to explore possible differences between groups of respondents. All p-values were calculated with a two-sided significance level of .05 and power was set at 0.80.

## 3. Results

### *3.1 Study Sample*

A total of 274 responses were collated, of which seven responses were removed due to ineligibility for the study. Responses received from 267 parents are reported.

Demographic information about the respondents is represented in Table 1. Participants responded from all eight Australian states and territories, with over half of parents living in New South Wales (32.6%) or Victoria (22.9%). Based on location, 183 respondents (68.5%) lived in metropolitan or regional cities (MM1-2), and 84 respondents (31.5%) lived in rural and remote areas (MM3-7). The highest proportion of parents living in rural and remote areas was in Northern Territory (70%).

**Table 1 -** Demographic information of participants

| State or Territory | N | % |
|---|---|---|
| *NSW* | 87 | 32.6 |
| *VIC* | 61 | 22.9 |
| *QLD* | 56 | 21.0 |
| *NT* | 23 | 8.6 |
| *WA* | 20 | 7.5 |
| *SA* | 9 | 3.4 |
| *ACT* | 6 | 2.3 |
| *TAS* | 5 | 1.9 |
| Participant location (Modified Monash category) | | |
| *Major city (1)* | 146 | 54.7 |
| *Inner regional (2&3)* | 48 | 18.0 |
| *Outer regional (4&5)* | 42 | 15.7 |
| *Remote (6)* | 28 | 10.5 |
| *Very remote (7)* | 3 | 1.1 |

### *3.2 Ankyloglossia Diagnosis*

#### *3.2.1 Age at diagnosis*

The diagnostic phase of the respondents' ankyloglossia experiences are depicted in Table 2. Of the parents who responded to the survey, 36 (13.5%) parents reported that their infant was diagnosed with ankyloglossia in their first day of life. Over one third of parents (35.6%) reported their infant was diagnosed with ankyloglossia in their first seven days of life, with 45% of infants being diagnosed before two weeks of age. Across the study participants, 262 (98%) parents reported that their child was diagnosed with ankyloglossia before the age of one.

#### *3.2.2 Factors and symptoms that led to diagnosis*

Over 80% (n=214) of parents reported that there was more than one factor that contributed to their infant being diagnosed with ankyloglossia, and over half of parents (52%, n=139) reported that there were three or more factors. The primary reason that led to a diagnosis of ankyloglossia was difficulties with feeding, as reported by 206 (77.2%) parents. This was followed by nipple pain (53.2%), appearance of the tongue (51.7%) and the health professionals' opinion (47.9%). Less common responses provided by parents were that there

was no specific reason that led to their infant being diagnosed with ankyloglossia (1.1%) and other (18.4%). Two (0.7%) parents reported that they were unsure of what led to their infant being diagnosed with ankyloglossia.

***3.2.3 Health professional involved in diagnosis of ankyloglossia***

Of the parents that responded to the survey, 95 (35.6%) parents reported that more than one health professional was involved in the diagnosis of ankyloglossia for their infant. In this study, there were five primary healthcare providers responsible for diagnosing ankyloglossia in Australia. Of these health professionals, lactation consultants issued the highest number of diagnoses in all regions of the country.

The parents of 131 infants reported their child was diagnosed by a lactation consultant, 66 diagnosed by a midwife, 61 self-diagnosed, 51 diagnosed by a doctor, 40 by a dentist, 30 by a health professional not specified in the survey (other), 14 by a speech pathologist, 11 by a nurse, and one parent who was unsure of the health professional who diagnosed their infant with ankyloglossia.

In rural and remote areas of Australia, 67.7% of infants were diagnosed with ankyloglossia by a lactation consultant, compared to 46.6% in metropolitan or regional cities. There was significant difference in the rate of infants diagnosed by a lactation consultant in metropolitan areas and rural and remote areas (Chi-square; $p=0.043$). Additionally, in rural and remote areas, dentists made no ankyloglossia diagnoses, compared to 16.9% of diagnoses in metropolitan or regional cities.

***3.2.4 Location diagnosis occurred***

The diagnosis of ankyloglossia was provided in a hospital setting for 75 infants (28%), community health service for 55 (20.6%), dental clinic for 32 (12.0%), GP office 17 (6.4%) and other for 88 infants (33.0%).

In rural and remote areas of Australia, over half of parents (51.6%) reported their infant was diagnosed with ankyloglossia in a hospital setting, 32.3% in a community health setting, 3.2% in a physician's office, and 12.9% in an unspecified location. In metropolitan and regional areas of Australia, a quarter of parents (25.0%) reported their infant was diagnosed with ankyloglossia in a hospital setting, with dental clinics (13.6%) and community health settings (19.1%) also being key locations where ankyloglossia was diagnosed.

**Figure 1** – Location of ankyloglossia diagnosis

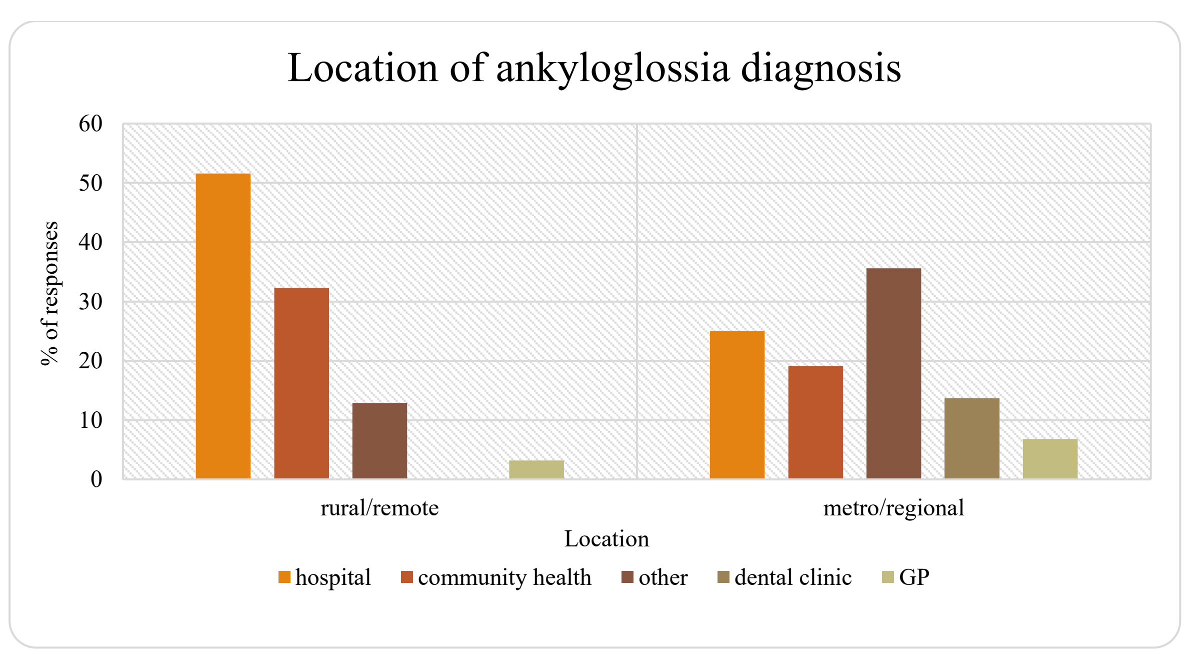



**Table 2** – Ankyloglossia diagnosis experiences among Australian parents

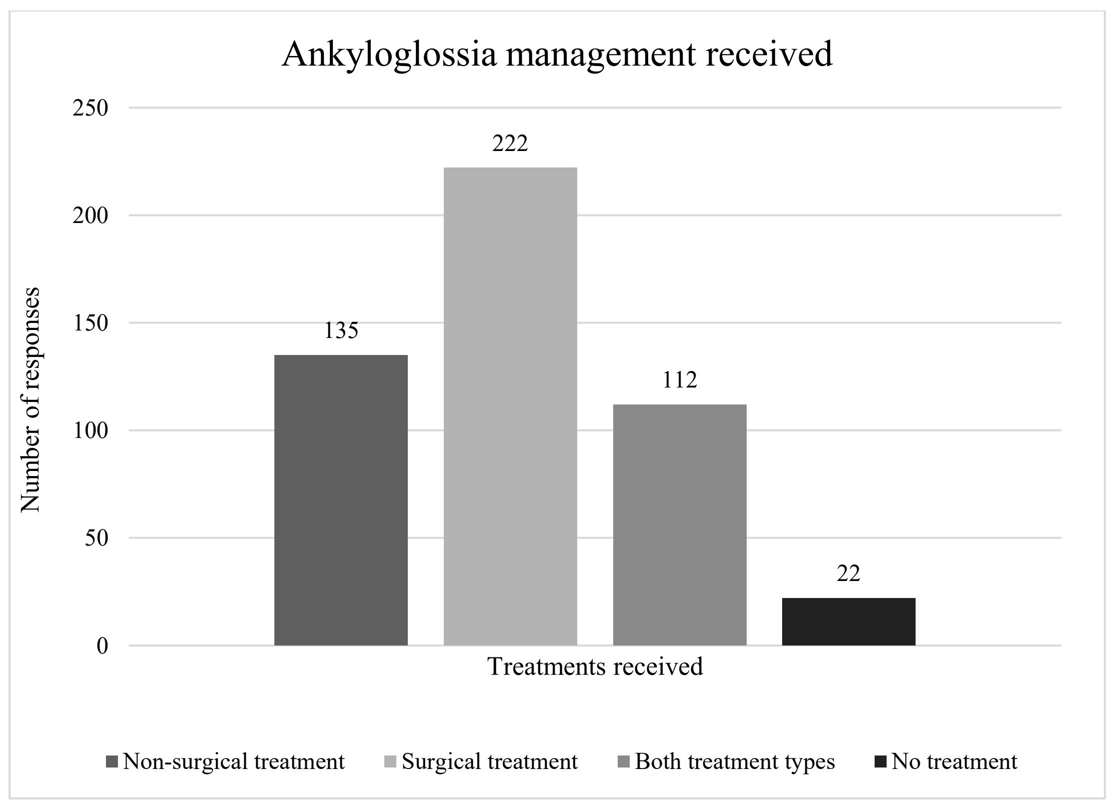
| | N | % |
|---|---|---|
| Age at diagnosis | | |
| *Less than 1 day* | 36 | 13.5 |
| *2-7 days* | 59 | 22.1 |
| *8-14 days* | 26 | 9.7 |
| *Between 2 weeks and 2 months* | 65 | 24.3 |
| *Between 2 months and 1 year* | 76 | 28.5 |
| *Between 1 year and 2 years* | 4 | 1.5 |
| *Over 2 years* | 0 | 0 |
| *Unsure* | 1 | 0.4 |
| Who diagnosed the ankyloglossia | | |
| *Lactation consultant* | 131 | 49.1 |
| *Midwife* | 66 | 24.7 |
| *Self-diagnosed* | 61 | 16.6 |
| *Doctor* | 44 | 16.5 |
| *Dentist* | 40 | 15.0 |
| *Other health professional* | 30 | 11.2 |
| *Speech Pathologist* | 14 | 5.2 |
| *Nurse* | 11 | 4.1 |
| *GP* | 7 | 2.6 |
| *Unsure* | 1 | 0.4 |
| Location of diagnosis | | |
| *Hospital* | 75 | 28.1 |
| *Community health clinic/community service* | 55 | 20.6 |
| *Dental clinic* | 32 | 12.0 |
| *General practitioner's office* | 17 | 6.4 |
| *Other* | 88 | 33.0 |
| What led to diagnosis of ankyloglossia | | |

| | | |
|---|---|---|
| *Difficulties with feeding (difficult latch, difficult suck, other)* | 206 | 77.2 |
| *Nipple pain* | 142 | 53.2 |
| *Appearance of the tongue (heart shaped tongue or other)* | 138 | 51.7 |
| *Health professional's opinion* | 128 | 47.9 |
| *Other* | 49 | 18.4 |
| *No specific reason* | 3 | 1.1 |
| *Unsure* | 2 | 0.8 |
| Other health professionals involved in diagnosis | | |
| *Lactation consultant* | 84 | 31.5 |
| *Dentist* | 67 | 25.1 |
| *None* | 53 | 19.9 |
| *Midwife* | 50 | 18.7 |
| *Other health professional* | 49 | 18.4 |
| *Doctor* | 47 | 17.6 |
| *Nurse* | 27 | 10.1 |
| *GP* | 19 | 7.1 |
| *Speech Pathologist* | 10 | 3.8 |
| *Unsure* | 3 | 1.1 |

### *3.3 Ankyloglossia Management*

Of the 267 parents that responded to the survey, 22 (8.2%) reported that their infant did not receive any management for their ankyloglossia. Conversely, 112 (41.9%) parents reported that their infant received both non-surgical management and surgical management of their ankyloglossia.

**Figure 2** – Ankyloglossia management received



### *3.3.1 Ankyloglossia management – non-surgical*

Of the parents who responded to the survey, 135 (50.6%) respondents reported that their infant received non-surgical treatments for the management of their ankyloglossia, including treatments such as feeding support and equipment changes.

Parents were asked in the survey to specify the non-surgical treatments their infant received, with most parents receiving support with positioning changes (80.7%) and support with latching (79.3%). Other non-surgical treatments received can be found in Table 3.

### *3.3.1 Ankyloglossia management –surgical*

Of the 267 parents who responded to the survey, 222 (83.1%) parents reported that their infant received surgical treatment for the management of their ankyloglossia, and 45 (16.9%) parents reported that their infant did not receive surgical intervention.

Fifteen (6.8%) of these parents reported that their infant received more than one surgical treatment, with 13 (86.7%) having received both a frenotomy performed with scissors or scalpel, as well as a frenotomy with laser.

Frenotomy using scissors or scalpel was the primary treatment that respondents' infants received, with 121 (50.6%) parents selecting this option. This was closely followed by 115 (48.1%) parents selecting laser frenotomy as the surgical treatment their infant received. Three (1.3%) parents reported that their child received a frenuloplasty (plastic surgery) procedure.

When parents were asked to select the health professionals involved in the surgical management of their infants, 49.5% (n=110) parents selected that more than one health professional provided surgical management to their infant. One hundred and twenty-two (55%) parents reported the surgical procedure was completed by a dentist. Other health professionals involved in the surgical management of ankyloglossia, as reported by parents, were lactation consultants (39.6%), general practitioners (20.7%), midwives (12.6%), paediatricians (9.9%), paediatric surgeons (5.9%), nurses (5%) and ENT (2.7%). Four parents reported that were unsure which health professionals were involved in their child's ankyloglossia surgery, and 24 (10.8%) parents reported that an 'other' health professional was involved.

Parents were asked to report on the aftercare recommendations they received from the health professional performing their infants' surgical procedure. Of the 222 parents whose infants received surgical treatments, only 18 parents (8.1%) did not receive any aftercare recommendations following their infant's surgical treatment. Over two thirds of parents (69.8%) were instructed to stretch the frenotomy wound after surgical treatment. Speech pathology intervention was recommended to 4% of parents for their infants following surgical management of ankyloglossia. Other post-surgical aftercare recommendations received can be found in Table 3.

**Table 3** – Management of ankyloglossia

| | N | % |
|---|---|---|
| Non-surgical treatments received | | |

| | | |
|---|---|---|
| *Positioning changes* | 109 | 80.7 |
| *Support with latching* | 107 | 79.3 |
| *Equipment changes* | 79 | 58.5 |
| *Supply support* | 35 | 25.9 |
| *Other feeding methods* | 28 | 20.7 |
| *Other* | 22 | 16.3 |
| Surgical treatments received | | |
| *Frenotomy (cut with scissors or scalpel)* | 121 | 54.5 |
| *Laser frenotomy* | 115 | 51.8 |
| *Frenuloplasty (plastic surgery)* | 3 | 1.4 |
| *Other* | 0 | 0 |
| Location of non-surgical treatment | | |
| *Private clinic* | 37 | 27.4 |
| *Community health centre* | 28 | 20.7 |
| *Hospital* | 27 | 20.0 |
| *At-home service* | 26 | 19.3 |
| *Dental clinic* | 7 | 5.2 |
| *General practitioner* | 6 | 4.4 |
| *Other* | 4 | 3.0 |
| Location of surgical treatment | | |
| *Dental clinic* | 105 | 47.3 |
| *General practitioner's office* | 38 | 17.1 |
| *Private clinic* | 38 | 17.1 |
| *Hospital* | 29 | 13.1 |
| *Community health centre* | 9 | 4.1 |
| *ENT clinic* | 2 | 0.9 |
| *Other* | 1 | 0.5 |
| Post-surgical aftercare recommendations | | |
| *Wound stretching* | 155 | 69.8 |
| *Breastfeeding support* | 122 | 55.0 |
| *Pain medication* | 117 | 52.7 |
| *Breastfeeding/expressed breastmilk/colostrum* | 110 | 49.6 |
| *Oral exercises* | 105 | 47.3 |
| *Skin to skin* | 86 | 38.7 |
| *Sucrose* | 23 | 10.4 |
| *None* | 18 | 8.1 |
| *Speech therapy* | 9 | 4.1 |

### *3.4 Education*

When asked whether parents received education from health professionals regarding the diagnosis or management of their infant's ankyloglossia, 222 (83%) parents reported that they received education about their infant's diagnosis of ankyloglossia. Most parents (n = 250, 94%) conducted their own research into ankyloglossia. Forty-five parents (17%) did not receive any education regarding ankyloglossia.

Verbal information about diagnosis and management of ankyloglossia were the most common types of information provided to parents, with 208 (93.7%) and 168 (75.7%) responses

respectively. Written information about diagnosis and management of ankyloglossia were received by 124 (55.9%) and 106 (47.7%) parents respectively. Other forms of education provided to parents were video information (25.7%), web pages (26.6%) and social media pages (13.1%). Five (2.3%) parents reported receiving ‘other’ forms of education, and two (0.9%) parents reported that they did not receive any of the aforementioned forms of education regarding their infants’ ankyloglossia diagnosis or management.

Parents were asked to rate their satisfaction of the education they received from health professionals on a Likert scale from 1 to 5. On this scale 1 indicated ‘extremely dissatisfied’ and 5 indicated ‘extremely satisfied’. The mean level of satisfaction among parents regarding the education they received from health professionals was 3.7 (SD±1.26, min-max 1-5).

### *3.5 Satisfaction of parents*

Parents were also asked to rate how effective they believe the treatment for their child’s ankyloglossia was on a Likert scale of 1 to 5. On these scales 1 indicated ‘not at all’ and 5 indicated ‘extremely’. Parents reported that surgical treatments were significantly more effective than non-surgical treatments (mean 4.36, SD±0.86 vs 2.71, SD±1.12; unpaired t-test; $p<0.001$).

When asked whether they would consent to the treatment their infant received again, on a Likert scale of 1 to 5 (1 indicating ‘extremely unlikely’ and 5 indicating ‘extremely likely’), parents reported being significantly more likely to consent to surgical treatments again compared to non-surgical treatments (mean 4.61, SD±0.77 vs 3.83, SD±1.34; unpaired t-test; $p<0.001$).

Parents were asked about their satisfaction with the level of support they received from the health professionals involved in their infant’s tongue-tie treatment. On a Likert scale of 1 to 5, where 1 indicated ‘extremely dissatisfied’ and 5 indicated ‘extremely satisfied’, on average, parents reported their satisfaction as 3.9 out of 5.

The satisfaction level of parents regarding the education they received from health professionals did not correlate with their likelihood to consent to the treatment again ($p=0.271$). Additionally, parents who conducted their own research on ankyloglossia rated their level of satisfaction with the support they received from health professionals as lower.

## 4. Discussion

This study proposed several hypotheses: (i) regional variations in parental experiences would be evident across Australia; (ii) diagnosing and managing infants with ankyloglossia would involve a diverse range of professions; and (iii) parents would articulate dissatisfaction with the care provided to their infants. These hypotheses were investigated through the parent survey, and further explored in data analysis.

Regional variations in parental experiences of ankyloglossia diagnosis and management were evident across Australia. In this study, dentists did not provide ankyloglossia diagnoses in rural and remote areas of Australia, while the occurrence of diagnoses by lactation consultants was

notably higher compared to metropolitan regions. As previously noted in the existing literature, Australian dental practitioners who administered laser frenotomy procedures were predominantly concentrated in metropolitan areas[8]. Prior research has established that remote health services commonly experience frequent staff turnover, have fewer specialist physicians available, and depend more on generalist health professionals[17-19]. This study reaffirmed this previously stated observation, as the procedures performed on infants in these geographically distant areas notably omitted laser frenotomy as a treatment option. This underscores the restricted availability of laser surgical interventions for infants residing in rural and remote regions of Australia, and the reliance on frenotomy procedures performed by other health professionals such as lactation consultants.

Our study sheds light on the considerable diversity among health professionals engaged in diagnosing and managing ankyloglossia in Australia, as previously noted in Australian literature[1, 8]. In a previous national survey, Australian health professionals working in the field of ankyloglossia outlined the services they provide, including assessment approaches, surgical and non-surgical management options, and post-procedure care recommendations [14]. That study offered a clinician-centred perspective on the landscape of ankyloglossia management in Australia. The present study extends this body of work by exploring how parents access these reported services and evaluating their satisfaction with the care received. While health professionals may describe defined service pathways and practices, parents' experiences in seeking assessment and treatment for their infant may differ substantially, particularly in the context of inconsistent guidelines and variable access. Taken together, the breadth of professionals involved and the range of services described reflect marked variability in clinical practice, highlighting the absence of standardized guidelines for ankyloglossia diagnosis and management in Australia and internationally [8, 21]. Considerable variations were identified in the post-treatment aftercare recommendations provided in this study, underscoring a lack of uniform protocols for after care practices. In this study, only 8% of parents whose infants received a frenotomy procedure reported that they were not recommended any aftercare treatments. This varies from recent literature where 40% of health professionals reported not recommending any aftercare treatments[20]. Wound stretching was recommend for over two thirds (69.8%) of the infants represented in this Australian study, compared to reports from 38% of American otolaryngologists on providing recommendations for stretching the frenotomy wound. The frequency of parents receiving recommendations to stretch their infants frenotomy wound is concerning, as there is no current evidence demonstrating the efficacy of such stretches[20]. It has been reported that providers of laser frenotomy procedures commonly instruct parents to perform post-procedure wound-stretching exercises multiple times daily for several weeks to help avoid wound reattachment during healing[21]. Further, stretching of surgical wounds is not recommended as it prolongs healing time and increases risk of scarring and infection[22]. The lack of a scientific reason for carrying out these stretches is a medico-legal risk for clinicians who recommend and use this approach, further highlights the lack of standardised guidelines. This study contributes substantively to the ongoing discourse surrounding the urgent need for evidence-based guidelines for all health professionals involved in ankyloglossia management.

The satisfaction of parents regarding the ankyloglossia diagnosis and management their infant received was explored in this study. It has been previously established that breastfeeding parents require adequate support, education, counselling, and being involved in shared-decision making discussions[2]. When health professionals provided information about ankyloglossia in general to parents, it resulted in heightened levels of parental satisfaction and overall contentment with the service they had received. When parents were provided with information about surgical treatments, their satisfaction levels increased, and they reported being more inclined to provide consent for future interventions of the same nature. Conversely, when parents were provided with information regarding non-surgical treatments, their satisfaction levels did not demonstrate a substantial rise, and their inclination to give consent for subsequent interventions was not evident. Parents expressed a favorable perception of the effectiveness of frenotomy and indicated their willingness to provide consent for it in the future. This aligns with existing literature, which reports a high concurrence rate, with 97% of parents expressing a desire to opt for frenotomy in comparable situations[23]. This suggests a general preference for surgical treatments among parents, with educational efforts having limited influence on their treatment preferences.

In this study, the sources of information that parents received, and their subsequent satisfaction regarding their infants' care were explored, as it has been established that healthcare information provided shapes patient decision making[13]. Parents who independently researched ankyloglossia rated their level of satisfaction with the support they received lower, however, their perception of the procedure's effectiveness was not affected. This phenomenon may be attributed to a belief that they possess a deeper understanding of the subject matter or a tendency to have preconceived notions regarding their preferences[24]. Dentists and medical practitioners consistently received positive feedback from parents regarding the care they provided to infants, however, it was noted that they showed relatively lower levels of involvement in educating parents. Although the present findings do not establish a direct or causal relationship, they point to a nuanced interaction between information provision, parental awareness, and reported satisfaction. Parental satisfaction appeared to be shaped by multiple factors, including perceived procedural effectiveness, suggesting that positive outcomes may at times mitigate limited education or counselling. It is possible that parents who received limited information from health professionals were more likely to seek out their own sources of information, which may have influenced their perceptions and satisfaction with care. These findings underscore the complexity of the relationship between education and satisfaction and highlight the importance of further research to clarify how the quality, timing, and depth of information provision influence parental experiences.

Although parents generally expressed satisfaction with the assistance offered by health professionals, it is crucial to highlight that this satisfaction did not consistently align with their willingness to grant consent for the intervention again. This aligns with a study by Ray and colleagues [10] exploring maternal perspectives of frenotomy, as reported by mothers in social media groups such as breastfeeding forums. Overall, more posts expressed positive experiences

in the diagnosis and treatment of their child's ankyloglossia, compared to negative or neutral ones[10]. This differs from findings in Canada, where parents reported a low level of satisfaction with the support provided by health professionals for their child's ankyloglossia[9]. Health professionals involved in ankyloglossia diagnosis and management should use these parental reports to guide their education practices, informed consent procedures and improve shared decision making.

It has been widely established that informed consent and shared decision making are fundamental principles in medical ethics and the cornerstone of patient-centered care[25, 26]. It upholds the principles of autonomy, transparency, and shared decision-making, ensuring that patients are fully informed and able to make choices that align with their values and preferences[27]. Including parents in all stages of their infants' ankyloglossia journey and upholding informed consent in healthcare facilities are paramount. This helps reduce decision conflict and promotes shared decision-making in the absence of robust clinical guidelines for diagnosing and managing ankyloglossia.

Limitations of this study included that the participants may not be representative of their respective groups, as the responses in this study are representative of the parents who are willing to participate in research studies. Secondly, the closed questions in this study were designed to facilitate a short survey response time for each participant, however, this led to a lack of clarity in some questions where parents were unable to provide further information.

The reasons leading to the diagnosis of ankyloglossia in our study closely mirror those documented in the existing literature, corroborating the previously established association between ankyloglossia and a spectrum of effects on feeding, encompassing challenges such as latching difficulty, feeding struggles, and maternal pain[4, 10, 28-30]. This agreement confirms the reliability of existing knowledge and reinforces the understanding that ankyloglossia is a complex condition affecting both infants and mothers during breastfeeding.

**5. Conclusion**

Findings from this study highlighted the multifaceted nature of the diagnosis and treatment of ankyloglossia, and its tangible impact on both infants and mothers during breastfeeding. Notably, variations in clinical practices, from diagnosis to aftercare, underscore the lack of standardized guidelines in the field. This emphasizes the pressing need for comprehensive and uniform clinical protocols for the diagnosis and management of ankyloglossia. The geographical concentration of laser frenotomy procedures in metropolitan areas, parental satisfaction with surgical interventions, and the importance of informed consent and shared decision making in healthcare emerge as critical themes in our findings. Findings from this study signal the need for the development of evidence-based guidelines to ensure consistent and optimal care for infants with ankyloglossia across diverse healthcare settings in Australia. This research sheds light on regional variations, underscores the importance of ethical healthcare practices, and emphasizes the need for uniformity in the care provided to infants with ankyloglossia nationwide.

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# Chapter 5

## Ankyloglossia in Australia: Parental experiences of treatment

*Research Article*

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### Ankyloglossia in Australia: Parental Experiences of Treatment

**Donna Akbari[1], Hans Bogaardt[2,3], and Kimberley Docking[1]**

**Abstract**

**Objectives:** To investigate the perspectives of parents on their treatment decisions for the management of their child's ankyloglossia (tongue-tie).

**Method:** Ninety-eight parents across Australia responded to an online survey about their perspectives on treatment for their infant's ankyloglossia. Descriptive statistics were used to analyse quantitative data, and thematic analysis was used to describe qualitative data.

**Results:** Participants were from all Australian states and territories. Ankyloglossia was most often diagnosed by lactation consultants and midwives within the first week of life, with nearly all cases identified during the first year. While all parents were offered non-surgical treatments, most reported persistent feeding difficulties. Surgical treatment, typically conventional or laser frenotomy, was offered to almost all parents. Surgical intervention was successful for most infants, though spontaneous recovery of feeding difficulties without intervention was also observed. Key reasons for declining surgery included positive experiences with non-surgical treatment, concerns about surgical risks, and conflicting information. Overall, parents were more likely to consent to surgical than non-surgical treatment in the future, though experiences of shared decision-making were rated more positively with non-surgical providers.

**Conclusions:** Parental involvement and engagement in managing infant ankyloglossia was linked to positive perceptions of outcomes. Surgical treatment showed favourable results, though some infants improved without intervention, underscoring the need for standardised protocols. Findings emphasise the need for clear communication and shared decision-making to support parents and reduce unnecessary treatment.

*Keywords:* infant, ankyloglossia, feeding, frenotomy, treatment

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### Introduction

Ankyloglossia, commonly referred to as tongue-tie, is a congenital oral anomaly characterised by an abnormally short or tight lingual frenulum or midline fold that can restrict tongue movement and function (Australian Dental Association, 2020; Mills et al., 2019; Walsh & McKenna Benoit, 2019). Importantly, it has been well established in recent literature that the presence of a visible or palpable lingual frenulum is a normal finding in young children and, on its own, should not be classified as tongue-tie unless it is associated with functional impairment (Haham et al., 2014). The impacts of ankyloglossia in infants are largely centred around breastfeeding and feeding in general. Cordray et al. (Cordray et al., 2023), in a systematic review and meta-analysis, found strong associations between ankyloglossia and indicators of unsuccessful breastfeeding, including infant symptoms such as poor latch, feeding fatigue, poor weight gain, and gastroesophageal reflux, as well as maternal symptoms such as nipple pain, breast engorgement, and nipple damage. Further, feeding-related challenges associated with ankyloglossia can take a substantial emotional toll, often evoking maternal feelings of desperation, guilt or shame, and disappointment, and have been shown to

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## Authorship Attribution Statement

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I, Donna Akbari Harris, made the following contributions:

- Designed the study with support from the supervisory team.
- Extracted the data
- Conducted the analysis
- Drafted and completed the manuscript with critical feedback and revision from the supervisory team.

*Advances in Communication and Swallowing* requires that the lead author must be the corresponding author.

As primary supervisor for the candidature upon which this thesis is based, I can confirm that the authorship attribution statements above are correct.

Associate Professor Kimberley Docking

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I, Donna Akbari Harris, as the candidature student, confirm that the authorship attribution statements above are correct.

Donna Akbari Harris

December 2025

**Ankyloglossia in Australia: Parental Experiences of Treatment**

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Ethical approval for this cross-sectional questionnaire study was granted by the University of Adelaide Human Research Ethics Committee (H-2024-114) on August 08, 2024.

**Abstract**

*Objectives*: To investigate the perspectives of parents on their treatment decisions for the management of their child's ankyloglossia (tongue-tie).

*Method*: Ninety-eight parents across Australia responded to an online survey about their perspectives on treatment for their infant's ankyloglossia. Descriptive statistics were used to analyse quantitative data, and thematic analysis was used to describe qualitative data.

*Results*: Participants were from all Australian states and territories. Ankyloglossia was most often diagnosed by lactation consultants and midwives within the first week of life, with nearly all cases identified during the first year. While all parents were offered non-surgical treatments, most reported persistent feeding difficulties. Surgical treatment, typically conventional or laser frenotomy, was offered to almost all parents. Surgical intervention was successful for most infants, though spontaneous recovery of feeding difficulties without intervention was also observed. Key reasons for declining surgery included positive experiences with non-surgical treatment, concerns about surgical risks, and conflicting information. Overall, parents were more likely to consent to surgical than non-surgical treatment in the future, though experiences of shared decision-making were rated more positively with non-surgical providers.

*Conclusions*: Parental involvement and engagement in managing infant ankyloglossia was linked to positive perceptions of outcomes. Surgical treatment showed favourable results, though some infants improved without intervention, underscoring the need for standardised protocols. Findings emphasise the need for clear communication and shared decision-making to support parents and reduce unnecessary treatment.

**Keywords**

Infant, ankyloglossia, feeding, frenotomy, treatment

## 1. Introduction

Ankyloglossia, commonly referred to as tongue-tie, is a congenital oral anomaly characterized by an abnormally short or tight lingual frenulum or midline fold that can restrict tongue movement and function[1-3]. Importantly, it has been well established in recent literature that the presence of a visible or palpable lingual frenulum is a normal finding in young children and, on its own, should not be classified as tongue-tie unless it is associated with functional impairment[4]. The impacts of ankyloglossia in infants are largely centred around breastfeeding and feeding in general. Cordray et al[5], in a systematic review and meta-analysis, found strong associations between ankyloglossia and indicators of unsuccessful breastfeeding, including infant symptoms such as poor latch, feeding fatigue, poor weight gain, and gastroesophageal reflux, as well as maternal symptoms such as nipple pain, breast engorgement, and nipple damage. Further, feeding-related challenges associated with ankyloglossia can take a substantial emotional toll, often evoking maternal feelings of desperation, guilt or shame, and disappointment, and have been shown to affect the maternal–child bond, thereby likely contributing to postpartum depression[6-8]. In addition to feeding difficulties in infants and young children, ankyloglossia has historically been linked to speech and oral development[9, 10]. However, recent literature shows no difference in tongue mobility or speech outcomes in young children regardless of intervention in infancy, and therefore does not support surgical treatment during this period solely to enhance later speech production[10, 11].

The reported prevalence of ankyloglossia in Australia has not been extensively recorded. However, estimates range from approximately 4.2% to 11%, based on international studies[12]. A study conducted in Central Australia found that 10.2% of infants under two years old were diagnosed with ankyloglossia, with a higher prevalence observed in males[13]. Prevalence across Australia could vary due to differences in diagnostic criteria and reporting practices[12, 14]. A variety of diagnostic and classification tools exist to evaluate and categorise ankyloglossia based on both appearance and functional impact. However, to date, no clinical consensus has been reached regarding the optimal tool for use across the Australian healthcare system.

The primary treatment types available can be classified into two approaches: non-surgical treatments and surgical treatments. Non-surgical treatments are often provided by trained health professionals including International Board-Certified Lactation Consultants (IBCLCs), midwives, child health nurses, speech-language pathologists and/or alternative health providers such as chiropractors and osteopaths[2, 15]. These treatments encompass feeding support, such as positional changes, latch optimisation, and the use of external tools like nipple shields or supplementary nursing systems. They also include alternative approaches such as bodywork and craniosacral therapy[2, 14, 15]. Surgical treatment for ankyloglossia primarily involves conventional frenotomy, in which the lingual frenulum is divided using scissors or a scalpel, although a laser may also be used[16-22]. Other surgical treatments include a frenuloplasty/Z-plasty[16]. Frenotomy is generally considered a safe and effective procedure for the management of breastfeeding challenges, however, complications such as bleeding, airway obstruction, scarring and oral aversions have been reported throughout literature[23-28].

Whilst ankyloglossia is a relatively common issue affecting infants, the diagnostic and treatment processes vary considerably[14, 29].

Understanding parental experiences is crucial, as parents are often the primary decision-makers in seeking assessment and treatment for ankyloglossia. Their perceptions of symptoms, treatment options, and anticipated outcomes directly influence whether and when intervention is pursued. Exploring the parental experience provides valuable insight into the factors shaping healthcare decisions, highlights potential barriers to accessing care, and can inform strategies to improve support and communication between providers and families[29]. The importance of shared decision making between parents and health professionals has been documented extensively, and is vital to making health care decisions that are individualized to the patient and incorporate their values and preferences[30, 31]. Further, it has been established that active and tailored support from healthcare professionals, along with coordinated multidisciplinary teamwork, strengthens parents' role in their child's healthcare and ensures they receive clear and consistent information[32].

In Australia, the clinical management of ankyloglossia varies considerably, with healthcare providers adopting a variety of approaches to diagnosis and treatment[14]. Despite increasing clinical attention, limited research has examined how parents experience navigating this condition on behalf of their children. Gaining insight into these perspectives and experiences is essential for improving care pathways, enhancing provider-parent communication, and strengthening parental support[33]. To date, international studies have investigated the perspectives of parents on ankyloglossia management through social media[34], however, there have been no Australian studies directly exploring the lived experiences of parents managing the process of ankyloglossia management. This study seeks to address this gap by examining the experiences of Australian parents whose infants have undergone treatment for ankyloglossia, with particular attention to: (i) their interactions with healthcare providers, (ii) their access to different treatment options, (iii) their perceptions of treatment outcomes, and (iv) their personal experiences throughout the care pathway and beyond.

## 2. Method

Ethical approval for this cross-sectional questionnaire study was granted by the University of Adelaide Human Research Ethics Committee (H-2024-114).

### *2.1 Survey design*

A survey was developed using Qualtrics software (www.qualtrics.com) to explore treatments of ankyloglossia experienced by Australian parents, and their outcomes as reported by parents. All questions in the survey were categorised into four blocks that included multiple choice and open response question formats. The blocks explored parents' background, treatment experiences, outcomes of treatment, research they had conducted and the provision of education. Open response questions were included.

Quantitative data regarding parental perspectives of treatment outcomes was compiled by utilizing multiple choice questions, and the Likert Scale 1–5 (1 – Very ineffective, 3 – Neutral,

5 – Very effective). Parents were asked to consider time frames for symptom resolution, education they received regarding various treatment options and their experiences with the health professionals involved in their infant's care.

### *2.2 Data collection*

Data for this study was collected using a survey developed and hosted on Qualtrics software (www.qualtrics.com). Australian parents of infants diagnosed with ankyloglossia were invited to participate in the anonymous online survey via a Qualtrics web link. Participants were recruited through multiple channels, including email, newsletters from professional bodies, interest groups, and social media platforms focused on pediatric feeding, ankyloglossia, and related topics. Additionally, recruitment efforts were supported by health professionals from speech pathology, midwifery, and nursing departments in hospitals and community health centers across Australia. The survey was distributed using a link and QR code generated by Qualtrics, which was non-specific to individual participants. An email outlining details of the study and containing the survey link was sent to moderators of relevant interest groups and managers of health services, requesting further dissemination to staff, colleagues, and group members. The survey link was also shared on social media platforms and posted on websites of professional organizations. The survey was open for responses from October 2024 until December 2024. Eligibility criteria included English-speaking parents with an infant diagnosed with ankyloglossia in Australia.

### *2.3 Data analysis*

Survey responses were exported into IBM SPSS Statistics for Windows (version 26) for quantitative analysis. Descriptive statistics were used to summarise overall trends and patterns within the data. Group differences were analysed using chi-squared tests for categorical variables, and Mann-Whitney U tests for ordinal or non-normally distributed continuous variables. All statistical tests were two-tailed, with significance defined as $p = 0.05$. A statistical power level of 0.80 was applied to ensure sufficient sensitivity to detect meaningful differences.

Qualitative data gathered from open-ended survey questions were entered into Microsoft Excel for the purpose of thematic analysis. This analysis focused on exploring parents' experiences related to the management of their child's ankyloglossia. Qualitative data were examined using Braun and Clarke's six-phase approach to thematic analysis [35]. To begin, two researchers (D.A. and H.B.) independently immersed themselves in the dataset through repeated readings, identifying patterns, recurring elements, and notable or unexpected responses. From this process, initial codes were systematically generated across the data and grouped into preliminary categories. These codes were then compared and discussed between the two researchers to strengthen analytic rigour. The lead researcher (D.A.) subsequently conducted further analysis to organise codes into potential themes. All authors reviewed the themes in relation to both the coded extracts and the entire dataset, refining and clearly defining them, with any disagreements resolved through discussion, consensus, or by the lead researcher where necessary. Finally, the themes were structured into a coherent analytic narrative by D.A., illustrated with representative quotes, to address the study's research questions.

## 3. Results

### *3.1 Study Sample*

A total of 132 survey responses were collected, with 34 excluded due to ineligibility. Data from the remaining 98 eligible parent respondents are presented.

The respondents were divided into four treatment groups, with 26 (26.5%) participants in the no intervention group, 5 (5.1%) in the non-surgical treatment group, 21 (21.4%) in the surgical treatment group, and 46 (46.9%) in the non-surgical and surgical dual treatment group.

Demographic characteristics of the participants are summarised in Table 1. Responses were received from all eight Australian states and territories, with the majority residing in Queensland (30.6%) or New South Wales (22.4%). In terms of geographic classification, 68 respondents (69.4%) were located in metropolitan or regional centres (MM1–2), while 30 respondents (30.6%) lived in rural or remote areas (MM3–7). There was no significant difference between treatment groups across the states of Australia (Chi-square; p=0.407), nor across geographical classifications (Chi-square; p=0.430).

**Table 1 -** Location information of participants

| State or Territory | N | % |
|---|---|---|
| *QLD* | 30 | 30.6 |
| *NSW* | 22 | 22.4 |
| *VIC* | 17 | 17.3 |
| *NT* | 13 | 13.3 |
| *WA* | 6 | 6.1 |
| *SA* | 5 | 5.1 |
| *ACT* | 3 | 3.1 |
| *TAS* | 2 | 2.0 |
| Participant location (Modified Monash category) | | |
| *Metropolitan/Regional City (1-2)* | 68 | 69.4 |
| *Rural and Remote (3-7)* | 30 | 30.6 |

### *3.2 Ankyloglossia Diagnosis*

Of the parents who responded to the survey, 40 (40.8%) parents reported that their infant was diagnosed with ankyloglossia in their first week of life, with 95 (96.9%) parents reporting in their first year of life. There were no significant differences in ages of diagnosis across the four treatment groups (Kruskal-Wallis; p=0.510), and no significant differences in ages across Australian states and territories (Chi-square; p=0.08). There were statistically significant differences in the age of ankyloglossia diagnosis across geographical locations, with infants in metropolitan areas being diagnosed earlier than in rural or remote areas (Chi-square; p=0.018).

The primary symptoms of ankyloglossia exhibited by infants in this study, as reported by their parents, were difficulties with feeding including poor latch and suck (68; 30%) and the appearance of the tongue (50; 22%).

The health professionals providing an ankyloglossia diagnosis to infants in this study were primarily lactation consultants (including IBCLCs) (53; 34%), midwives (32; 20.5%), dentists (17; 10.9%) and paediatricians (12; 7.7%). Self-diagnosis was also reported amongst parents responding to this study (14; 9%). The diagnostic phase of the respondents' ankyloglossia experiences is depicted in Table 2.

**Table 2** – Diagnostic information

| | N | % |
|---|---|---|
| Age at diagnosis | | |
| *Less than 1 day* | 17 | 17.3 |
| *2-7 days* | 23 | 23.5 |
| *8-14 days* | 5 | 5.1 |
| *Between 2 weeks and 2 months* | 29 | 29.6 |
| *Between 2 months and 1 year* | 21 | 21.4 |
| *Between 1 year and 2 years* | 3 | 3.1 |
| Primary symptoms of ankyloglossia | | |
| *Difficulties with feeding (difficult latch, difficult suck, other)* | 72 | 31.7 |
| *Appearance of the tongue (heart shaped tongue or other)* | 52 | 22.9 |
| *Nipple pain* | 44 | 19.4 |
| *Health professional's opinion* | 40 | 17.6 |
| *Other* | 17 | 7.5 |
| *No specific reason* | 1 | 0.4 |
| *Unsure* | 1 | 0.4 |
| Health professional providing ankyloglossia diagnosis | | |
| *Lactation consultant/IBCLC* | 53 | 34 |
| *Midwife* | 32 | 20.5 |
| *Dentist* | 17 | 10.9 |
| *Self-diagnosed* | 14 | 9 |
| *Paediatrician* | 12 | 7.7 |
| *Speech Pathologist* | 8 | 5.1 |
| *Nurse* | 8 | 5.1 |
| *General practitioner* | 7 | 4.5 |
| *Unsure* | 2 | 1.3 |
| *Osteopath* | 2 | 1.3 |
| *Obstetrician* | 1 | 0.6 |

### *3.3 Ankyloglossia Management*

Of the 98 parents that responded to the survey, 79 (80.6%) were offered treatment for their infants ankyloglossia, with 74 (93.7%) being offered surgical treatment and 57 (72.2%) being

offered non-surgical treatment. Nineteen (19.4%) parents were not offered treatment for their infants' ankyloglossia.

### *3.3.1 Ankyloglossia management – non-surgical*

Among the parents who responded to the survey, 57 (73.1%) were offered non-surgical treatment, while 21 (26.9%) were not. Of those offered non-surgical treatment, 51 (89.5%) consented, 1 (1.8%) was unsure, and 5 (8.8%) did not consent to the treatment for their infant. Positioning changes (51; 33.6%), support with latching (44; 28.9%) and equipment changes (32; 21.1%) were the most common non-surgical treatments provided. All parents were offered multiple types of non-surgical treatment, with the majority receiving offers of either two options (29.8%) or three options (35.1%)

Of the 51 parents who consented to non-surgical treatment, 23 (45%) reported involvement of both a midwife and lactation consultant. Non-surgical care was most often provided by lactation consultants (39; 38.2%) and midwives (29; 28.4%), with additional involvement from chiropractors (8), osteopaths (8), nurses (7), doctors (5), speech pathologists (2), and dentists (2). Two parents were unsure of the provider. Overall, 70.6% of parents reported that two or more professionals were involved in their infant's non-surgical care.

Parents were asked to rate how effective they believe the non-surgical treatment for their child's ankyloglossia was on a Likert scale of 1 to 5. On these scales 1 indicated 'very ineffective' and 5 indicated 'very effective'. The mean rating of effectiveness reported by parents was 2.46 (SD±0.994, min-max 1-5). There were no significant differences in parental-reported effectiveness of non-surgical treatment across geographical categories in Australia (Kruskal-Wallis; $p=0.232$).

Ongoing symptoms following non-surgical treatment were explored in Q26 and Q27 using content and thematic analysis, with 39 (78%) of parents reporting their infant had ongoing symptoms of ankyloglossia following non-surgical treatment, 4 (8%) parents reporting they were unsure, and 7 (14%) parents reporting no ongoing symptoms following non-surgical treatment of their infant's ankyloglossia. There was no significant difference in prevalence of ongoing symptoms following non-surgical treatment across geographical categories in Australia (Chi-square; $p=0.748$).

The perspectives of the 39 parents who reported that their infant had ongoing symptoms of ankyloglossia following non-surgical treatment were examined in greater detail through thematic analysis, and these symptoms were grouped into the following key themes: latching difficulties, pain and nipple damage, poor weight gain, air intake and reflux and tongue restriction

Significant difficulty with latching was reported by 28 participants, despite attempts to address the issues, which in turn affected their ability to breastfeed or bottle-feed successfully. One participant shared that their baby was "*unable to latch and breastfeed properly, unable to take a bottle.*" (P7). Another parent noted persistent difficulties, stating that their child had "*trouble latching/feeding, fussing, [and] biting*" (P5). For some families, latching difficulties remained unresolved despite various interventions. One parent reported that their baby experienced

"*poor latch and [was] sick, restricted tongue lateralisation, [with an] obvious heart-shaped tongue tip due to short frenulum*" (P48).

Pain during breastfeeding was a common concern among respondents, with some experiencing significant nipple trauma. One participant described the challenge succinctly, stating they had "*pain with breastfeeding"* (P2). Another explained that their baby's poor latch resulted in *"++ nipple pain and bleeding"* (P9), making breastfeeding particularly difficult. Some participants described *"continued nipple pain and damage"* (P94) that did not resolve over time. These experiences highlight the physical toll of breastfeeding difficulties, which often required ongoing management.

Concerns around inadequate weight gain and inefficient feeding were frequently mentioned, often linked to poor latch and prolonged feeding sessions. One parent reported that their baby was *"not gaining weight"* (P7), while another described how their infant experienced *"difficult feeding, reduced weight gain"* (P15). In some cases, ineffective feeding led to exhaustion for both the infant and caregiver. One participant described how their baby would *"work so hard to feed that [they'd] fall asleep after 20 to 30 minutes and wake up starving"*, creating a *"cycle of constant feeding with little improvement"* in intake (P80).

Problems with excessive air intake during feeding were highlighted by 13 respondents, leading to gas, reflux, and discomfort for their infants. One parent described how their baby experienced *"painful gas, nipple pain, falling off, choking on milk and spluttering, [and] distress"* (P32). Another explained that their child had *"wind from sucking in air from not latching properly"* (P76), further exacerbating feeding difficulties.

Reflux was also a concern, with one participant reporting that their baby had *"latch issues, reflux due to excess air, [and] nipple pain"* (P76). Another parent described how feeding difficulties led to *"constant and severe wind"* (P30), while another observed *"mucousy poos, severe gas pain, vomiting, clicking at breast, and difficulty extracting milk from breast"* (P91). These feeding-related complications significantly impacted both infant comfort and parental stress levels.

Several participants noted that their infants had restrictions in tongue movement, which contributed to feeding difficulties. One parent reported that their baby was *"unable to poke tongue out"* (P20), while another described *"poor tongue protrusion/elevation"* (P33). One participant explicitly linked their child's feeding struggles to tongue restriction, explaining that their baby had *"restricted tongue lateralisation [and an] obvious heart-shaped tongue tip due to short frenulum"* (P44). These findings highlight the structural challenges that can complicate breastfeeding and require further assessment.

For some families, non-surgical intervention did not lead to significant improvements. One participant noted that their baby's feeding challenges remained the *"same as at diagnosis"* (P27), indicating that despite efforts to address the issue, their difficulties persisted.

When asked whether they would consent to their infant receiving the same non-surgical treatment again, using a 5-point Likert scale (1 = 'extremely unlikely', 5 = 'extremely likely'), just over half of parents (53.4%) indicated they would be 'likely' or 'extremely likely' to do so,

while 11.1% reported they would be 'unlikely' or 'extremely unlikely'. The remaining 16 parents (35.5%) expressed a neutral stance (mean 3.62, SD±0.994, min-max 1-5).

Parents who declined non-surgical treatment after it was offered were asked to indicate the time taken for their infants' ankyloglossia-related feeding difficulties to resolve. Forty percent reported resolution within one week, while 20% reported resolution within 1–2 weeks, another 20% within 2 weeks to 1 month, and the remaining 20% within 1–6 months.

#### *3.3.1 Ankyloglossia management –surgical*

Surgical treatment was offered to 74 (93.7%) parents. When surgical treatment was offered to parents, 60 (81.1%) parents consented to this treatment, and 14 (18.9%) did not consent. Of the 14 parents who did not initially consent to surgical treatment, 6 (42.9%) then went on to later consent to surgical treatment, and 8 (57.1%) parents opted for their infant to not receive surgical treatment.

The surgical treatments offered to parents for the management of their infants ankyloglossia included conventional frenotomy using scissors or scalpel (57.5%), laser frenotomy (41.4%) and frenuloplasty (1.1%). 13 (17.6%) parents were offered more than one surgical treatment – both laser and conventional frenotomy.

Of the parents who consented to surgical treatment for their infants' ankyloglossia, 38 parents (38.7%) reported that more than one health professional was involved in the surgical treatment of ankyloglossia for their infant. In this study, the two primary healthcare providers involved in the provision of surgical treatment were lactation consultants (32; 26.2%) and dentists (31; 25.4%). Other health professionals involved in surgical treatment were midwives (12.3%), general practitioners (9.8%), paediatricians (9.0%), paediatric surgeons (8.2%), nurses (3.3%), chiropractors (2.5%) and osteopaths (0.8%). Two parents (1.6%) were unsure of who the health professional was who was involved in their infant's surgical treatment, and one parent (0.8%) reported that an 'other' health professional was involved.

Parents who responded to this survey were asked about why they initially declined surgical treatment when it was initially offered. Responses varied amongst parents, however, the primary themes surrounded a preference for non-surgical approaches, uncertainty and conflicting professional advice, and the emotional toll to decision making. Four parents reported that they *"preferred to try non-surgical options first"* (P57) and that they *"wanted more time to consider available options"* (P5).

> *"I wanted to try non-invasive treatments first (which did improve things but not get rid of all symptoms), then move on to surgical options next if needed."* (P68)

The emotional toll of the decision was highlighted by four parents, who reported *"uncertainty about the effectiveness of the surgery"* and *"lack of clarity"* in diagnosis, leading to them feeling *"unsupported and overwhelmed"*, and *"highly anxious"* (PP80; P91).

> *"I did not want to put my 6-week-old through a surgical procedure as I was highly anxious and nervous. Also, I wanted to try other options before ultimately consenting to surgical treatment."* (P91)

Ongoing symptoms following the decision to not receive surgical treatment were explored. Among the seven cases where parents declined surgical treatment for their infants' ankyloglossia, symptoms resolved spontaneously in five infants. Of these five, four received no interventions, while one received non-surgical treatment. The infants with ongoing symptoms of ankyloglossia were reported to exhibit three primary concerns – delayed speech, mouth breathing and appearance: *"Just appearance. Forked tongue however it did not actually cause issues, just an appearance fortunately"* (P14)

When asked about their decision-making process, the eight parents (57.1%) who chose not to pursue surgical treatment for their infant identified three key themes: positive experiences with non-surgical management, concerns about the potential risks of surgery, and challenges in navigating conflicting information.

> *"I didn't feel I needed it as she was able to breastfeed well and had no issues with solids when she started, nor has she had issues needing to talk. I didn't want to cause unnecessary surgical treatment if I could avoid it, but I am open to treatment in the future if necessary."* (P14)

> *"The IBCLC seemed to diagnose every baby with this in our local area and it seemed to be a 'fashion'. I did not want to risk an oral aversion due to laser treatment when baby was growing fine and no pain – just shallow latch."* (P90)

Overall, parents who chose not to pursue surgical treatment for their infant self-reported high levels of satisfaction with their decision, with 100% of responses being either satisfied (16.7%) or very satisfied (83.3%) (mean 4.83, SD±0.408, min-max 4-5).

Parents were asked whether their infants experienced ongoing symptoms of ankyloglossia following surgical treatment and how long it took for these symptoms to resolve. Ten parents (26.3%) reported that their infants continued to have symptoms after surgery, 23 parents (60.5%) indicated that the surgical treatment resolved their infants' symptoms, and five parents (13.2%) were unsure whether the symptoms had fully resolved. Regarding the timeframe for symptom resolution, just over half of parents (51.1%) reported that their infants' symptoms resolved within two weeks, and the majority (87.2%) observed symptom resolution within six months following surgical treatment. There was no significant difference in prevalence of ongoing symptoms following surgical treatment across geographical categories in Australia (Chi-square; p=0.687).

The responses of parents to the question of what their infant's ongoing symptoms were following surgical treatment were analysed through both content and thematic analysis and overall themes of ongoing feeding challenges, post-surgical outcomes and lingering concerns, and broader functional and developmental impacts emerged. For example, ongoing feeding difficulties were reported by 6 parents, who commented that their infants' challenges included *"pain while breastfeeding"* (P37, P45)

> *"Ongoing coordination difficulties and persistent breast aversion"* (P84)

Post-surgical outcomes and timings were highlighted by parents, with some parents highlighting the potential long-term effects of untreated ankyloglossia.

*"Late diagnosis led to entrenched poor oral habits" (P97)*

*"Later speech pathology identified remaining tongue tie potentially affecting speech"* (P43)

When asked whether they would consent to their infant receiving the same surgical treatment again, using a 5-point Likert scale (1 = 'extremely unlikely', 5 = 'extremely likely'), the majority of parents (80.7%) indicated they would be 'likely' or 'extremely likely' to consent again, while only 8% reported they would be 'unlikely' or 'extremely unlikely' (mean 4.38, SD±1.013, min-max 1-5). Parents reported being significantly more likely to consent to surgical treatments again compared to non-surgical treatments (mean 4.38, SD±1.01 vs 3.62, SD±1.07; Mann-Whitney; $p<0.001$).

### *3.4 Research and information gathering*

Parents were asked whether they did their own research about tongue-tie, and 75 parents (81.5%) reported that they did, and 17 parents (18.5%) reported that they did not do their own research. The parents who conducted independent research into ankyloglossia were asked about the type of information, and where they had found the information they had sourced. Options included verbal information about diagnosis and management, written information about diagnosis and management, video information and other. 68% of parents reported that they had used four or more types of information.

Parents reported finding information through a variety of sources, including friends/family/networks/word of mouth, social media, online forums, video platforms, web pages, and through other sources. A majority of respondents used more than one source for information (median 2; mean 2.4). The most frequent combination was the use of two sources (Friend/Family and Webpages) as reported by 37 of the 47 respondents (78.7%). The types and sources of information sought by parents can be found in Table 3.

When asked whether the information they found independently was the same as that provided by health professionals, the majority of parents responded 'somewhat' (37 parents; 50.7%). Fewer parents responded 'yes' (20; 27.4%) or 'no' (11; 15.1%).

Parents were asked whether the information they found independently influenced their views on the management of their infant's tongue-tie. Most parents (43; 58.9%), reported that it did not change their perspective. Nineteen (26.0%) said it did, while 11 (15.1%) were unsure. The perspectives of the 19 parents who reported that their own research influenced their views on managing their infants' tongue-tie were examined in greater detail through thematic analysis and can be grouped into four key themes: independent research and self-advocacy, conflicting advice and lack of professional support, decision-making and justification for surgery, and distrust and frustration with health professionals.

**Table 3 –** Types and sources of information sought by parents

| Type of information | N | % |
|---|---|---|
| *Verbal information about diagnosis* | 44 | 44.9 |
| *Verbal information about management options* | 40 | 40.8 |
| *Written information about diagnosis* | 58 | 59.2 |
| *Written information about management options* | 57 | 58.2 |
| *Video information* | 18 | 18.4 |
| *Other* | 13 | 13.3 |
| Sources of information | | |
| *Friends/family/networks/word of mouth* | 47 | 48.0 |
| *Social media* | 25 | 25.5 |
| *Online forum* | 11 | 11.2 |
| *Video platform* | 10 | 10.2 |
| *Web Page* | 57 | 58.2 |
| *Other* | 15 | 15.3 |

Parents often relied on both persistence, and their own research to understand tongue tie and guide treatment decisions. This helped them advocate for their child when professional advice was lacking or inconsistent.

> *"Although there isn't a lot of evidence from what I could find, it helped me to understand that treating the tongue tie could help with the difficulties I was having with feeding…"* (P4)

> *"His tongue tie was snipped 3 times… I did my own research on this despite seeing an IBCLC weekly for 12 weeks."* (P64)

Parents frequently encountered conflicting advice and contradictory opinions from health professionals, which made decision-making difficult. Some felt dismissed or unsupported by a lack of professional support.

> *"We felt there was judgement and pressure to get the tongue tie cut… medical advice on this was contrary."* (P8)

> *"There was lots of conflicting evidence and opinions… extremely difficult when determining whether to go ahead with the release."* (P9)

> *"The hospital tried to put it down to difficulty feeding… found a private dentist who did a consultation and then severed both upper lip tie and tongue tie for us."* (P48)

Parents' research often led to choosing surgery as the most effective solution.

> *"Confirmed our decision to proceed with surgical intervention."* (P31)

As reported by parents, non-surgical approaches were tried but often insufficient.

> *"After trying non-surgical options for 1–2 months… then knew I needed to proceed with surgical treatment."* (P68)

Many parents expressed frustration and distrust toward health professionals, feeling unsupported or misinformed, while others were confused by recommendations provided.

> *"Health professionals know f--- all and it's really hard to advocate for your child when no one wants to listen to you."* (P75)

> *"Discovered laser wasn't the best option."* (P37)

### *3.5 Experiences with shared decision-making*

Parents were surveyed within a shared decision-making framework regarding their interactions with health professionals involved in their infant's surgical and non-surgical care[31]. Survey items addressed parental input in treatment discussions, comparison of available options, consideration of values and preferences, and evaluation of treatment decisions. Responses were measured on five-point Likert scales, where 1 indicated "strongly disagree" and 5 indicated "strongly agree". The results showed that parents rated their experiences with non-surgical treatment providers significantly more positively across four out of five dimensions of shared decision-making (Mann-Whitney; $p<.050$ for four of five questions).

Parental experiences with shared decision-making can be found in Table 4.

**Table 4 –** Shared decision-making framework

| | Non-surgical (mean, SD, min-max) | Surgical (mean, SD, min-max) | Mann-Whitney; p |
|---|---|---|---|
| *Asked for my input during the discussions about the treatment* | 4.2<br>0.99<br>1-5 | 3.0<br>1.27<br>1-5 | 0.012* |
| *Helped me explore and compare my options* | 3.8<br>1.24<br>1-5 | 2.8<br>1.47<br>1-5 | 0.102 |
| *Took my values and preferences into account* | 4.1<br>1.22<br>1-5 | 3.0<br>1.41<br>1-5 | 0.048* |
| *Helped me reach my decision for treatment* | 4.1<br>1.20<br>1-5 | 2.7<br>1.03<br>1-5 | 0.006* |
| *Helped me to evaluate my treatment decision* | 3.9<br>1.36<br>1-5 | 2.5<br>1.76<br>1-5 | 0.038* |

### 4. Discussion

This study represents the first focused investigation into the lived experiences of Australian parents managing ankyloglossia in their infants. Parents most commonly first encountered a diagnosis through lactation consultants or midwives shortly after birth, with almost all cases identified within the first year. While non-surgical interventions were widely offered, many

parents continued to experience feeding challenges, leading most to pursue surgical options such as conventional or laser frenotomy. Although surgical treatment was generally effective, some infants showed improvement without intervention, and parents' decisions about surgery were influenced by prior positive experiences with non-surgical care, concerns about procedural risks, and conflicting information from healthcare providers. Notably, parents reported that shared decision-making felt more collaborative when engaging with non-surgical providers, yet they were overall more inclined to consent to surgical treatment in the future. By capturing these perspectives, the study provides a rich understanding of the factors shaping parental decision-making, satisfaction, and perceptions of care throughout the ankyloglossia management process.

This study further underscores the considerable diversity among health professionals involved in managing ankyloglossia in Australia, and illustrates the large range of practitioners providing both non-surgical and surgical interventions, as previously reported in Australia[2, 14, 29]. Such diversity among health professionals supports the reports of variation in clinical practice of ankyloglossia management, thus highlighting the absence of standardized guidelines both in Australia and internationally. By documenting these detailed consumer perspectives, this study strongly supports the urgent need for evidence-based guidelines for all health professionals involved in ankyloglossia care, in order to ensure consistent and optimal outcomes for children with ankyloglossia.

The outcomes of surgical treatment were examined in this study, with parents reporting a high rate of symptom resolution following frenotomy. These findings align closely with the positive outcomes consistently documented in other settings worldwide, reinforcing the effectiveness of frenotomy in alleviating symptoms related to ankyloglossia[28, 38]. Parents described improvements in key areas such as latching, maternal nipple pain, and infant weight gain, highlighting the breadth of benefits attributed to surgical management of ankyloglossia previously reported in literature[26-29, 39, 40]. Importantly, the timelines associated with these improvements varied: over half of parents reported noticeable changes within two weeks of the procedure, while the vast majority observed resolution of symptoms within six months. Evidence describing the timeframe of symptom resolution remains scarce internationally, and is largely absent in the Australian context. Only one study has examined post-surgery outcomes at multiple follow-up points, assessing symptoms at one, two and four weeks after surgery, and found that most symptoms resolved following frenotomy, demonstrating its overall effectiveness in improving breastfeeding outcomes [41]. These findings align with parent perceptions in our study, highlighting that while many improvements occur early, further improvements may continue over several weeks. This positions the present study as the first to provide empirical data, from a parent perspective, on both the perceived effectiveness and the temporal course of post-surgical outcomes for infants with ankyloglossia in Australia.

The health professionals involved in the surgical management of ankyloglossia in this study are consistent with those identified in previous Australian literature, with lactation consultants and dentists being reported as the primary providers[29]. A recent study by Diercks et al. [36]highlighted the increasing role of dentists in performing these procedures. However, these

findings in an Australian context were notably lacking otolaryngologists and surgeons; providers that are commonly reported performing surgical procedures for ankyloglossia overseas.

Decisions surrounding consent to surgical treatments were explored amongst parents in this study, and highlighted the uncertainty faced by parents when making decisions about their infants' care. Some parents reported feeling uncertain about the effectiveness of surgical treatment and feeling unsupported and overwhelmed, leading them to decline surgical treatment for their infant. Parental perspectives on non-treatment were explored, with responses often reflecting concerns about the risks of surgery. Although the literature reports relatively low risks associated with surgical treatment for ankyloglossia and demonstrates its efficacy, it remains essential that these risks are discussed as part of informed decision-making between healthcare providers and parents[23, 28, 31, 37]. Interestingly, while just over one quarter of parents reported that their infants continued to experience symptoms following surgical treatment, the vast majority nevertheless indicated they would choose surgery again if faced with the same decision. This suggests that, for many parents, the perceived benefits of surgery outweighed any ongoing challenges. In contrast, parents who declined surgical intervention expressed high levels of satisfaction with their choice, reflecting confidence in their decision-making and acceptance of non-surgical pathways.

The outcomes of surgical treatment were examined in this study, with parents reporting a high rate of symptom resolution following frenotomy. These findings align closely with the positive outcomes consistently documented in other settings worldwide, reinforcing the effectiveness of frenotomy in alleviating symptoms related to ankyloglossia[28, 38]. Parents described improvements in key areas such as latching, maternal nipple pain, and infant weight gain, highlighting the breadth of benefits attributed to surgical management of ankyloglossia previously reported in literature[26-29, 39, 40]. Importantly, the timelines associated with these improvements varied: over half of parents reported noticeable changes within two weeks of the procedure, while the vast majority observed resolution of symptoms within six months. Despite the clinical importance of such information, literature describing the timeframe of symptom resolution following frenotomy remains scarce for international settings and absent in the Australian context, with limited papers reporting on timeframes of outcomes[41]. This positions the present study as the first to provide empirical data on both the effectiveness and the temporal course of post-surgical outcomes for infants with ankyloglossia in Australia.

Although surgical intervention was associated with generally positive outcomes perceived by parents in this study, instances of both spontaneous symptom resolution and ongoing symptom persistence were also documented. In some infants offered surgical treatment for ankyloglossia, feeding difficulties resolved without intervention, pointing to the risk of misdiagnosis, overdiagnosis and unnecessary procedures[13, 14, 42]. These findings reinforce the need for clearer diagnostic and management guidelines both in Australia and internationally. This study also identified ongoing feeding difficulties after surgical treatment, along with less commonly reported issues in the ankyloglossia literature, including sleep and speech challenges. Recent evidence suggests that young children show no significant differences in tongue mobility or

speech outcomes, irrespective of whether they received tongue-tie intervention during infancy, and as a result, surgical treatment in infancy is not recommended solely to improve future speech development[11].

Findings from this study reinforce the importance of actively involving parents in decision-making and engaging in meaningful, transparent dialogue to ensure that healthcare decisions reflect what matters most to families[30, 32]. Parents reported considerable emotional strain related to making treatment decisions and coping with outcomes, highlighting the need for health professionals to provide clear and consistent communication throughout the entire care pathway, from diagnosis through to treatment follow-up. Experiences with non-surgical providers were rated more favourably across most domains of shared decision-making, despite parents rating surgical outcomes more positively than non-surgical outcomes. This finding suggests that surgical providers may benefit from strengthening shared-decision making approaches to achieve optimal outcomes for infants and their caregivers. Ensuring that parents feel informed, supported, and confident in their understanding of surgical procedures and potential outcomes is critical to fostering trust and improving care experiences[30].

In this study, the identified themes pertained specifically to those who shared their experiences and may not represent their broader populations. Participation was voluntary, introducing the potential for sample bias, as parents with particularly strong views or experiences may have been more likely to contribute. Additionally, as with all qualitative research, interpretation is inherently subjective, and other researchers may have categorized parental perspectives differently[43, 44]. Furthermore, the wording of survey questions may have influenced how parents interpreted and reported their experiences, shaping the emphasis placed on particular aspects of care. As individuals from different cultural or national backgrounds may respond differently to Likert scale questions[45], open-ended questions were integral to the survey, providing an opportunity for participants to elaborate on their perspectives in greater detail.

**5. Conclusion**

Findings from this study underscore the importance of parental involvement in all aspects of care for infants diagnosed with ankyloglossia, as this engagement is closely linked to positive perceptions of treatment outcomes across both surgical and non-surgical approaches. Surgical treatment was generally associated with favourable outcomes and high levels of parental satisfaction. However, the spontaneous resolution of feeding difficulties among some untreated infants observed in this study highlights the urgent need for comprehensive and standardised clinical protocols for the diagnosis and management of ankyloglossia to minimise the risks of over-diagnosis and unnecessary intervention. This research further illustrates the central role of parents in the decision-making process, as well as the significant burden that decision-making can place on families navigating complex and sometimes conflicting information. These findings emphasise the responsibility of health professionals to engage in open, meaningful, and thorough discussions with parents about both treatment and non-treatment options, ensuring families are fully informed and supported throughout the care process.

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# Chapter 6

## Discussion

## Discussion

The predominant objective of this thesis was to systematically explore how ankyloglossia is diagnosed and managed in Australia. Through a medical record audit and a series of mixed-methods studies involving both health professionals and parents, this work exposes the full scope of current practice, and the gaps that leave families navigating uncertainty and inconsistent care. When synthesised, the findings demonstrate recurring patterns of variability in clinical approaches across professional groups and geographic contexts. Parents' experiences further highlight the emotional and practical toll of these fragmented pathways. By integrating both professional and parental perspectives, this thesis not only illuminates the shortcomings of current care, but also lays a powerful foundation for meaningful reform – paving the way for more consistent, compassionate, and evidence-based approaches that can transform the experience of care for infants with ankyloglossia and their families.

This final chapter of this thesis brings these findings together and discusses challenges and future directions. The chapter is structured in two sections: the first section discusses research themes in relation to thesis aims and the second section considers clinical implications, limitations, and further research.

### Research themes

1. To determine the prevalence of ankyloglossia in infants over time in a rural Australian setting

The findings of Chapter Two (medical file audit) indicate that the prevalence of ankyloglossia among infants in this rural and remote Australian region was 10.2%, which is higher than most rates reported in the existing literature [1-6] This suggests that infants in rural areas may be diagnosed more frequently, and that local diagnostic practices likely differ from those in metropolitan settings. The higher prevalence of ankyloglossia in rural areas highlights broader systemic inequities in healthcare access, resourcing and professional expertise, which can leave families navigating inconsistent or delayed care. This disparity in care across geographical regions underscores the urgent need for standardised, consistent assessment protocols for the diagnosis of ankyloglossia,

ensuring that all infants, regardless of where they live, have equitable access to evidence-based evaluation. The demographic distribution reported in Chapter Two, with a higher proportion of males than females affected by ankyloglossia, aligned with trends reported in previous studies [4, 7, 8] .

This body of work also revealed a significant increase in the number of ankyloglossia diagnoses over the six-year period, from 4.3% in 2013 to 8.2% in 2018 ($p < 0.01$). Several factors may account for this trend. Increased awareness of breastfeeding challenges and the association with ankyloglossia, particularly in a Baby-Friendly Hospital context, may have contributed to more proactive assessment and diagnosis. Additionally, the absence of validated tools or standardised criteria for diagnosing ankyloglossia in this setting likely introduced significant variability in clinical practice amongst practitioners, which resulted in higher rates of identification over time. Without clear guidance, health professionals must rely on personal experience, local norms, or subjective judgement, which can lead to inconsistent identification of ankyloglossia cases across rural and remote areas of Australia. This variability likely contributes to the increasing rates of ankyloglossia diagnosis over time. It also raises significant concerns about both over- and under-identification of infants who may or may not benefit from intervention. Such inconsistency in clinical practice highlights the critical need for validated, evidence-based assessment protocols to support practitioners in making accurate, reliable and equitable diagnostic decisions.

An unexpected finding in Chapter Two was the relatively high proportion of posterior ankyloglossia compared to anterior presentations. This contrasts with the majority of literature, which typically reports a predominance of anterior tongue-ties, and highlights a notable divergence in diagnostic patterns[9, 10]. The concept of posterior ankyloglossia is highly controversial internationally, with many health professionals involved in this field questioning whether it exists as a distinct anatomical entity at all[11]. Given this uncertainty, it is particularly striking that so many infants in this remote setting were diagnosed with posterior ankyloglossia. These findings suggest that diagnostic interpretation may be heavily influenced by practitioner experience, local clinical protocols, or other contextual factors. In rural and remote health services, diagnoses are often made by generalist health professionals rather than specialists, and limited access

to ongoing education, training, and resources may further contribute to variability in both the frequency and type of diagnosis. By documenting a higher prevalence of posterior ankyloglossia diagnoses compared with anterior cases – an observation not widely reported in the existing literature – this thesis provides unique, empirically grounded evidence that contributes to an ongoing international debate. These findings underscore the limitations of current diagnostic frameworks, and highlight the need for clearer, standardised diagnostic criteria. Furthermore, this work emphasises the importance of enhanced training and guidance for health professionals to improve the accuracy and consistency of ankyloglossia assessment, ensuring that ankyloglossia is appropriately recognised and managed. In doing so, this research not only fills a critical knowledge gap, but also strengthens the evidence base for future clinical and policy decisions within Australia and worldwide.

These findings have important implications for clinical practice and service delivery. The higher prevalence of ankyloglossia reported in Chapter Two underscores the need for standardised assessment protocols, validated diagnostic tools, and targeted professional development to support accurate identification of ankyloglossia, and to reduce the potential of under or over diagnosis. Ensuring consistency in diagnosis is particularly important in rural settings, where specialist services are limited, and clinical decisions may have a substantial impact on infant feeding outcomes and parental experiences. Overall, these results highlight the potential interplay between local healthcare contexts, practitioner practices, and observed prevalence, emphasising the need for evidence-based approaches to support both health professionals and families in the diagnosis of ankyloglossia.

2. To describe the patterns of clinical assessment and management practices for ankyloglossia across Australia

This body of work identified notable patterns and regional variations in the assessment and management of ankyloglossia across Australia, highlighting both systemic and contextual influences on clinical practice.

As previously discussed, the prevalence of ankyloglossia in the remote Australian sample was at the higher end of previously reported ranges, raising questions about potential overdiagnosis. This trend is likely influenced by the absence of standardised diagnostic criteria or validated assessment tools, consistent with concerns identified in prior literature regarding inconsistent and potentially subjective diagnostic practices[8, 12].

Chapter Two reported a significant increase in ankyloglossia diagnoses observed between 2013 and 2018, while the rate of frenotomy did not show a corresponding significant increase. Concerningly, the proportion of infants with diagnosed ankyloglossia undergoing surgical intervention in Chapter Two (97.9%) exceeded previously reported ranges of 85–94%, with some procedures performed despite no documented feeding difficulties. This highlights the consequences of overdiagnosis and raises important questions about the basis for surgical decision-making in rural settings, where access to specialist consultation is limited and health services are reliant on clinicians with generalist skills across many areas of practice. Consistent with international literature, these findings underscore concerns regarding unnecessary frenotomy procedures and the need for careful assessment and justification of surgical interventions[13-17].

Surgical treatment was effective in resolving feeding difficulties for just over half of infants whose records were audited in Chapter Two, while other infants, particularly those with structural anomalies but no functional deficits, derived limited benefit. This emphasises the need for judicious consideration of non-surgical management strategies. Despite evidence supporting non-surgical interventions as effective first-line approaches, fewer than half of infants in the study reported in Chapter Two received such management, indicating a significant gap between recommended practice and clinical reality[18, 19].

Regional disparities were evident in both the assessment and management of ankyloglossia across Australia, likely reflecting variations in workforce composition, resource availability, and service delivery models. Chapter Three highlighted that in rural and remote areas, 67.7% of infants were diagnosed by lactation consultants, compared to 46.6% in metropolitan and regional settings. Of note, dentists contributed no diagnoses in these rural and remote areas, in contrast to 16.9% in metropolitan and

regional cities. This highlights the reliance on lactation consultants in rural contexts, which may be driven by limited access to dentists and other specialists, may also introduce variability in diagnostic consistency due to differences in training and experience. Furthermore, Chapter Three identified that laser frenotomy was largely inaccessible in rural and remote regions. Laser frenotomy is a treatment option more commonly available in metropolitan areas, emphasising inequities in access to advanced surgical interventions in rural and remote settings of Australia. These differences in available treatment modalities may affect clinical decision-making, with generalist or non-specialist providers in remote areas more likely to perform conventional frenotomy or refer less frequently for surgical management, potentially influencing outcomes for infants[20].

Age at diagnosis also varied geographically in Chapter Four, with infants in metropolitan areas diagnosed significantly earlier than those in rural or remote settings. Delayed diagnosis in remote regions may have important clinical implications, including prolonged breastfeeding difficulties, increased maternal nipple pain, and missed opportunities for early intervention when functional impairments are present. Collectively, these regional disparities found in Chapters Two to Four suggest that infants in rural and remote settings may experience both overdiagnosis and delayed or limited access to optimal treatment. This underscores the need for standardised diagnostic criteria, improved workforce training, and equitable access to both surgical and non-surgical management strategies across all regions of Australia.

Health professional confidence in assessing ankyloglossia varied by geography. Chapter Three found that professionals in metropolitan areas reported higher confidence in their assessment skills than those in rural and remote areas, though confidence in managing ankyloglossia surgically or non-surgically did not differ significantly by location. Lower confidence in rural and remote areas is likely driven by multiple factors, including high staff turnover, limited specialist availability, and the pressure of providing care in the absence of clear diagnostic criteria[21-24]. This lower confidence does not appear to stem from differences in access to professional development, which were similar across geographical regions of Australia.

Overall, the findings In Chapters Two to Five illustrate that the assessment and management of ankyloglossia in Australia is highly variable and influenced by geographic location, professional role, and access to specialist resources. In remote settings, the combination of high diagnosis rates, limited treatment options, and reliance on generalist health professionals may contribute to overdiagnosis and a high proportion of surgical interventions. These observations underscore the importance of standardised diagnostic protocols, enhanced professional education, and equitable access to both surgical and non-surgical management options across all regions of Australia.

3. To explore parents' experiences and satisfaction with the care their infant received, including treatment, access to information, and interactions with health professionals.

Throughout Chapters Four and Five, parents' experiences of the care their infant received for ankyloglossia reflected diverse management pathways, varying degrees of support, and differing levels of satisfaction. Consistent with the findings presented in Chapters Two and Three, these results underscore the complexity and variability of ankyloglossia care in Australia, where access to services, professional roles, and information sources appears to be fragmented, and often inconsistent. This fragmented and inconsistent care was evident in the parent experiences reported in Chapters Four and Five, where families described widely varying levels of satisfaction with their infant's care and recounted feeling pressured or confronted with conflicting professional opinions throughout the process. Given that few studies have explored parental experiences of ankyloglossia care in the Australian context, these findings provide unique insights that inform the development of family-centred care models. They highlight the need for clearer guidance and supportive resources to help parents navigate their infants' care journey, ensuring that families are empowered, informed and supported at every stage.

Across the parent cohort studied in Chapter Five, most reported that their infants received some form of management for ankyloglossia. A large proportion (93.7%) of parents reported that their infant received surgical treatment for ankyloglossia, with around half also engaging in non-surgical approaches such as feeding support or

equipment modification. Many families described pursuing multiple forms of management, often sequentially, reflecting an ongoing search for symptom resolution when initial strategies did not provide sufficient improvement. For parents, this often translates into a complex and sometimes prolonged care journey, marked by uncertainty about which approach will best support their infant. These findings reflect broader uncertainty within the field regarding the optimal approach to care, and the perceived effectiveness of different interventions.

Parents studied in Chapters Four and Five generally viewed surgical treatment as more effective than non-surgical approaches and expressed greater willingness to consent to surgery again if faced with the same situation. While many parents who opted for surgery reported positive outcomes and satisfaction with their decision, those who pursued non-surgical care were more varied in their experiences, with some continuing to encounter feeding difficulties despite intervention. These divergent experiences highlight the urgent need for clear, evidence-based guidelines to support parents in making informed choices. Providing accessible guidance can help families understand the potential benefits and limitations of different approaches, reduce uncertainty, and ensure that care decisions align with both clinical evidence and family priorities.

Parental comments in Chapter Five suggested that non-surgical approaches, though often used as first-line management, were associated with persistent feeding challenges including poor latch, nipple pain, reflux, and inadequate weight gain. In contrast, parents generally described improvement following surgical intervention, with over half of parents reporting symptom resolution within two weeks. From a clinical perspective, these findings suggest that while non-surgical strategies should remain the initial approach to management, there is a need to establish clearer referral criteria for surgical intervention. Shared decision-making and informed discussion of both expected benefits and limitations are essential to ensure that surgical treatment is pursued appropriately, in a timely manner, and with realistic expectations.

The parents participating in this research also reported substantial variation in the types of professionals involved in providing care to their infants. Dentists were most commonly identified as performing frenotomies, while lactation consultants and general practitioners were also frequently involved. Many parents described the participation of

multiple health professionals in both surgical and non-surgical management, suggesting that care for infants with ankyloglossia often occurs within a multidisciplinary context, though not always in a coordinated manner. While multidisciplinary involvement may offer comprehensive support, the diversity of professionals ranging from lactation consultants and midwives to more complementary practitioners, such as chiropractors and osteopaths, also raises questions about consistency of assessment, communication, and adherence to evidence-based practice. As outlined in Chapters Two and Three, this professional variation appears less pronounced in rural and remote contexts, where role substitution may occur in the absence of specialist services. Clinically, this underscores the need for clearer communication amongst health professionals, shared care protocols, and nationally consistent practice guidelines to promote cohesive and coordinated care for families navigating this complex condition in such a vulnerable time of their infant's life.

Chapter Four found that parental education appeared to be a key factor shaping both satisfaction and decision-making. Most parents recalled receiving some form of information about their infant's ankyloglossia diagnosis, typically through verbal explanations. While many parents valued the education they received, uncertainty often remained, prompting them to seek additional information on their own. A large number turned to social media, online forums, or peer networks for further guidance. An interesting finding from this study was that parents who undertook extensive independent research often felt less supported by health professionals, especially when the information they found conflicted with the advice they received in clinical settings. This tendency for parents to seek information independently reflects both the high level of parental engagement and the significant information gaps within current models of care. As observed internationally, social media platforms often amplify anecdotal experiences and promote surgical intervention as a straightforward solution, potentially influencing parental expectations[25, 26]. Clinicians must therefore be cognisant of the role of online information in shaping parental decision-making and take proactive steps to provide balanced, evidence-informed education. The development of consistent, accessible resources, delivered at the point of diagnosis could help reduce

misinformation and improve alignment between professional advice and parental understanding.

Parents' narratives across Chapters Four and Five also highlighted the emotional complexity of decision-making surrounding surgical treatment. In Chapter Five, several parents who initially declined surgery described feelings of uncertainty, anxiety, and conflicting professional advice, while others expressed reluctance to expose their infant to a procedure perceived as invasive. These findings mirror the broader controversy and professional disagreement described in Chapter Three and suggest that parental ambivalence often arises in response to inconsistent professional messaging rather than a lack of willingness to engage in care. Clinically, this reinforces the importance of a supportive, empathetic approach to counselling that acknowledges uncertainty, validates parental concerns, and incorporates shared decision-making principles.

While parents were often satisfied with the support received from health professionals, Chapter Four found that this satisfaction did not always align with their willingness to consent to treatment again, indicating that positive care experiences do not always lead to satisfaction with outcomes. Most parents recalled receiving some form of aftercare advice following surgical intervention, however, the nature of this guidance varied considerably. The most commonly reported aftercare recommendation in Chapter Four - stretching the frenotomy site- remains controversial and lacks consistent evidence to support its effectiveness[27]. The frequent use of such advice underscores the need for clear, evidence-based, and standardised post-operative protocols. Establishing consistent guidance across professional groups would help improve parental confidence and promote more predictable clinical outcomes.

The differences in post-operative guidance, clarity of information, and the quality of interactions with health professionals reported in Chapter Four, highlight how parents' experiences of care extend beyond the treatment itself. Variability in advice, follow-up practices and communication appear to influence satisfaction and trust, reinforcing the importance of consistent communication and cohesive support throughout the care journey. Interestingly, parents in Chapter Five rated their experiences with non-surgical treatment providers significantly more positively across most domains of shared decision-making compared with surgical providers. This may reflect the often

collaborative and discussion-focused nature of non-surgical care, where ongoing support and education are emphasised. For clinicians providing non-surgical and surgical management, these findings highlight the importance of embedding shared decision-making into all stages of care by explicitly exploring parental goals, values, and concerns.

Taken together, the insights from Chapters Four and Five, which explored parental experiences, suggest that while most parents were satisfied with their infant's management, the care landscape remains fragmented. Variability in the quality of information and inconsistency in professional advice contribute to confusion, and in some cases, distress for parents. Clinically, there is a clear need for a coordinated, multidisciplinary, and family-centred approach to care for infants with ankyloglossia. Standardised assessment tools, shared decision-making frameworks, and national guidelines for both surgical and non-surgical management would help ensure that parents receive consistent, evidence-based support regardless of geography or service type. Strengthening communication and collaboration across professions, while providing clear, accessible educational resources to families, has the potential to improve satisfaction, reduce uncertainty, and ultimately enhance outcomes for infants and parents navigating the challenges of ankyloglossia care in Australia.

4. To formulate preliminary, evidence-based recommendations for Australian health professionals, parents and policy makers to assist with ankyloglossia diagnosis and management decisions, pending the development of formalised guidelines

Preliminary, evidence-based recommendations for Australian health professionals, parents and policy makers have been developed to support decision-making around the diagnosis and management of ankyloglossia. While some guidance has previously been offered to health professionals, this is the first time comprehensive recommendations have been created specifically for parents – many of whom are not health professionals and must navigate a complex, fragmented healthcare system in an era of endless and often conflicting information. For policy makers, these recommendations highlight

critical system-level gaps and identify opportunities to strengthen governance, refine service pathways, and ensure that families across Australia have access to consistent, evidence-informed care. By translating the findings of this research into actionable priorities, policy makers are positioned to drive meaningful and sustainable reform. These recommendations are intended to provide practical guidance in the absence of formalised national guidelines and are informed by the findings of this study, including parent experiences, professional perspectives, and current practices. Detailed suggestions for health professionals, parents and policy makers can be found in the Clinical Implications section of this thesis, offering a critical step towards empowering families, promoting consistent and evidence-informed care, and bridging the gap between clinical expertise and the real-world challenges parents face – ultimately laying the foundation for more equitable, family-centred approaches to ankyloglossia care throughout Australia.

## Strengths, limitations, clinical implications and further research

This thesis addressed a range of research questions that collectively highlight current clinical practices in ankyloglossia in Australia. It included questions across areas of diagnosis, management and education. What sets this work apart is its exploration of ankyloglossia in Australia from a variety of lenses – remote health, health professionals involved in the condition and the parents and caregivers with lived experiences.

### *Strengths*

A notable strength of this thesis lies in its methodological approaches. The mixed-methods design, combined with perspectives from health professionals and parents and caregivers provided unique insights into the complex, unknown and often controversial practices occurring in ankyloglossia diagnosis and management in Australia that could not be captured through quantitative methods alone. Quantitative data enabled examination of broader trends, regional variation and demographic differences, while qualitative accounts offered rich detail that illuminated the real-world consequences of these patterns. This methodological integration ensured that the recommendations emerging from this body of work are scientifically rigorous, grounded in lived experience,

and more likely to be feasible and relevant within Australian healthcare contexts. Crucially, this is the first body of work to integrate prevalence data, professional practices, and parental experiences within the Australian context, providing a truly comprehensive perspective on ankyloglossia. Including parent perspectives ensured that the research captured both clinical and experiential dimensions of ankyloglossia care. Parents offered valuable insights into how professional practices translates into real-world outcomes, satisfaction, and emotional experiences. This inclusion of multiple dimensions revealed critical gaps between clinical intent and family experience, and illuminated impacts when parents and caregivers are left navigating uncertainty in the absence of clear guidelines.

By bringing together prevalence, practice and lived experience, this work offers a broad, all-encompassing view of ankyloglossia in Australia, establishing a foundation for evidence-informed improvements in care. It delivers actionable insights that can guide health professionals seeking clarity in a field currently characterised by variability and controversy, and empower families who are desperate for reliable information and support. The findings in this work have the potential to shape clinical guidelines, inform policy decisions, and promote more consistent, equitable and family-centred approaches across diverse Australian settings. In doing so, this program of work not only fills a critical evidence gap but also provides a roadmap for transforming ankyloglossia care in Australia, with tangible benefits for both health professionals and the families they support.

### *Limitations*

Some challenges and limitations of this body of work are also acknowledged.

The absence of standardised or validated survey instruments for examining ankyloglossia diagnosis and management introduced the potential for bias in survey design across Chapters Three to Five. To mitigate this, the surveys were informed by established instruments used in related areas of health services and professional practice research. Relevant peer-reviewed surveys were reviewed to guide question structure, content and response formats [28-30]. This supported clarity and consistency, while enhancing methodological rigour in the absence of a validated tool specific to this topic. The surveys

used to capture perspectives on the diagnosis and management of ankyloglossia across Australia (Chapters Three to Five) relied on self-reported data, which is inherently vulnerable to recall and social desirability bias. In addition, participation was voluntary, introducing the potential for self-selection bias, whereby health professionals and parents with particularly strong views or experiences may have been more motivated to participate, particularly given the emotive and contentious nature of ankyloglossia. The online, written modality of the surveys may have further contributed to sampling bias, as participation required English language proficiency, adequate literacy, and reliable internet access, potentially excluding some families and communities. While this Australian-first program of work may therefore have attracted respondents with heightened interest in the topic, dissemination of the surveys across multiple networks and platforms was used to minimise bias by maximising reach and providing broad opportunities for participation. Parental contributions in Chapters Four and Five were essential for understanding how variations in clinical practice affect families and infants. However, some parents may have been reflecting on events that occurred several years earlier, creating potential for recall bias. Despite limitations of self-reported data, these retrospective accounts remain highly valuable as they illuminate the enduring effects of navigating a disjointed healthcare system, and demonstrate how early experiences of ankyloglossia care continue to shape family perceptions, confidence and outcomes.

As with many survey-based studies, variability in how health professionals interpreted specific terms and concepts may have introduced inconsistency in responses throughout Chapter Three. While careful survey design aimed to minimise this, differences in terminology and clinical language across professionals may have influenced how questions were understood. This variability further underscores the lack of clear, shared definitions in the field, with health professionals often using different terms to describe the same phenomena. Such inconsistency reinforces one of the central themes of this body of work: that the absence of standardised criteria for ankyloglossia diagnosis and management continues to complicate both clinical practice and research.

As with all survey-based research, the responses provided by parents in Chapters Four and Five may have been constrained by the format of the instrument, limiting

opportunities for parents to elaborate on their experiences or clarify nuanced perspectives. Surveys do not allow for follow-up questions, meaning that areas of ambiguity or incomplete responses could not be explored in greater depth. While the survey was carefully designed to capture a broad range of experiences, any inherent brevity of parent responses may have resulted in the loss of important contextual detail. This limitation highlights the challenges of relying on survey methodologies to understand complex and emotionally charged care journeys, and reinforces the need for future studies to employ additional qualitative approaches to more fully capture the richness of parental perspectives.

The data sample in Chapter Two and survey sample in Chapter Three may not fully represent all professional groups or geographical contexts, particularly in rural and remote regions where healthcare structures vary substantially between Australian states and territories. As Australia's public health system is largely administered by individual state and territory governments, service models, funding arrangements (and therefore staffing), and clinical pathways can differ markedly across jurisdictions[31]. These contextual differences may limit the generalisability of certain findings from Chapters Two and Three, however, the insights drawn from participants in remote settings remain valuable. Remote regions across Australia – while not identical – tend to face broadly similar challenges related to workforce shortages, service accessibility, and limited specialist availability[22, 23, 32]. This body of work provides valuable insights and can serve as a useful guide to understanding challenges commonly encountered by both health professionals and infants with ankyloglossia in diverse service environments across Australia.

The cross-sectional approach employed in Chapter Two captured practices at a single point in time, limiting the ability to examine how these may evolve. Given the rapidly changing evidence base and shifting public discourse surrounding ankyloglossia, future longitudinal research would be valuable to document changes in clinical practice, professional confidence, and parent-decision making over time. Such work would build on the foundation established in this thesis and provide important temporal context for ongoing developments in care.

Collectively, these limitations emphasise the need for caution when interpreting the results of individual studies, but they also reinforce the overall value of this body of work. By synthesising data across varied methodologies and stakeholder perspectives, this program of work provides a comprehensive and integrated understanding of ankyloglossia practices and experiences in Australia, while laying a robust foundation for future research and the development of national clinical guidelines.

### *Clinical implications and recommendations*

The findings of this thesis provide a unique and comprehensive evidence base for improving the diagnosis and management of ankyloglossia in Australia. Drawing on data from prevalence analysis, professional practice surveys, and parental experiences, the following recommendations represent the culmination of a multi-study program of research. They address critical gaps identified throughout this thesis - such as the absence of national guidelines, variability in clinical practice, and the emotional and practical challenges faced by families, and offer actionable steps to transform care.

Drawing on these insights, practical, evidence-informed preliminary guidelines are presented to support parents, health professionals and Australian policy makers in decision-making, improving communication, and optimising outcomes for infants with ankyloglossia. These recommendations translate the study's findings into actionable guidance while acknowledging the current absence of national guidelines and the importance of shared decision-making. These recommendations have been informed by the findings and insights from Chapters Two to Five, which collectively uncovered high variability in diagnostic practices, inequities in access to care, and parental uncertainty in decision-making. By drawing on these findings, this section translates the evidence from across the thesis into practical strategies aimed at promoting consistency, equity, and family-centred care.

### For health professionals

1. **Conduct comprehensive functional assessments using validated tools.**

Diagnosis should focus on the infant's functional abilities rather than anatomical appearance alone. Assess tongue mobility, latch quality, and feeding efficiency using validated tools where possible, and investigate maternal symptoms such as nipple pain. Collaboration with lactation consultants, speech pathologists, and paediatricians is recommended for thorough evaluation.

*Key supporting evidence*

Prioritising comprehensive functional assessment is supported by findings in Chapter Two, where the relatively high prevalence of ankyloglossia suggested the potential for overdiagnosis when evaluation focuses on anatomical appearance rather than functional impact. Further, investigating maternal symptoms such as nipple pain responds directly to parental narratives in Chapters Four and Five, which highlighted nipple pain as a central factor influencing the diagnosis of ankyloglossia, emphasising the need to consider the breastfeeding dyad holistically. Incorporating validated assessment tools is warranted by the evidence presented in Chapter Three, which revealed clinicians' low confidence in diagnosis and inconsistent use of instruments, including informal tools that were not validated. This highlights the importance of structured, evidence-informed approaches to guide clinical decision-making.

2. **Recognise variation in professional practice but provide clear guidance for families.**

   When providing care to infants with ankyloglossia, clinicians may encounter differing opinions among colleagues. It is important to provide consistent, evidence-informed advice to families and clarify the rationale for recommended management strategies.

   *Key supporting evidence*

   Acknowledging variation in professional practice is important, as Chapter Three revealed that clinicians do not always provide consistent education to families, highlighting the potential for mixed messages and uncertainty. Ensuring families receive evidence-informed advice responds to findings in Chapters Four, where

parents reported seeking information independently due to gaps or inconsistencies in the guidance provided by health professionals. Clarifying the rationale for management strategies is supported by the parental narratives in Chapter Five, which suggested that parents experienced confusion and distress when explanations from health professionals conflicted. This emphasises the need for transparency and clear communication in care planning.

3. **Consider surgical intervention if feeding difficulties and maternal nipple pain are present.**

   If the infant experiences feeding difficulties and the parent reports nipple pain affecting breastfeeding, surgical management (conventional or laser frenotomy) should be considered. Evidence demonstrates that these procedures are generally safe and effective for resolving functional feeding issues. Clinicians should engage in balanced discussions with parents regarding the potential benefits, limitations, and risks.

   *Key supporting evidence*

   The notion that surgical intervention should be considered when infants experience significant feeding difficulties or when parents report nipple pain that impacts breastfeeding, is reflective of evidence from Chapters Two, Four and Five demonstrating the perceived effectiveness of frenotomy in resolving functional feeding issues. Parental preference for surgical management, highlighted in Chapters Four and Five, further supports the inclusion of frenotomy as an appropriate option when indicated.

4. **Prioritise shared decision-making and parental education.**

   Families should be actively involved in all decisions regarding assessment and management. Providing education about ankyloglossia, available treatment options, expected outcomes, and potential risks is essential. Shared decision-making ensures that parents' values, preferences, and concerns are considered alongside clinical judgement.

*Key supporting evidence*

Active involvement of families in all decisions regarding assessment and management is essential, reflecting findings from Chapter Three, where fewer than half of health professionals consistently provided education to parents. Providing clear, accurate information about ankyloglossia, treatment options, expected outcomes, and potential risks responds to experiences described in Chapter Four, where some parents reported receiving no information, and overall satisfaction with education was moderate. Emphasising shared decision-making responds to parental narratives in Chapter Five, which highlighted confusion and distress caused by conflicting advice from different health professionals.

5. **Address misinformation and social-media influence.**

   Parents may encounter inconsistent or inaccurate advice online. Health professionals should offer evidence-informed guidance, correct misconceptions where appropriate, and direct families to reliable resources to support informed decision-making.

   *Key supporting evidence*

   Findings from Chapter Four showed that some clinicians directed parents to social media pages as a form of education, while Chapter Five revealed that many parents conducted their own research, often encountering misinformation or conflicting advice. By offering accurate, evidence-based information and correcting misconceptions when they arise, clinicians can help parents navigate complex decisions with greater confidence. Strengthening clinician-led education not only ensures that families access reliable resources but also promotes informed decision-making and reduces the anxiety that can accompany uncertainty in care pathways.

6. **Coordinate care across disciplines.**

   Optimal outcomes are likely to involve multiple qualified professionals. Collaboration between lactation consultants, speech pathologists, general

practitioners, paediatricians, and dentists ensures a coherent, consistent approach to care.

*Key supporting evidence*

The recommendation to coordinate care across disciplines reflects findings from Chapter Two, where some infants underwent frenotomy without improvement in feeding difficulties, or received the procedure despite having no functional deficits, highlighting the need for thorough, multidisciplinary assessment. It is further supported by Chapter Three, which showed that a broad range of health professionals were involved in care, emphasising the importance of collaboration to ensure a coherent and consistent approach. Finally, fostering collaboration among lactation consultants, speech pathologists, paediatricians, and other relevant professionals aligns with findings from Chapter Two, where most infants were assessed by a single clinician, highlighting the risk of fragmented care and potential loss of the benefits of multidisciplinary perspectives for accurate diagnosis and appropriate management.

7. **Provide follow-up and ongoing monitoring.**

   If frenotomy is performed, follow-up evaluation of feeding and oral function is critical. Referral to lactation support or feeding therapy may be necessary to optimise outcomes and address any residual challenges.

*Key supporting evidence*

The recommendation to provide follow-up and ongoing monitoring reflects findings from Chapter Four, where aftercare recommendations were highly variable, and Chapter Five, which highlighted that some infants continued to experience feeding difficulties following surgical management, emphasising the need for continued evaluation and support. Integrating timely access to lactation support and feeding therapy is particularly important, as these services can address persistent breastfeeding challenges, optimise feeding efficiency, and help families navigate difficulties that may not be resolved through surgery alone[33, 34]. Ensuring that families receive specialised care can therefore

improve feeding outcomes and enhance overall support across the post-intervention period.

8. **Engage in professional development and adhere to guidelines where available.**
   Stay informed regarding emerging evidence and local protocols, and contribute to research to strengthen the Australian evidence base. Where able, work with professional bodies (such as Speech Pathology Australia, the Australian Dental Association, and Lactation Consultants of Australia and New Zealand) to develop nationally relevant education and practice guidelines for ankyloglossia management.

   *Key supporting evidence*

   This recommendation to engage in professional development and guideline awareness is reflective of findings from Chapter Three. Over a quarter of health professionals reported not undertaking any further training in ankyloglossia, and many of those who did engage in professional development had relied on informal or self-directed learning. It is further supported by Chapter Three's finding that over half of health professionals expressed dissatisfaction with current service delivery, highlighting the need to work with professional bodies to develop nationally relevant guidelines and strengthen the Australian evidence base.

### For parents

1. **Seek a comprehensive functional assessment.**
   Diagnosis should be based on how the ankyloglossia affects feeding or oral function, rather than appearance alone. It is appropriate to ask whether a clinician uses a comprehensive tool when assessing ankyloglossia. Health professionals with specific experience in infant feeding can observe breastfeeding or bottle-feeding and determine whether tongue movement is truly restricted. Parents can ask health professionals about their clinical experiences in infant feeding.

*Key supporting evidence*

The recommendation to seek diagnosis based on feeding and function, and to prioritise health professionals who use comprehensive assessment tools, is informed by findings from Chapters Two and Three, which highlighted the consequences of limited functional evaluation and the inconsistent use of validated tools in clinical practice.

2. **Be aware of variation in professional opinions.**

   There is currently no national guideline or universally accepted diagnostic tool for ankyloglossia in Australia. Health professionals may therefore differ in their recommendations. This variation does not necessarily indicate poor care but reflects ongoing uncertainty in the evidence base. Parents should seek advice from registered professionals such as International Board-Certified Lactation Consultants (IBCLCs), speech pathologists, paediatricians, or general practitioners.

   *Key supporting evidence*

   The recommendation to be aware of variation in professional opinions reflects findings from Chapter Three, where health professionals reported widely differing diagnostic and management practices, likely due to the absence of validated assessment tools and national guidelines. It is further supported by Chapter Five, where parents described confusion and uncertainty arising from conflicting professional advice.

3. **Seek surgical treatment if feeding difficulties and maternal nipple pain are present.**

   If the infant is experiencing feeding difficulties and the parent reports nipple pain that affects breastfeeding, surgical intervention (conventional or laser frenotomy) should be considered. Evidence suggests that these procedures are generally safe and effective for resolving functional feeding issues, and are

generally preferred and seen as effective by most parents. Families should discuss potential benefits, risks, and expected outcomes with a qualified clinician to make an informed decision.

*Key supporting evidence*

The recommendation to consider surgical treatment when infants experience feeding difficulties and parents report nipple pain reflects findings from Chapter Two, which demonstrated the effectiveness of frenotomy in resolving feeding symptoms related to ankyloglossia. It is further supported by Chapter Four, where parents expressed a preference for surgical intervention, and Chapter Five, which suggested high rates of resolution of feeding difficulties following the procedure.

4. **Be cautious of information shared on social media.**

   Social media groups and online forums can offer emotional and social support, but they often contain inconsistent or inaccurate information. Posts may reflect individual experiences rather than general outcomes, and some may promote specific providers or procedures. Parents are encouraged to discuss online advice with trusted clinicians before making decisions.

   *Key supporting evidence*

   The recommendation to be cautious of information shared on social media reflects findings from Chapter Five, where parents who conducted their own research encountered misinformation online. It is further supported by Chapter Four, which showed that parents who sought information independently reported lower satisfaction with the support they received from health professionals, highlighting the potential impact of conflicting advice from online sources versus clinicians.

5. **Seek continuity and collaboration of care.**

   Effective management often involves multiple professionals. A coordinated approach, where lactation consultants, general practitioners, paediatricians,

and speech pathologists communicate about care can help ensure that decisions are consistent and informed by the most recent evidence.

*Key supporting evidence*

This recommendation is supported by Chapters Three, Four and Five, which found that care often involved a wide range of health professionals, emphasising that coordinated communication across disciplines is essential to ensure consistent, evidence-informed decision-making. Ensuring continuity and collaboration of care is vital, reflecting findings from Chapter Two, where some infants underwent frenotomy without improvement, or received the procedure despite having no functional deficits, highlighting the need for comprehensive, multidisciplinary evaluation.

6. **Ask about risks, benefits, and alternatives.**

   Before consenting to any procedure, parents should be fully informed of possible benefits, limitations, and potential risks such as bleeding, infection, and oral aversion. Parents can request this information in plain language and ask questions if unsure.

   *Key supporting evidence*

   The recommendation to ask about risks, benefits, and alternatives reflects the emphasis on shared decision-making highlighted in parental narratives in Chapter Five, where conflicting professional advice caused confusion and distress. As per shared decision-making principles outlined in Chapter Five, ensuring that parents receive clear, plain-language information about potential benefits, limitations, and risks such as bleeding, infection, or the development of oral aversion supports informed decision-making and helps families feel confident in their choices. Encouraging questions and discussion empowers parents to actively participate in care planning and ensures that clinical decisions align with both the infant’s needs and the family’s values and preferences.

7. **Monitor feeding and development after intervention.**

   If frenotomy is undertaken, follow-up with a feeding professional such as a Speech Pathologist, is important to support optimal outcomes and address any potential persistent challenges.

   *Key supporting evidence*

   Ongoing follow-up after frenotomy is essential, reflecting findings from Chapter Two, where some infants underwent the procedure with no improvement and therefore required additional management for persistent symptoms. It is further supported by Chapter Four, which highlighted inconsistent aftercare recommendations, and Chapter Five, where parents reported ongoing feeding difficulties following surgical treatment. Structured follow-up ensures that residual challenges are identified and addressed, supporting better functional outcomes and continuity of care.

### For Australian policy makers

The combined findings of this thesis underscore an urgent need for reform in how ankyloglossia is diagnosed and managed in Australia. Collectively, the evidence points to clear opportunities to enhance clinical consistency, improve diagnostic confidence, and support more reliable decision-making across professional groups. A key step forward may be the establishment of a formal accreditation program for clinicians involved in ankyloglossia assessment and frenotomy procedures. Such accreditation could enhance diagnostic accuracy and help reduce reliance on invasive surgical interventions. Comparable frameworks, such as the New Zealand Ministry of Health's guidelines outlining educational and competency requirements for midwives, medical practitioners, and dental surgeons performing frenotomy, offer a compelling and practical template for adaptation across Australian health services.

Implementing these recommendations for health professionals, parents and policy makers has the potential to reduce unnecessary surgical interventions, improve feeding outcomes, and ensure that families receive consistent, evidence-informed guidance regardless of geography. This is not only a clinical imperative but a matter of equity and support for families during a critical stage of infant development.

*Future research*

The findings of this thesis underscore a critical need for continued research. One important avenue for future investigation is the impact of introducing validated assessment tools across Australia, and particularly in rural and remote settings. Research exploring how diagnostic patterns shift when health professionals consistently use a single, standardised tool over time would provide valuable evidence regarding reliability, prevalence trends and clinical consistency. In addition, examining whether sustained use of validated tools enhances health professionals' diagnostic confidence, especially in settings with limited access to specialist services, would offer important insights into workforce support and capacity building.

Further research is also required to understand the long-term impacts of different management pathways, particularly the comparative outcomes of frenotomy and non-surgical interventions. While the current findings of this thesis highlight a strong parental preference for surgical treatment, the effectiveness of non-surgical approaches remains insufficiently understood. Targeted evaluations of these interventions are therefore warranted, both to clarify their clinical value and to inform whether they should continue to form part of routine care for ankyloglossia or be reconsidered in light of emerging evidence into parental preferences and frenotomy effectiveness.

Broadening methodological approaches will be essential in progressing the field of ankyloglossia diagnosis and management. Longitudinal studies, intervention trials, qualitative work with both parents and health professionals, and hospital- or clinic-based audits across representative metropolitan, regional, and rural/remote settings would generate crucial data on how diagnostic and management practices evolve over time. Clinic and hospital-based studies, in particular, have the potential to reduce self-

selection bias inherent in survey-based research and provide a more systematic picture of clinical practice. Collectively, these approaches may reveal trends in parental satisfaction, evaluate the real-world impact of clinical guidelines and professional training, and illuminate how families perceive and navigate the current care landscape. Future research should also explore how parental information-seeking behaviours interact with professional communication, shared decision making, and perceived quality of care, particularly in contexts where clinical guidance is inconsistent or contested. Focused qualitative methods would further offer a nuanced understanding of the human and systemic factors shaping care experiences.

Finally, this thesis highlights an urgent need for policy and guideline development that reflects contemporary evidence and the lived realities of service delivery across Australia. Implementation research examining how guidelines are adopted in practice, alongside studies focused on models of workforce training and development would be instrumental in improving consistency and equity of care for infants with ankyloglossia. Importantly, this work should be led collaboratively by the professional bodies involved in ankyloglossia assessment and management. A cohesive national guideline clearly outlining roles, responsibilities and best-practice approaches would represent a significant step toward reducing fragmentation in the ways ankyloglossia is diagnosed and managed within the Australian health care system. Such guidance must also explicitly account for the unique challenges faced by rural and remote health professionals and families, offering practical pathways for managing infants with ankyloglossia in contexts where specialist support may be limited.

## Conclusion

Despite increasing global attention, ankyloglossia continues to be diagnosed and managed with marked inconsistency. By integrating clinical and parent perspectives, this thesis demonstrates that ankyloglossia care in Australia is fragmented and features significant variation in assessment, management pathways, and the support families receive, and reflects the emotional and practical burden placed on families. These disparities create uneven access to care and persistent uncertainty for parents seeking

guidance for their infants, reinforcing the urgent need for consistent, evidence-based care. Crucially, it also foregrounds the experiences of rural and remote communities, identifying structural and workforce barriers that shape access and outcomes. Together, these insights create a strong foundation for future research, policy development, and coordinated national approaches to improve equity in ankyloglossia management.

The findings of this thesis point to concrete priorities: validated assessment tools, shared terminology, evidence-based treatment pathways, coordinated professional training, and genuine incorporation of parent experiences into service delivery and practice. Addressing these gaps through sustained and collaborative action offers a critical opportunity to improve ankyloglossia care for infants in Australia – ensuring all infants and families receive care that is consistent, equitable and grounded in robust evidence.

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# Appendices

# Appendix 1

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# Ankyloglossia in Central Australia: Prevalence, identification and management in infants

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ABSTRACT

*Purpose:* To investigate the prevalence and management of ankyloglossia for infants in Central Australia.
*Method:* Retrospective chart review consisting of a medical file audit of infants (n = 493) <2 years old diagnosed with ankyloglossia from January 2013 to December 2018 in the primary hospital in Central Australia. Patient characteristics, reason for diagnosis, reason for procedure and outcomes of procedures routinely recorded in the patient clinical files were recorded.
*Results:* The overall prevalence of ankyloglossia in this population was 10.2%. Frenotomy was performed in 97.9% of infants diagnosed with ankyloglossia. Infants with ankyloglossia were more likely to be male (58% vs 42%), diagnosed and managed with a frenotomy on the third day of life. Most ankyloglossia diagnoses were identified by a midwife (>92%). Most frenotomy procedures were completed by lactation consultants who were also midwives (99%) using blunt-ended scissors. More infants were classified with posterior ankyloglossia than anterior ankyloglossia (23% vs 15%). A frenotomy procedure resolved feeding issues in 54% of infants with ankyloglossia.
*Conclusions:* The prevalence of ankyloglossia and rate of frenotomy procedures were high when compared to previous reports in the general population. Frenotomy for ankyloglossia in infants with breastfeeding difficulties was found to be effective in more than half of the reported sample, improving breastfeeding and decreasing maternal nipple pain. A standardised approach and validated screening or comprehensive assessment tool for the identification of ankyloglossia is indicated. Guidelines and training for relevant health professionals on non-surgical management of the functional limitations of ankyloglossia are also recommended.

## 1. Introduction

Ankyloglossia (also known as tongue-tie) refers to the limited movement of the tongue causing functional limitations, as well as a visually restricted lingual frenulum [1]. The anatomy of the lingual frenulum has recently been described as a structure formed by the dynamic elevation of a midline fold in the floor of mouth fascia; not a band or cord, as it has previously been described [2]. Whilst these definitions are used most frequently, there are no established universal criteria. The cause of ankyloglossia is unknown and requires further investigation, however, literature has reported hypotheses of an association between higher frequencies of pre-conception folic acid intake, as well as a genetic link [3,4].

The role of the health professionals in ankyloglossia assessment and management has not been well-defined through published position papers or clinical guidelines by professional bodies internationally. The Academy of Breastfeeding Medicine, American Academy of Otolaryngology and the Canadian Paediatric Society's publications on ankyloglossia and breastfeeding highlight the feeding difficulties that can arise as a result of ankyloglossia, and outline the importance of a multidisciplinary approach to diagnosis and management, however, do not specify the specific roles of health professionals [5–7]. As ankyloglossia can impact an infant's feeding ability, many health professionals provide vital contributions to ankyloglossia assessment and management.

Prevalence rates of ankyloglossia have been reported to range between 0.02% and 11% [8–10]. Various tools have been established to identify, rate the severity of and determine the need for management of ankyloglossia. These tools lack reliability and standardisation and are

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therefore a likely contributor to the broad prevalence rates reported.

Ankyloglossia can be classified as anterior or posterior, based on where the frenulum is attached on the ventral surface of the tongue [11]. Anterior ankyloglossia encompasses two types: Type I where the insertion of the lingual frenulum is on the top of tongue; and Type II, where the insertion of the lingual frenulum is slightly behind the tongue tip [12]. Posterior ankyloglossia also encompasses two types: Type III where the lingual frenulum is located inferiorly at the mid-tongue; and Type IV where the lingual frenulum is not visible, referred to as a submucosal frenulum [12]. The severity of ankyloglossia has also been classified using measurements of the lingual frenulum, as outlined by Kotlow [13], who suggested that lingual frenulum lengths between 0 and 16 mm be given severity ratings of mild, moderate, severe and complete, in increments of 4 mm. These tools were designed to describe the lingual frenulum appearance but do not assess tongue function.

The Hazelbaker Assessment Tool for Lingual Frenulum Function (ATLFF) assesses infants with ankyloglossia through five appearance items and seven function items [14]. The ATLFF was designed to determine the severity and extent of ankyloglossia [15]. The tool has been found to have a high inter-rater reliability within the appearance component and in providing a recommendations for frenotomy, however, the researchers reported a lack of agreement on the function items related to infant sucking, and suggested that the function items should be altered [15]. Similarly to the ATLFF, the Lingual Frenulum Protocol for Infants consists of a two-part protocol designed to evaluate the lingual frenulum in infants [16]. The first section contains a clinical history with specific questions about breastfeeding, and the second part includes a clinical examination of the tongue, and sucking evaluations. This tool was established to assess and diagnose anatomical differences of the lingual frenulum, and identify the possible impacts of these on breastfeeding.

The Bristol Tongue Assessment Tool (BTAT) was developed using principles from the ATLFF to rate severity of ankyloglossia [17]. The BTAT is a four item, eight-point assessment tool which measures tongue tip appearance, attachment of the frenulum to the lower gum ridge, lift of tongue with mouth wide and protrusion of tongue [17]. An adjunct to the BTAT is The Tongue-tie and Breastfed Babies (TABBY) assessment tool, that was developed to provide a pictorial representation of the BTAT [18].

Ankyloglossia is asymptomatic in most infants, however, it has been recognised as a condition that results in breastfeeding difficulties in 12–44% of infants with ankyloglossia [19]. Ankyloglossia may restrict the movement of the tongue, causing significant functional impairments in infants, including poor latch, sucking mechanics, breastmilk transfer and maternal nipple pain and trauma while breastfeeding [5,6,20].

There is a vast disparity of opinions among health professionals regarding management of ankyloglossia [21]. Currently, frenotomy is the primary intervention used to manage ankyloglossia. Frenotomy for ankyloglossia is a procedure where the lingual frenulum is divided either in the midline or at the underside of the tongue, using sharp blunt-ended scissors [21]. Other less common surgical procedures to manage ankyloglossia include frenuloplasty - releasing and suturing the lingual frenulum, Z-plasty – releasing the frenulum and creating flaps and suturing these, and laser interventions – used by dentists to ablate and separate the frenulum tissue [22,23]. Further research is required to support claims regarding the superiority of frenotomy techniques [7]. Surgical management should be undertaken by appropriately trained health professionals within appropriate clinical settings. These settings must be equipped to manage possible complications [1].

Non-surgical interventions can be provided by relevant, trained health professionals such as International Board Certified Lactation Consultants (IBCLCs), midwives, child health nurses and speech-language pathologists [1,24]. Non-surgical managements of breastfeeding difficulties arising from ankyloglossia include strategies such as positional changes, the alteration of feeding frequency, providing support to mothers to maintain a milk supply, latch optimisation and the use of external tools such as nipple shields or supplementary nursing systems [1].

An increase of 420% in the rate of frenotomy procedures was reported in Australia between 2006 and 2016 [25]. These increasing rates of frenotomy have also been mirrored internationally in Canada and the United States, at rates of increase as high as 400% and 866% respectively [8,26]. A lack of standardised indications for the procedure have also been highlighted in recent literature, with more research required to develop diagnostic standards and examine long term outcomes of frenotomy procedures [1,6,25,27]. Messner and colleagues reached consensus that the potential benefits of frenotomy include relief of maternal pain, however, also reached consensus that frenotomy is not always effective in relieving maternal pain and breastfeeding difficulty [7]. O'Shea et al. [28] reported a lack of consistent positive breastfeeding outcomes associated with frenotomy, despite a reduction in short-term nipple pain. This Cochrane review examined the efficacy of frenotomy procedures in 2017, and found that frenotomy reduced breastfeeding mothers' nipple pain in the short term, however, the efficacy of frenotomy procedures was questioned as there were no consistent positive effects on infant breastfeeding [28].

There are only a few reports documenting the prevalence and management of ankyloglossia in Australia [25], with a complete lack of studies conducted in rural and remote areas of Australia. Further, there is also a complete lack of studies investigating ankyloglossia in remote settings both in Australia and internationally. Central Australia is a unique rural environment that is home to an estimated 38,737 people, and encapsulates an expansive catchment area of 827,861 square kilometres covering Alice Springs, Tennant Creek and numerous communities and outstations [29,30]. Underrepresentation of this large population in current literature means that the prevalence of ankyloglossia in Central Australia is currently unknown. Kapoor and colleagues reported 22 cases of ankyloglossia that were surgically managed in the Northern Territory in 2016 [25]. As this data was obtained from Medicare records, these cases are not a true representation of the Central Australian region; an area which relies heavily on the public health care system where Medicare rebates are not applied [31]. The small sample size does not make this paper suitable for more general conclusions about the management of ankyloglossia in Central Australia.

This study therefore aimed to examine and provide a world-first report on the prevalence and management of ankyloglossia for infants in Central Australia. Reporting on ankyloglossia management in remote areas such as Central Australia will inform future health care and the development of policies to meet the needs of rural health care settings in Australia.

## 2. Methods

Ethical approval for this retrospective medical file audit was granted by the Central Australian Human Research Ethics Committee (CA19-3338).

Data were collected from Central Australian Health System database which contains the medical files of all live born infants and children under two years of age in Central Australia between January 2013 and December 2018. This database includes all births occurring in a hospital (majority of births in Central Australia) within Central Australia [32]. Diagnoses in the database were coded using the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification (ICD-10-AM), and procedures were coded using the Australian Classification of Health Interventions (ACHI). Ankyloglossia (Q381) and frenotomy (3027802) were identified using appropriate codes.

Within the health system targeted in this study, ICD-10-AM codes are allocated through manual medical coding by medical coding staff members reviewing paper charts to identify key diagnostic words (e.g., tongue-tie/ankyloglossia/frenotomy/tongue-tie cut). These target diagnostic words are then correlated to a relevant diagnostic code. This

data were then extracted from medical files and entered into Statistical Package for Social Sciences (SPSS) (version 25). The proforma was prescriptive with a combination of variables including free text (e.g., description of feeding difficulty) and numerical coding (e.g., type of ankyloglossia). Participants in the study were infants born in the maternity unit of a large regional hospital in Central Australia. This hospital services a rural and remote community, with approximately 800 births annually. It has received baby-friendly designation, indicating that its policies promote and support breastfeeding in the early postpartum period [33,34]. Eligible participants were <24 months of age, male or female, with a diagnosis of ankyloglossia. Demographic data collected from hospital records are outlined in Table 1.

Data variables were entered into SPSS for analysis. Summary measures were calculated, and chi-squared tests were used to compare target years. All p-values were calculated with a two-sided significance level of .05.

## 3. Results

### 3.1. Study sample

From 2013 to 2018, 4728 live births were reported in Central Australia (Table 2). Birth numbers ranged from 759 to 825 across the target six years with a mean of 788 births per year.

### 3.2. Ankyloglossia diagnosis and management

Of the 4728 births in Central Australia across 2013 to 2018, there were 478 cases of ankyloglossia reported, yielding an overall prevalence of 10.2%.

Of the 797 births in 2013, 34 infants (4.3%) were diagnosed with ankyloglossia, and 33 infants (4.1%) underwent frenotomy, representing a frenotomy rate of 97.1%. Of the 785 births in 2018, 64 infants (8.2%) were diagnosed with ankyloglossia, demonstrating a significant increase from 2013 ($p = 0.002$). Sixty-four infants (8.2%) underwent frenotomy, representing a frenotomy rate of 100%. Across the data collection period, ankyloglossia was diagnosed by midwives (45%), midwives who were also lactation consultants (49%), nurses (2%), physicians (1%) and other sources such as speech-language pathologists and parents (3%).

In total, there were 474 infants who were managed surgically with frenotomy, representing 97.9% of cases diagnosed with ankyloglossia. No significant differences between the rates of frenotomy were found over time, when comparing 2013 and 2018 ($p = 0.553$). Frenotomies were completed by lactation consultants who were also midwives using the cold steel method with blunt-ended scissors in 471 infants (99%). The procedures were completed during the infants' newborn (birth) admission in hospital.

Throughout the retrospective data collection period, non-surgical management involving positional changes were provided by the midwife or lactation consultant to 41 infants with ankyloglossia (8.3%). Following this, 40 (98%) of these infants also received a frenotomy procedure. Non-surgical management was not offered to 452 infants (92%) with ankyloglossia.

The highest prevalence of ankyloglossia was reported in 2015 with 13.9% of infants diagnosed. The highest rates of frenotomy procedures were in 2016 and 2018, with 100% of infants diagnosed with ankyloglossia receiving a frenotomy procedure. The lowest rate of ankyloglossia was in 2013, with 4.3% of all births receiving a diagnosis of ankyloglossia. The lowest rate of frenotomy was in 2015, with 96.4% of infants with ankyloglossia receiving a frenotomy procedure. (Fig. 1).

A trend indicating higher prevalence of ankyloglossia was reported for males with an average of 58% compared to 42% in females across the target years. This result, however, was not statistically significant ($p = 0.388$). A significantly higher proportion of infants were classified with posterior ankyloglossia (23% vs 15%) ($p < 0.01$). Prior to 2016, a significant difference was noted between anterior and posterior ankyloglossia diagnoses in 2013–2015 ($p < 0.01$). In 2017 and 2018, classifications of anterior and posterior ankyloglossia were comparable.

On average, ankyloglossia was diagnosed on the third day of life across all years in the reporting period. Frenotomy procedures were completed on the same day as diagnosis in all years except 2018, where frenotomy procedures were completed two days post diagnosis on average.

Across 2014 to 2018, more than 92% of infants with ankyloglossia were identified by a midwife, or a lactation consultant (Table 3). Prior to this period, in 2013, there was greater variability in the discipline of the health professional diagnosing ankyloglossia.

There was a significant increase in infants diagnosed with ankyloglossia, with 4.3% diagnosed in 2013 to 8.2% diagnosed in 2018 ($p < 0.01$). The rate of frenotomy did not increase significantly during that period ($p = 0.553$) (Table 2; Fig. 1).

**Table 1**
Overview of analysed data.

| | |
|---|---|
| Human record number | Other issue leading to identification of ankyloglossia (description of issue as stated in medical file) |
| Date of birth | Documented type of management |
| Gender | Reason for frenotomy (as listed on procedure consent form in medical file) |
| Date of admission | Patient age at frenotomy (days of life) |
| Date of discharge | Documented outcome post procedure |
| Type of ankyloglossia identified | |
| Method of identification of ankyloglossia | |
| Patient age at identification of ankyloglossia | |
| Discipline of health professional who identified ankyloglossia | |
| Feeding issue leading to identification of ankyloglossia | |

**Table 2**
Prevalence of ankyloglossia and frenotomy rates within target years of 2013–2018. Percentages are calculated out of all births for diagnoses, and out of all diagnoses for procedures.

| | *2013 n (%)* | *2014 n (%)* | *2015 n (%)* | *2016 n (%)* | *2017 n (%)* | *2018 n (%)* |
|---|---|---|---|---|---|---|
| *Births* | 797 | 769 | 793 | 825 | 759 | 785 |
| *Ankyloglossia diagnoses* | 34 (4.3) | 75 (9.8) | 110 (13.9) | 112 (13.6) | 87 (11.5) | 64 (8.2) |
| *Frenotomy procedures* | 33 (97.1) | 73 (97) | 106 (96.4) | 112 (100) | 86 (98.9) | 64 (100) |

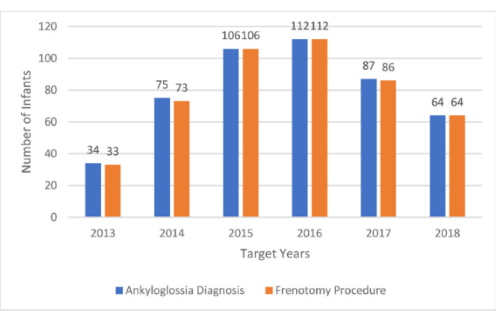


**Fig. 1.** [Please display in colour in print] Trends in ankyloglossia diagnosis and frenotomy rates in Central Australia within target years of 2013–2018. (For interpretation of the references to colour in this figure legend, the reader is referred to the Web version of this article.)

**Table 3**
Demographic and diagnostic data of infants diagnosed with ankyloglossia within target years of 2013–2018. Percentages are calculated out of all diagnoses.

| | 2013 n (%) | 2014 n (%) | 2015 n (%) | 2016 n (%) | 2017 n (%) | 2018 n (%) |
|---|---|---|---|---|---|---|
| *Gender* | | | | | | |
| *Male* | 20 (59) | 40 (53) | 70 (66) | 69 (62) | 47 (54) | 34 (53) |
| *Female* | 14 (41) | 35 (47) | 36 (34) | 43 (38) | 40 (46) | 30 (47) |
| *Mean age at diagnosis (days)* | 4 | 3 | 4 | 3 | 3 | 3 |
| *Mean age at procedure (days)* | 4 | 3 | 4 | 3 | 3 | 5 |
| *Type of tongue tie* | | | | | | |
| *Anterior* | 5 (15) | 4 (5) | 8 (7.5) | 16 (14) | 20 (23) | 16 (25) |
| *Posterior* | 5 (15) | 23 (31) | 40 (38) | 27 (24) | 9 (10) | 14 (22) |
| *Anterior + Posterior* | 1 (3) | 1 (1) | 0 | 2 (2) | 0 | 0 |
| *Other* | 0 | 0 | 0 | 2 (2) | 1 (1) | 8 (13) |
| *Not specified* | 23 (68) | 47 (63) | 58 (55) | 67 (60) | 57 (66) | 26 (41) |
| *Discipline identified* | | | | | | |
| *Midwife/ Lactation Consultant* | 20 (59) | 73 (97) | 100 (94) | 111 (99) | 84 (97) | 59 (92) |
| *Nurse* | 9 (27) | 0 | 1 (1) | 0 | 0 | 1 (2) |
| *Physician* | 1 (3) | 0 | 0 | 0 | 3 (3) | 2 (3) |
| *Other* | 4 (12) | 2 (3) | 5 (5) | 1 (1) | 0 | 2 (3) |

### *3.3. Clinical outcomes*

Table 4 highlights the reported rationale and outcomes of frenotomy procedures, which included poor latch, sucking issues and maternal nipple pain.

Latching issues and maternal nipple pain were reported as the primary reason for frenotomy procedures across all target years, at a rate of 70% and 39% respectively. Following a frenotomy procedure, 60% of infants demonstrated an improved latch, 79% had decreased nipple pain, and 57% had improved sucking ability across the target years. The mean length of admission for infants with ankyloglossia was 5 days. These improvements were noted by the lactation consultant who performed the frenotomy, as well as midwives and nursing staff during the admission period. Once discharged from hospital, follow up was not documented in the clinical files.

Overall, in 54% of infants, a frenotomy procedure was effective in the resolution of feeding issues.

A total of eighty-seven infants (18%) underwent a frenotomy procedure with no feeding difficulty identified prior to procedure. The rates of these cases ranged from as low as 3% (in 2018) up to 27% (in 2015). These infants presented with a structural defect only and had no functional deficits, and therefore were not indicated for surgical intervention.

### *3.4. Adverse events*

Adverse events were reported in the data. Bleeding, ulcers and swelling were the primary issues reported post frenotomy throughout the study (Fig. 2; Table 4).

Five infants were re-admitted to hospital for ongoing feeding difficulties throughout the target years. The primary reasons for readmission

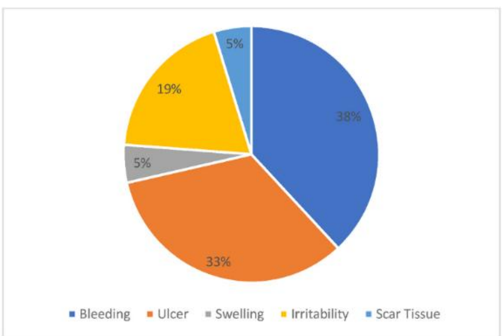


**Fig. 2.** [Please display in colour in print] Characteristics of adverse events following frenotomy recorded throughout 2013 to 2018. (For interpretation of the references to colour in this figure legend, the reader is referred to the Web version of this article.)

**Table 4**
Outcomes of infants who underwent frenotomy procedures within target years of 2013–2018. Percentages are calculated out of all infants who underwent frenotomy procedures.

| | 2013 (n = 33) | | *2014 (n=73)* | | *2015 (n=106)* | | *2016 (n=112)* | | 2017 (n = 86) | | *2018 (n=64)* | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Yes | No | Yes | No | Yes | No | Yes | No | Yes | No | Yes | No |
| *Latching issues resolved (total number of latching issues n=334)* | 15 (68%) | 7 (32%) | 15 (36%) | 27 (64%) | 40 (58%) | 27 (40%) | 47 (64%) | 26 (36%) *1 with nil issues developed latching issues post procedure (total 27 (36%)) | 45 (67%) | 21 (32%) *1 with nil issues developed latching issues post procedure (total 27 (36%)) | 39 (67%) | 19 (33%) |
| *Maternal pain resolved(total n=187)* | 5 (56%) | 4 (44%) | 13 (62%) | 8 (38%) | 16 (80%) | 4 (20%)*2 with nil pain prior to procedure with more pain post total 6 (27.3%) | 36 (82%) | 8 (18%) *1 with nil issues developed latching issues post procedure (total 22 (33%)) | 35 (81%) | 8 (19%) | 43 (92%) | 4 (9%) |
| *Sucking issues resolved(total n=138)* | 15 (79%) | 4 (21%) | 12 (57%) | 9 (43%) | 21 (55%) | 17 (45%) *2 with nil issues prior to procedure deteriorated (total 19 (48%)) | 15 (65%) | 8 (35%)*1 with nil issues prior to procedure deteriorated (total 9 (38%) | 11 (46%) | 13 (54%) | 4 (40%) | 6 (60%) |
| *No feeding issues (total n=87)* | 4 (12%) | | 18 (25%) | | 29 (27%) | | 27 (24% | | 7 (8%) | | 2 (3%) | |
| *Adverse events (total n=21)* | 8 | 25 | 2 | 71 | 7 | 99 | 0 | 112 | 3 | 83 | 1 | 63 |
| *Readmissions to hospital(total n=5)* | 1 | | 3 | | 1 | | 0 | | 0 | | 0 | |

were difficulties with feeding, poor weight gain, and maternal challenges such as bleeding nipples. In one of these infants, ankyloglossia was identified during the birth admission on day 3 of life, and the infant was discharged without any surgical intervention. The infant was readmitted on day 7 of life and had a frenotomy procedure on day 8 of life (Table 4).

## 4. Discussion

This study aimed to examine the prevalence and management of ankyloglossia for infants in Central Australia. The demographics of infants diagnosed with ankyloglossia in this study were consistent with prevalence literature, which reported that ankyloglossia is more common in male patients by around 1.6 to 3-fold [8,35,36]. The significantly higher proportion of posterior ankyloglossia are reported among infants in this study compared to anterior ankyloglossia (23% vs 15%) has not been previously reported. Previous studies have reported a higher proportion of anterior ankyloglossia [12,37]. This discrepancy with findings in the present study may have been due to a lack of consistent or standardised criteria used by health professionals tasked with diagnosing ankyloglossia in this population.

An average prevalence rate of 10.2% of all infants born in Central Australia diagnosed with ankyloglossia in this study reflects the upper end of the previously range reported for children in other studies and locations [9]. The baby-friendly hospital status of the major hospital in Central Australia may be a contributing factor to an increased awareness of ankyloglossia compared to other sites. The identification and management of ankyloglossia during newborn admissions in the literature showcase sporadic and symptom-prompted identification such as poor feeding or maternal pain [35]. This was also reflected in the current study in the Central Australian population, with ankyloglossia being identified in infants the third day of life, and frenotomy procedures occurring on the day of identification in majority of cases. Buryk, Bloom [38] in their randomized controlled trial cited the mean age at frenotomy as 6.7 days, however, the optimal age of infants at the time of frenotomy has not yet been examined [39]. Factors including the length of time that the infant has practiced feeding and the mothers' prior breastfeeding experience play a significant role in infant feeding and should be considered in ankyloglossia management guidelines.

The rate of frenotomy reported in Central Australia (97.9%) in the current study was higher than previously reported rates ranging from 85 to 94% [40]. The Canadian Paediatric Society [6] published a position statement on ankyloglossia and breastfeeding in 2015 and reaffirmed their position in 2018, outlining that based on available evidence, frenotomy cannot be recommended for all infants with ankyloglossia. They also concluded that whilst frenotomy cannot be recommended in all cases, it should be conducted by an experienced clinician if ankyloglossia is contributing to substantial breastfeeding difficulties [6]. This was mirrored in both the Australian Dental Association and the American Academy of Otolaryngology's Clinical Consensus Statement, stating that a frenotomy should only be performed in the presence of a functional deficit [1,7]. In this study, a frenotomy procedure was performed on a total of 87 infants (18%) who had no reported feeding difficulties prior to the procedure. This highlights uncertainty about why these infants received a diagnosis of ankyloglossia, and further, why they then received a surgical procedure. The significant number of unnecessary frenotomy procedures has been highlighted in recent literature, and requires further investigation within all health services [7]. In light of the recommendations around frenotomy in the literature and reports stating that most ankyloglossia cases may be asymptomatic, the rate of frenotomy procedures in Central Australia should be rigorously examined [36].

The nature of remote health services may be reflected in the prevalence of ankyloglossia and rates of frenotomy in Central Australia. In Central Australia, frenotomy was performed exclusively by IBCLCs who are also midwives, whereas in metropolitan health settings, frenotomy is generally performed by dentists, general practitioners, lactation consultants, otolaryngology surgeons, paediatricians and paediatric surgeons [41]. Remote health services often lack specialist physicians, and therefore rely on health professionals developing generalist skills to cover these areas [42]. The development of these skills is reliant on balanced education programs and professional development courses that can provide education on tools to accurately diagnose ankyloglossia as well as conduct frenotomy. Such programs are often difficult to access due to staffing pressures and budgeting restrictions in remote settings. These factors may have led to an overdiagnosis of ankyloglossia and a high frenotomy rate, due to limited education and training on ankyloglossia, and limited specialist services to provide advice or follow-up.

The current study revealed that frenotomy procedures led to adverse effects in an average of 6.5% of infants in the Central Australian population, similar to the rates found in previous studies [19,43,44]. Adverse events found in the current study such as irritability, bleeding, ulceration, scar tissue formation and oral aversion have also been previously documented [45,46]. Further to these recorded adverse events, there is also evidence that infants experience prolonged pain and stress [45]. These findings highlight the importance of ongoing education for health professionals on the potential complications of frenotomy procedures. Further, awareness of potential complications and accurate success rates of the procedure are imperative for parents consenting to frenotomy procedures to facilitate informed consent.

Frenotomy for ankyloglossia in infants with breastfeeding difficulties was found to be effective 54% of the reported sample, improving breastfeeding and decreasing maternal nipple pain. These results are consistent with available literature examining the effectiveness of frenotomy procedures, however, the retrospective nature of this study does not allow for follow-up data and the exploration of consistent and long term frenotomy effectiveness [21,28,47]. Variability in the success rate of frenotomy was also examined in our study; although more than half of the sample experienced an improvement in symptoms, 46% of infants who underwent a frenotomy procedure did not demonstrate discernible benefits following the procedure.

The 46% rate of infants-mother dyads who did not benefit from frenotomy examined in this study highlight that further consideration should be given to non-surgical management strategies in clinical practice. As an alternative to frenotomy, these strategies can be an effective first-line therapy for the management of functional limitations associated with ankyloglossia [7,48]. Breastfeeding difficulty can often improve with time or non-surgical intervention by a lactation consultant or speech-language pathologist who specialises in breastfeeding issues [49,50]. Non-surgical strategies for management of ankyloglossia include advice on positioning, latch optimisation, feed frequency, supporting mothers to maintain milk supply, and the use of external tools such as nipple shields or supplementary nursing systems [1]. Non-surgical management was provided by midwives and lactation consultants to only 41% of infants with ankyloglossia in this study, highlighting the importance of education and training in these strategies. Speech-language pathologists were not involved in the non-surgical management of ankyloglossia within this study, highlighting a lack of multi-disciplinary collaboration. It is important for both health professionals and caregivers to understand that there are alternative and non-surgical treatment options that may eliminate the need for frenotomy procedures. Future studies investigating the effectiveness of multidisciplinary non-surgical interventions are warranted.

Previous researchers have emphasised the value of clinical judgement and establishing the cause of the breastfeeding difficulty for each infant-mother pair before intervening [51]. This highlights the role of a multidisciplinary team in implementing screening and holistic decision-making for ankyloglossia in infants. These principles should be at the forefront of rural and remote health services for infants with ankyloglossia to ensure the most appropriate management is provided.

The lack of formal accreditation for health professionals performing frenotomy procedures in Australia [52], as well as the lack of

standardised screening tools [8] may also be responsible for the higher prevalence rates of ankyloglossia in the current study. Further, the lack of involvement of speech-language pathologists, as health professionals trained in the assessment and management of infant feeding difficulties, in the assessment and management of ankyloglossia in this study is notable. These factors may also contribute to the high frenotomy rate for infants with ankyloglossia.

The development of a formal accreditation package for health professionals involved in ankyloglossia and frenotomy procedures may improve the accuracy of diagnosis of ankyloglossia and may reduce the high rates of invasive surgical management reported in our study. Similar publications, such as the guideline for the educational and ongoing competency requirements for midwives, medical practitioners and dental surgeons to perform frenotomy, from the New Zealand Government's Ministry of Health [46] should be considered for implementation across all health services. Further, clinical guidelines clearly defining the roles of health professionals in the assessment and management of ankyloglossia should be considered to establish roles and responsibilities within the multidisciplinary team.

Limitations reporting retrospective file data were evident in this study. The methods and tools used to diagnose ankyloglossia were not outlined in the clinical files. Inconsistent terminology and reporting in medical notes across professions may have impacted accurate and complete reporting of data points, including the severity and type of ankyloglossia.

The low rate of adverse events following frenotomy reported in this study will assist healthcare professionals in decision-making processes and inform consent discussions. Future prospective cohort studies following long-term outcomes of infants in remote settings who both underwent frenotomy and were untreated would be beneficial in further identifying the efficacy of frenotomy procedures that occur in this Central Australian healthcare setting. Additionally, studies gathering the perspectives of health professionals on their role in the assessment and management of ankyloglossia would be beneficial.

## 5. Conclusion

The prevalence of ankyloglossia in infants was 10.2% between 2013 and 2018. The frenotomy rate of 97.9% in this study setting was higher than rates previously reported in the literature. The 46% of infants who had a frenotomy procedure with no improvement in feeding difficulties, and the high proportion of infants who received a frenotomy in the absence of functional deficits highlight the importance of establishing a standardised and multidisciplinary approach, involving relevant professionals such as speech-language pathologists, lactation consultants, midwives and nurses. This study also reiterated the need for a validated screening or comprehensive diagnostic tool for the identification of ankyloglossia and clear clinical guidelines outlining the indications for frenotomy, as well as the requirement for health professionals to receive education and training in non-surgical strategies for the management of ankyloglossia.

These recommendations, in combination with future data from metropolitan regions, may provide the necessary information for the development of clinical guidelines for the identification and management of ankyloglossia in rural and remote health services in Australia.

## Declaration of competing interest

The authors report no declarations of interest. This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

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# Appendix 2

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# Ankyloglossia in Australia: Practices of health professionals

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ABSTRACT

*Objectives:* To investigate the opinions and practices of health professionals involved in ankyloglossia diagnosis and management in Australia.
*Method:* Two hundred and thirty-seven health professionals across Australia responded to an online survey including their diagnostic and management practice of ankyloglossia. Descriptive statistics, content analysis and thematic analysis were used to analyse quantitative data and open-ended responses, respectively.
*Results:* Most (91.6%) respondents reported they are responsible for the assessment and diagnosis of ankyloglossia in their clinical practice. A majority (56.7%) reported using more than one assessment tool in clinical practice. Less than half (46.4%) reported providing treatment to manage ankyloglossia. Surgical management was used by 44.5%, and 56.4% used non-surgical management as their primary treatment of ankyloglossia. Of the total sample, 26.6% had completed no further training or professional development in the field. 46% of respondents stated they always educate parents about ankyloglossia diagnoses, whereas 29.5% reported they always educate parents about management of ankyloglossia. Of respondents, a high level of confidence was reported by 62.6% of health professionals in the assessment of infants with ankyloglossia. Of those who perform surgical management, 53.7% reported feeling extremely confident in their skills. Fifty-two percent of respondents reported they were dissatisfied with the current service delivery for infants with ankyloglossia.
*Conclusions:* The diagnosis, management and education practices varied greatly amongst health professionals in Australia. Clinical guidelines for all relevant health professionals are needed to ensure standardised diagnosis and management processes. In future, this will help guide evidence-based diagnosis and intervention for infants with ankyloglossia.

## 1. Introduction

Ankyloglossia refers to the limited movement of the tongue causing functional limitations, as well as a visually restricted lingual frenulum [1]. The anatomy of the lingual frenulum has recently been described as a structure formed by the dynamic elevation of a midline fold in the floor of mouth fascia; not a band or cord, as it has previously been described [2]. Whilst these definitions are used most frequently, there are no established universal criteria [3]. Internationally and within Australia, a broad range of health professionals are involved in the diagnosis and management of ankyloglossia [1]. With a lack of clinical guidelines, the diagnostic criteria, diagnostic tools and management pathways for ankyloglossia likely vary greatly amongst these health professionals [3, 4].

Tools that have been developed to classify ankyloglossia diagnoses include the Coryllos criteria, which classifies ankyloglossia into two types – anterior (types I and II), and posterior (types III and IV) [5]. Classification systems to describe the severity of ankyloglossia based on the length of the lingual frenulum have also been developed [6]. The tools were designed to describe the lingual frenula but do not address the functionality of the tongue, and should be used with caution. Several tools have been developed to examine the impact of ankyloglossia on function. The Hazelbaker Assessment Tool for Lingual Frenulum Function (HATLFF) was developed to determine the severity and functional impact of ankyloglossia [7]. The Lingual Frenulum Protocol for Infants [8] was established to assess and diagnose anatomical differences of the lingual frenulum, and identify the possible impacts of these on breastfeeding. The Bristol Tongue Assessment Tool (BTAT) was developed using principles from the HATLFF to rate severity of ankyloglossia by measuring the tongue tip appearance, attachment of the frenulum to the

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lower gum ridge, lift of tongue with mouth wide and protrusion of tongue [9]. An adjunct to the BTAT is The Tongue-tie and Breastfed Babies (TABBY) assessment, which was developed to provide a pictorial representation of the BTAT [10]. Despite a variety of tools to classify and assess the impact of ankyloglossia, these tools lack reliability and standardisation, and consensus regarding a preferred ankyloglossia grading system has not been established [3]. The tools are often used in conjunction with informal functional assessments which are likely to be variable amongst health professionals [1].

Non-surgical management of ankyloglossia can include strategies such as positional changes, the alteration of feeding frequency, providing support to mothers to maintain a milk supply, latch optimisation and the use of external tools such as nipple shields or supplementary nursing systems [1,11]. These strategies are recommended to be implemented by relevant, trained health professionals such as International Board Certified Lactation Consultants (IBCLCs), midwives, child health nurses and/or speech-language pathologists [1]. Currently, frenotomy is the primary surgical intervention used to manage ankyloglossia. This surgical intervention involves cutting the frenulum found between the inferior surface of the tongue and the floor of the mouth [12]. Although frenotomy is generally considered a safe procedure, complications may include bleeding, airway obstruction, damage to salivary structures, scarring and oral aversion [3]. Increases in the rate of frenotomy in Australia have been reported as high as 420% [13], and reiterated internationally [14]. Other less common surgical procedures to manage ankyloglossia include frenuloplasty - releasing and suturing the lingual frenulum, Z-plasty – releasing the frenulum and creating flaps and suturing these, and laser interventions – used by dentists to remove and separate the frenulum tissue [15,16]. These surgical procedures have been recommended to be performed by suitably trained health professionals, and to be considered only following unsuccessful non-surgical management [1].

There are only a few reports documenting the practices of health professionals in the diagnosis and management of ankyloglossia internationally [4,17], with no literature investigating practices in Australia. There is also a complete lack of studies investigating the identification and management practices of health professionals in the field of ankyloglossia in remote settings, both in Australia and internationally. Reports of a lack of professional education in the field of ankyloglossia, and a lack of consensus amongst health professionals on assessment and diagnostic tools has led to inconsistencies in clinical practice amongst clinicians [17]. These inconsistencies, as well as the increase in frenotomy rates has led to greater interest in the clinical practices and thoughts of health professionals managing ankyloglossia. It has become increasingly important to address the issue of overdiagnosis and overtreatment of ankyloglossia in this context.

The lack of standardised guidelines and varying interpretations of ankyloglossia have contributed to the potential for overdiagnosis of the condition. In some cases, infants may undergo frenotomy without a genuine clinical need, leading to unnecessary interventions [18]. This overdiagnosis can result from the subjective judgements made by health professionals in the absence of clear diagnostic and management criteria. Awareness of the clinical practices in ankyloglossia diagnosis and management across all health care settings in Australia will allow for clinical guidelines that are sensitive to the resources available in all areas of Australia.

This study, therefore, aimed to examine the opinions and practices of Australian health professionals in the assessment and management of ankyloglossia. It was hypothesised that (i) opinions about ankyloglossia will vary between professions, (ii) the diversity of professions involved in the diagnosis and management of infants with ankyloglossia will be numerous, (iii) the majority of clinicians do not use established tools to guide management of babies with suspected ankyloglossia and (iv) clinicians would have low confidence in their skills due to a lack of standardised diagnostic and management guidelines. Reporting on the current ankyloglossia diagnostic, management, and educational practices of health professionals in Australia will inform the future development of policies to standardise processes nationally.

## 2. Method

Ethical approval for this cross-sectional questionnaire study was granted by the Central Australian Human Research Ethics Committee (CA20-3629).

### 2.1. Survey design

A survey was developed using Qualtrics software to evaluate the opinions and practices of Australian health professionals working with ankyloglossia. All questions in the survey were categorised into four blocks that included multiple choice and open response question formats. The four blocks explored health professionals' background and clinical experience, assessment practices, management practices and the provision of education. Open response questions were included.

The first block surveyed health professionals on their qualifications, geographical location based on Modified Monash Model classifications [19], clinical setting and years of experience. Participants were asked whether they have completed any professional development in the area of ankyloglossia or frenotomy and were provided with an open response text box to describe the training. The assessment practices section contained questions about factors leading to assessment of infants for ankyloglossia, the assessment/screening tools used, and revisions made to these assessment tools. A 5-point Likert scale ranging from 1 – 'Not confident' to 5 – 'Extremely confident' was used to identify the health professionals' self-reported confidence level in assessing ankyloglossia. Fixed anchor points were used as they have been recommended as more reliable when making quantitative comparison [20]. The management of ankyloglossia was explored using multiple choice questions for the type of treatment provided, number of treatments provided per month, timeframes for intervention and improvements in management. Likert scales were used to ascertain the self-reported confidence levels in the surgical management of ankyloglossia and non-surgical management of ankyloglossia, and satisfaction levels with the current service delivery for infants with ankyloglossia. The frequency of education provided about ankyloglossia and frenotomy was explored through two 5-point Likert scales.

### 2.2. Data collection

Data was collected from a survey developed and published using Qualtrics software (www.qualtrics.com). Australian health professionals who practiced in the area of ankyloglossia were invited to complete an online survey through the Qualtrics web link. Health professionals were recruited via email, professional body newsletters, interest groups and through social media groups for paediatric feeding, ankyloglossia, and related topics, as well as via managers of speech pathology, midwifery and nursing departments throughout a number of hospitals and community health centres across Australia. The survey was disseminated through a link generated by the online survey tool. This link was not personalised to any one participant and an email outlining the study and survey was sent to moderators of the interest groups and managers of health services asking them to disseminate to staff and/or colleagues, as well as posted on relevant social media pages and professional body websites. Eligible participants for this study included English speaking health professionals with clinical experience in the diagnosis and/or management of ankyloglossia in Australia.

### 2.3. Data analysis

Responses were downloaded into IBM SPSS Statistics For Windows (version 26) [21] for further analysis. Descriptive statistics were used to describe general trends. Additionally, chi-squared and Mann-Whitney U

tests were used to explore differences between groups of respondents. All p-values were calculated with a two-sided significance level of 0.05 and power was set at 0.80.

Responses to open-ended questions were transferred to Microsoft Excel for content analysis. Content analysis was completed to determine practices of health professionals in the areas of assessment and management of ankyloglossia. A thematic analysis was used to identify key themes.

## 3. Results

### 3.1. Study sample

A total of 357 responses were collated, of which 120 responses were removed due to incomplete survey data or lack of consent to participate in the study. Responses received from 237 health professionals are reported.

Demographic information about the respondents is represented in Table 1. Speech pathologists were the largest participant group (40.1%), followed by lactation consultants (20.7%) and paediatricians (7.6%). Several health professionals, including midwives, dentists, nurses, chiropractors, general practitioners, osteopaths and other professionals, responded to the questionnaire in fewer numbers.

Participants responded from all eight Australian states and territories, with most health professionals practicing in New South Wales (31.6%) and Queensland (29.1%). Based on workplace location, 177 respondents (74.7%) worked in metropolitan or regional cities, whereas 60 respondents (25.3%) worked in rural and remote areas. The highest proportion of health professionals working in rural and remote areas was in Northern Territory.

Majority of participants worked in a hospital setting (41.4%), followed by private practices (36.7%). Participants also worked in settings including community-based government health services, other settings and non-profit organisations. Most health professionals reported working in the field of ankyloglossia for over 10 years (34.6%), with over 90% of the respondents working in the field for longer than two years.

**Table 1**
Demographic information of participants.

| | N | % |
|---|---|---|
| Profession | | |
| *Speech Pathologist* | 95 | 40.1 |
| *Lactation Consultant* | 49 | 20.7 |
| *Midwife* | 14 | 5.9 |
| *Nurse (RN)* | 12 | 5.1 |
| *Paediatrician* | 18 | 7.6 |
| *Chiropractor* | 11 | 4.6 |
| *Osteopath* | 6 | 2.5 |
| *Dentist* | 13 | 5.5 |
| *GP* | 11 | 4.6 |
| *Other* | 8 | 3.4 |
| Work setting | | |
| *Hospital* | 98 | 41.4 |
| *Community-based government health* | 44 | 18.6 |
| *Private practice* | 87 | 36.7 |
| *Non-profit organisation* | 3 | 1.3 |
| *Other* | 5 | 2.1 |
| State or Territory | | |
| *ACT* | 6 | 2.5 |
| *NSW* | 75 | 31.6 |
| *NT* | 19 | 8.0 |
| *QLD* | 52 | 21.9 |
| *SA* | 11 | 4.6 |
| *TAS* | 2 | .8 |
| *VIC* | 46 | 19.4 |
| *WA* | 26 | 11.0 |
| Workplace location | | |
| *Major city* | 136 | 57.4 |
| *Inner regional* | 41 | 17.3 |
| *Outer regional* | 35 | 14.8 |
| *Remote* | 22 | 9.3 |
| *Very remote* | 3 | 1.3 |
| Years of clinical experience | | |
| *0* | 1 | 0.4 |
| *1–2* | 21 | 8.9 |
| *3–4* | 40 | 16.9 |
| *5–6* | 42 | 17.7 |
| *7–8* | 28 | 11.8 |
| *9–10* | 23 | 9.7 |
| *10+* | 82 | 34.6 |

### 3.2. Ankyloglossia diagnosis

Of the health professionals who responded to the survey, 217 (91.6%) respondents reported that they assess and diagnose ankyloglossia in their clinical practice.

#### 3.2.1. Factors that led to assessment

When health professionals were asked what led them to assess for ankyloglossia in infants, it was revealed that the factors preceding ankyloglossia assessment were often multifactorial. Over half of the respondents reported that they assess all infants (56.7%). Health professionals also reported that they assessed for ankyloglossia due to the infant demonstrating a poor latch (56.2%), the appearance of the tongue (55.3%), poor suck (52.1%), and due to maternal nipple pain (4.5%).

#### 3.2.2. Assessment tools

Most health professionals reported using more than one assessment tool in their clinical practice. The most frequently used tools were observation (72.2%), an informal screening tool (44.3%) and the HATLFF (41.4%).

The responses of health professionals to the question of why this was their assessment tool of choice were analysed through both content and thematic analysis and overall themes of a preference for a functional assessment, and limitations in training, availability of tools and time emerged. These themes and subthemes are depicted in Table 2.

Thirty-three participants reported that they had a "no formal training" in the tools they were using (P39; P92) and that they "haven't heard of the others" (P91). As a result, their clinical practice was impacted by their level of expertise.

> "I do not have confidence I have the skills or tools to complete a formal Ax [assessment], nor feel it is within my scope of practice." (P81)

Conversely, health professionals that were more familiar with diagnostic tools believed using "a combination of assessment/screening tools" (P77) achieves "a thorough assessment of the mobility and function of the tongue" (P187).

Health professionals were asked why they use the assessment tools they use in their clinical setting (Q3.3). A variety of limitations were reported by 57 health professionals to be a contributing factor as to why they used the assessment tools selected. For example, limitations in time were reported by 5 health professionals, who commented that they had "no time to complete formalised assessment tools" (P15), highlighting the fast-paced nature of many health care settings.

> "I run a drop-in for breastfeeding mothers so I haven't got time to do a lengthy assessment." (P175)

The availability of tools was a limitation for 19 health professionals, who reported that they use their current tool as it "is what the health service uses" (P78). A health professional in a regional setting had additional availability constraints due to the logistics of their health service.

**Table 2**
Assessment practice of health professionals.

| Assessment tool | N | % |
|---|---|---|
| *Observation* | 171 | 72.2 |
| *Informal screening/tool* | 105 | 44.3 |
| *Hazelbaker Assessment Tool for Lingual Frenulum Function (HATLFF)* | 98 | 41.4 |
| *Bristol Tongue-Tie Assessment Tool* | 31 | 13.1 |
| *Unspecified* | 20 | 8.4 |
| *Lingual Frenulum Protocol (Martinelli)* | 18 | 7.6 |
| *Frenotomy Decision Tool for Breastfeeding Dyads (Dobrich)* | 9 | 3.8 |
| *Functional assessment* | 9 | 3.8 |
| *Neurological exam* | 4 | 1.7 |
| *Kotlow classification protocol* | 2 | 0.8 |
| *Referral* | 2 | 0.8 |
| *Coryllos classification system* | 1 | 0.4 |
| **Factors that led to assessment** | **N** | **%** |
| *All infants are assessed* | 123 | 56.7 |
| *Poor latch* | 122 | 56.2 |
| *Poor suck* | 113 | 52.1 |
| *Maternal nipple pain* | 118 | 54.4 |
| *Poor weight gain* | 98 | 45.2 |
| *Appearance of tongue* | 120 | 55.3 |
| *Other* | 43 | 19.8 |
| **Other factors that led to assessment** | **N** | **%** |
| *General feeding difficulties* | 13 | 30.2 |
| *Routine screening* | 9 | 20.9 |
| *Request for an assessment* | 5 | 11.6 |
| **Reasons for assessment tool selection** | **N** | **%** |
| *Preference for a combination of assessments* | 26 | 12 |
| *Dissatisfaction with other tools* | 14 | 6.4 |
| *Preference for a tool that is easy to use* | 37 | 17 |
| *Evidence base behind the tool* | 10 | 4.6 |
| *Preference for a functional assessment* | 53 | 24.4 |
| *Limitation of time* | 5 | 2.3 |
| *Limitation in tool availability* | 19 | 8.8 |
| *Limitation in training* | 33 | 15.2 |
| *Referral to other services for assessment* | 20 | 9.2 |

> "I work in remote [supplied] region and am unable to bring all of my assessments with me due to weight limits on planes and large caseloads." (P237)

Functional assessments were a priority when selecting assessment tools for 53 health professionals, who reported that they "take a very function-based approach to the assessment" (HP90).

> "Not aware of any screening tool with strong evidence to support its use over functional assessment and clinical observation of feeding" (P140)

### 3.2.3. Revision of assessment tools

A total of 37 health professionals (15.6%) reported that they have made revisions to existing ankyloglossia assessment tools. Revisions were made to the HATLFF by 19 health professionals, the BTAT by 5 health professionals, and 13 respondents indicated that they had revised another existing informal screening tool. Further, 10 health professionals reported combining tools and adding test items, as well as revising tools which were not listed, including informal assessment tools developed specifically for their organisation. Some health professionals (40.5%) reported that they had made more than one type of revision to the above tools. The types of revisions made to these assessments are depicted in Fig. 1.

## 3.3. Ankyloglossia management

Of the health professionals who responded to the survey, 110 (46.4%) respondents reported that they provide treatment for and manage ankyloglossia. Of these, surgical procedures were performed by 49 health professionals (44.5%) as primary treatment for ankyloglossia. These procedures included frenotomy (29%), frenuloplasty/z-plasty (5.5%) and laser surgery (10%). Non-surgical management was provided by 62 health professionals who treat or manage ankyloglossia (56.4%). Health professionals were asked to specify the non-surgical treatments that they provide, which can be seen in Table 3.

Other treatments were reported by 60 health professionals (54.5%). Content analysis of these treatments found common themes, included using a multidisciplinary approach to treatment (8.5%), non-invasive treatments such as feeding therapy, oral therapies and compensatory feeding treatments such as positioning changes (64.8%), and referring to

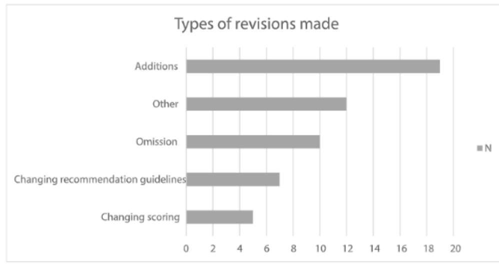


**Fig. 1.** Revisions made to assessment tools.

**Table 3**
Management practices of health professionals.

| | N | % |
|---|---|---|
| Treatment | 110 | 46.4 |
| *Non-surgical* | 62 | 56.4 |
| *Frenotomy* | 32 | 29.1 |
| *Laser surgery* | 11 | 10 |
| *Frenuloplasty/Z-plasty* | 6 | 5.5 |
| *Other treatment* | 60 | 54.5 |
| Number of surgical treatments provided (per month) | | |
| *0–5* | 23 | 46.9 |
| *5–10* | 1 | 2.0 |
| *10–20* | 4 | 8.2 |
| *20–30* | 14 | 28.6 |
| *30+* | 7 | 14.3 |
| Non-surgical treatments provided | | |
| *Positioning changes* | 25 | 24 |
| *External tools e.g. nipple shield, dummy* | 11 | 10.6 |
| *Oral exercises* | 11 | 10.6 |
| *Latch optimisation* | 9 | 8.7 |
| *Osteopathic treatment* | 9 | 8.7 |
| *Myofunctional therapy* | 8 | 7.7 |
| *Chiropractic treatment* | 7 | 6.7 |
| *Referral to other providers* | 7 | 6.7 |
| *Feeding therapy e.g. sucking therapy* | 6 | 5.8 |
| *Education* | 5 | 4.8 |
| *Other* | 3 | 2.9 |
| *Speech therapy* | 2 | 1.9 |
| *Sensorimotor exercises* | 1 | 1 |
| Preferred time frame for intervention | | |
| *Immediately* | 24 | 10.4 |
| *1-3 days* | 32 | 13.9 |
| *3-7 days* | 30 | 13 |
| *7+ days* | 38 | 16.5 |
| *Other* | 107 | 46.3 |
| Preferred time frame for intervention (other) | | |
| *Individualised* | 44 | 62.9 |
| *Age-dependent* | 9 | 12.9 |
| *As soon as possible* | 7 | 10 |
| *Following assessment and non-surgical* | 6 | 8.6 |
| *Management at the discretion of the health professional* | 4 | 5.7 |

other providers for management (27.8%).

The frequency of surgical procedures for the management of ankyloglossia was examined. Over half of the health professionals performed less than five surgical treatments per month, with five health professionals (11.6%) working in private practice settings providing over 30 surgical procedures per month (See Fig. 2). These health professionals encompassed three dentists, one lactation consultant and one 'other' health professional. Of the 15 health professionals performing more than ten procedures per month, 11 were dentists, 1 was a surgeon, 1 was a general practitioner, and 2 were midwives. Ten of these health professionals used lasers as their surgical tool.

A Mann-Whitney $U$ test revealed that there was no significant difference in the number of procedures performed by health professionals when comparing metropolitan/regional locations and rural/remote locations ($p = 0.220$).

The Australian health professionals who responded to this survey were asked about their preferred timeframe from diagnosis to intervention in Q4.7. Responses varied among the health professionals, with 24 (10.4%) reporting intervention should occur immediately, 32 (13.9%) preferred 1–3 day time frame, 30 (13%) preferred 3–7 days, 38 (16.5%) preferred over 7 days, and 107 (46.3%) reported that they would prefer a different time frame. The responses of health professionals were analysed through content and thematic analysis. The themes and subthemes are depicted in Table 3.

In Q4.7.5, health professionals were asked to give details about their preferred timeframe from diagnosis to intervention, as they had selected 'other' in Q4.7. Various timeframes and ideas were reported by health professionals.

Individualised timeframes were preferred by 44 health professionals, who reported that the management timeframe "Depends on the presenting patient in every case" (P207).

> "Optimal timing of release is imperative for good outcomes. There is no one size fits all approach as each infant is different in relation to function. Each dyad is treated individually. I feel release of restricted oral tissue is vital for all dyads but the timing is also very important for good outcomes." (P48)

Intervention for ankyloglossia as soon as possible was a priority for seven health professionals, who reported that a procedure should occur "As soon as diagnosis is made" (P153).

> "Ideally if impacting feeding they would be seen and given intervention ASAP." (P158)

When asked what should be improved in the field of ankyloglossia management, multiple areas for improvement were identified by health professionals. Improved education for staff and clinicians was an area identified by 88.2% of health professionals. Improved education for parents was highlighted by 74.3%, regular training by 55.7% and different screening tools by 26.2%. Other areas of improvement were identified by 24.9% of health professionals, and included themes such as the creation of clinical guidelines, equitable access to ankyloglossia services, and further research.

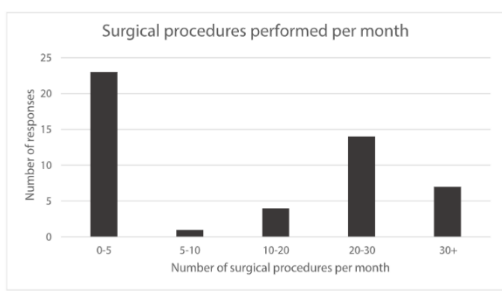


**Fig. 2.** Average number of surgical procedures performed per month.

### 3.4. Education to parents

When surveyed, less than half (46%) of health professionals reported that they always educate parents about ankyloglossia, and 72% of health professionals provided education to parents about ankyloglossia in over half of their clinical interactions. A smaller proportion (27.5%) of health professionals provide education to parents on ankyloglossia half of the time or less.

Education to parents on frenotomy procedures was completed in all clinical interactions for 29.5% of health professionals. Over half of health professionals (57%) practicing frenotomy procedures reported that they educate parents on frenotomy in more than half of their clinical interactions. Frenotomy education was provided to parents half of the time or less by 36.2% of health professionals. One participant stated that they never provide education on ankyloglossia, and 15 (6.3%) participants stated they never provide education on frenotomy.

Health professionals in Australia used a variety of tools, and often used more than one modality to educate parents and caregivers on ankyloglossia and frenotomy procedures. Health professionals primarily used verbal explanations when providing education to parents and caregivers (94.5%). Written education was provided by 44.7% of health professionals, as well as the use of web-based education materials (31.6%) and video resources (12.2%). Australian health professionals also reported providing education to parents and caregivers through other methods.

### 3.5. Professional development

Professional development was completed by 174 (73.4%) of health professionals, with 26.6% of respondents having completed no further training in the field. There was no significant difference in the rates of professional development among health professionals working in metropolitan and rural/remote regions (Chi-square; $p = 0.171$).

The types of professional development completed by Australian health professionals were group following content analysis and fell into three categories. These included formal training (e.g., specialist training in paediatric dentistry) completed by 36 (20.8%) of respondents, informal training (e.g., attendance at conferences and workshops) completed by 122 (70.5%) of respondents, and self-directed professional development (e.g., reading of published literature) completed by 15 (8.7%) of health professionals.

### 3.6. Confidence and satisfaction of health professionals

Health professionals were asked to rate their confidence on a Likert scale from 0 to 5 in the areas of assessment, non-surgical management, and surgical management of ankyloglossia. On this scale 0 indicated 'no confidence' and a 5 indicated 'extremely confident'. The responses of

**Table 4**
Confidence of health professionals.

| | Assessment | | Non-surgical management | | Surgical management | |
|---|---|---|---|---|---|---|
| | N | % | N | % | N | % |
| 0 (no confidence) | 0 | 0.0 | 1 | 1.3 | 4 | 9.8 |
| 1 | 4 | 2.0 | 1 | 1.3 | 0 | 0.0 |
| 2 | 17 | 8.4 | 3 | 3.9 | 0 | 0.0 |
| 3 | 55 | 27.1 | 15 | 19.5 | 5 | 12.2 |
| 4 | 81 | 39.9 | 35 | 45.5 | 10 | 24.4 |
| 5 (extremely confident) | 46 | 22.7 | 22 | 28.6 | 22 | 53.7 |
| | 203 | | 77 | | 41 | |

health professionals are outlined below and in Table 4.

Of the 203 health professionals who conducted assessment of ankyloglossia, 62.6% reported a high level of confidence about their assessment skills, rating themselves as confident or extremely confident. More than one-third (37.5%) of health professionals rated their confidence as moderately confident or less. No health professionals rated themselves as having no confidence in the assessment of ankyloglossia.

A majority (74.1%) of health professionals performing non-surgical management reported they are moderately to extremely confident in their skills. Average to minimal confidence in their non-surgical management skills was reported by 24.7% of health professionals. One health professional reported no confidence in their non-surgical management skills.

Over half of respondents (53.7%) who perform surgical management of ankyloglossia reported that they feel extremely confident in their skills. Most participants (90.3%) rated moderate to extreme confidence in their surgical management of ankyloglossia. Four health professionals (9.8%) who perform surgical management reported no confidence in their skills. Of the 15 health professionals providing more than 10 surgical procedures per month, 14 reported they were 5/5 confident in their surgical skills.

Further analysis using a Mann-Whitney *U* test revealed that there was a significant difference found in the confidence of health professionals when asked about their assessment skills. The confidence of health professionals practicing in metropolitan areas was rated higher than in rural areas (mean 3.9; SD = 0.83 vs mean 3.3; SD = 1.18; p = 0.001). There was no significant difference in the confidence of health professionals practicing in metropolitan and rural areas when it came to non-surgical or surgical management of ankyloglossia (p = 0.973 and p = −0.628 respectively). This can be seen in Table 5.

Over half (52%) of the health professionals involved in this study reported that they were dissatisfied with the current service delivery for infants with ankyloglossia, compared to 29.9% who reported that they were satisfied with the current service delivery.

## 4. Discussion

This study aimed to explore the diversity and practices of health professionals working in the field of ankyloglossia assessment and management in Australia. The Australian health professionals working in the field of ankyloglossia were diverse regarding disciplines. The cohort included speech pathologists, lactation consultants, midwives, nurses, paediatricians, chiropractors, osteopaths, dentists, general practitioners and other health professionals such as craniosacral therapists, dietitians and oro-facial myologists. The type of health professionals who responded to our questionnaire were largely consistent with those listed as key relevant professionals in the field in Australia [1].

The spread of locations in which these health professionals practice reinforced that ankyloglossia assessment and management is occurring across all areas of Australia. In addition, the health professionals working in this field are incredibly varied in their training backgrounds. The variance in location and discipline highlights the importance of health professionals involved in ankyloglossia assessment and management being unified in diagnostic and management pathways. The experience levels of the health professionals working with infants with ankyloglossia were high, with one third of professionals having worked with infants with ankyloglossia for over ten years.

Professional development that is relevant to the scope of practice of a health professional is vital in maintaining, improving and broadening knowledge, expertise and competency [22]. Continuing professional development is a legal requirement for health professionals in Australia since the establishment of the National Registration and Accreditation Scheme (National Scheme) in 2010. The National Scheme is enacted in each state and territory of Australia since 2009 and 2010 and is regulated by a corresponding National Board for each discipline of health professional. This ensures that Australian health professionals are competent in the areas that they provide care. The professional development rate of 73.4% in our study showcases that over one quarter of health professionals working in the field of ankyloglossia have not completed further training in this area of practice. There was no significant difference in the rates of professional development among health professionals working in metropolitan and rural/remote areas, highlighting that access to professional development did not appear to be the challenging factor. Of the health professionals who had completed professional development in the area of ankyloglossia, 79.2% reported that they had completed informal and self-directed professional development, including reading literature and attending workshops and conferences.

The AHPRA 2021/2022 annual report reported that following routine audits which encompass professional development and recency of practice, 0.23% of health professionals were non-compliant with the registration requirements of their profession [23]. This rate contrasts with the professional development rate of health professionals in our study. This may be due to the lack of training courses in Australia that allow health professionals to register as specialists or experts in the identification or treatment of ankyloglossia [1]. This is likely compounded by the diversity in health professionals involved in the assessment and management of ankyloglossia, with no clear guidelines on the requirements of health professionals working in this field.

In this current study, observations and informal screenings were the most common tools used by health professionals to identify ankyloglossia, with 72.2% and 44.3% using these methods respectively. This is reflected in the comments of health professionals in this study reporting a preference for tools that include functional assessment methods that are individualised to the infant breastfeeding dyad. The health professionals in our study also highlighted a lack of access and training in other ankyloglossia assessment tools. These findings are consistent internationally, with only 33% of Canadian health professionals reporting the use of a framework or policy such as the HATLFF or Frenotomy Decision Tool for Breastfeeding Dyads (FDTBD) to assess ankyloglossia in their clinical practice [24]. Additionally, over 50% of health professionals in this study reported that every infant is assessed for ankyloglossia. This is a higher proportion of respondents compared to available literature from Canada stating 11% of health professionals suggested that every infant regardless of their symptoms should be

**Table 5**
Confidence of health professionals in metro vs rural settings.

| | Assessment | | | Non-surgical management | | | Surgical management | | |
|---|---|---|---|---|---|---|---|---|---|
| | All | Metro | Rural | All | Metro | Rural | All | Metro | Rural |
| N | 203 | 152 | 51 | 77 | 62 | 15 | 41 | 32 | 9 |
| *Mean* | 3.7 | **3.9**[a] | **3.3**[a] | 3.9 | 3.9 | 4.0 | 4.0 | 3.9 | 4.4 |
| *SD* | 0.97 | **0.83** | **1.18** | 0.98 | 1.02 | 0.85 | 1.51 | 1.65 | 0.73 |
| *Median* | 4.0 | 4.0 | 3.0 | 4.0 | 4 | 4 | 5 | 5 | 5 |
| *Variance* | 0.94 | 0.69 | 1.39 | 0.96 | 1.04 | 0.71 | 2.27 | 2.73 | 0.52 |
| *Min-Max* | 1–5 | 2–5 | 1–5 | 0–5 | 0–5 | 3–5 | 0–5 | 0–5 | 3–5 |

[a] = Mann-Whitney *U* test; p = 0.001.

assessed for ankyloglossia [24]. The consensus statement released by the Australian Dental Association [1] outlines that the key pre-requisites for qualified health professionals making a suspected ankyloglossia diagnosis are a thorough case history, an objective functional assessment of tongue function using a diagnostic system and a complete assessment of functional issues impacted by the suspected ankyloglossia. This discrepancy between published literature and clinical practice may be contributing factors to the high rates of tongue-tie seen in Australia [13].

The Australian Dental Association's states "Surgical management should only be undertaken by appropriately trained health professionals" [1]. However, further detail outlining what is 'appropriately trained' is not provided, which may have contributed to the diversity of health professionals who performed surgical procedures to management ankyloglossia in this study. This lack of clarity around the necessary training required to perform frenotomy procedures may also be reflected in the low confidence self-ratings in some health professionals conducting these surgical procedures.

The frequency of frenotomy procedures per month was not consistent with the rising rates of frenotomy reported as high as 400% in Canada, and 866% in the United States [25,26]. In our study, most providers of surgical procedures for the management of ankyloglossia performed less than five procedures per month.

The current study revealed that dentists performed the highest frequency of surgical procedures for ankyloglossia, using laser as their primary tool. This is consistent with reports of increased laser use in frenotomy procedures, with dentists performing 88% of frenotomies by laser [27–29]. A recent study has found that use of the lasers to perform frenotomy was significantly associated with oral aversion and feeding refusal as a complication, however, was associated with less reported bleeding than use of scissors/scalpel for frenotomy [28]. Further studies and protocols should be established to ensure the efficacy of these procedures in Australia, given the insufficient evidence to support laser as a superior technique for frenotomy [3].

Amongst the 237 health professionals who completed the survey and were involved in ankyloglossia assessment and management, satisfaction levels were reported as low regarding the current service delivery for infants with ankyloglossia. These health professionals reported that they are revising assessment and diagnostic tools, and using a combination of tools to assess infants, which highlights the likelihood that these health professionals are not satisfied with the tools currently available to them [17,28].

The confidence ratings among the workforce in remote areas was lower than that of the workforce in metropolitan areas. It is likely that the reason for this difference is multifactorial. Remote health services are often characterized by high staff turnover, limited numbers of specialist physicians and a reliance on more generalist health professionals [30,31]. Additionally, the current study highlighted that there was no significant difference in the rates of professional development amongst health professionals working in remote settings and metropolitan areas. These considerations may imply that the lower confidence ratings of health professionals in rural and remote areas is unlikely to be due to a lack of training, but perhaps the pressure of diagnosing and managing ankyloglossia without clear published diagnostic criteria, and without specialist physicians, in an isolated setting [17,32].

The rates of education provided to parents by health professionals on frenotomy and associated procedures were considered low. Whilst frenotomy is generally considered a low-risk procedure regardless of the instrument used to perform the division, risks such as bleeding, ulceration, oral aversion and swelling should be considered [1,3,33]. These risks should be discussed with parents prior to all frenotomy procedures, as part of the informed consent process [3]. Concerningly, the 15% of health professionals providing frenotomy procedures in this study reported that they only 'sometimes' educate parents on the procedure. Health professionals should ensure that they are adherent to the codes of conduct and ethical standards outlined by their professional governing bodies [34].

Potential sample bias was considered to be a limitation of the current study, in that Australian health professional survey participants were recruited based on their own perception of previous experience with infants with ankyloglossia. Additionally, a limitation of this study is the inconsistent and varied terminology used for ankyloglossia management. Terms such as frenotomy, laser surgery, and frenectomy are often used interchangeably and without necessary details of surgical practices. A lack of clarity regarding these procedure names may have impacted the responses of the health professionals responding to the survey. This discrepancy may result in challenges in applying research findings to clinical practice. A further limitation is the use of Likert scales, as may be considered a subjective method of evaluation. Evidence suggests that responses to a question on a Likert scale may vary across people from different cultures and countries [35]. This limitation was managed through the integration of open-ended questions, which offered participants the opportunity to provide detail about their current clinical practice.

Future directions in extending the current study may include examination of parental experiences with current diagnostic and management practices for ankyloglossia. This may lead to a clearer idea of the impact of clinical practice on parental experiences and informed consent. Future studies may explore the professional development opportunities for health professionals when expanding their scope of practice to ankyloglossia diagnosis and management.

## 5. Conclusion

This study was designed to explore the practices of Australian health professionals identifying and managing ankyloglossia in infants, and is the largest survey conducted to date regarding clinical practice in the field of ankyloglossia. At present, ankyloglossia diagnosis and management is occurring across Australia, by a broad range of health professionals including speech-language pathologists, lactation consultants, midwives, nurses, dentists, as well as medical professionals. The diagnosis, management and education practices varied greatly amongst health professionals in this study. Rates of professional development among health professionals were low. The health professionals performing over 30 frenotomy procedures per month reported high levels of confidence in their skills. Over half of the health professionals involved in this study were dissatisfied with the current service delivery for infants with ankyloglossia. Clinical guidelines for all relevant health professionals are needed to ensure standardised diagnosis and management processes, and to improve clinical confidence and satisfaction. Emphasis on a multidisciplinary approach is essential. These guidelines will help facilitate evidence-based diagnosis and intervention for infants with ankyloglossia.

## Declaration of competing interest

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# Appendix 3

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# Ankyloglossia in Australia: Experiences and perspectives of parents and caregivers

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ABSTRACT

*Objectives:* To investigate the perspectives and experiences of parents of infants with ankyloglossia in Australia.
*Method:* Two hundred and sixty-seven parents across Australia responded to an online survey including their experiences of having a child with ankyloglossia. Descriptive statistics were used to analyse quantitative data.
*Results:* Participants were from all Australian states and territories, with the majority residing in New South Wales and Victoria. Ankyloglossia diagnoses typically occurred within the first two weeks of life, driven mainly by difficulties with feeding. Lactation consultants played a prominent role in diagnosis, particularly in rural areas. Surgical interventions were common, with frenotomy using scissors or scalpel being the primary treatment. Aftercare recommendations, including stretching the frenotomy wound, were prevalent. Most parents received education about ankyloglossia, primarily through verbal and written information. Parents generally reported high satisfaction with the effectiveness of treatments, favouring surgical interventions. However, satisfaction with health professionals' support did not consistently correlate with the likelihood of consenting to the treatment again, and those who conducted their own research on ankyloglossia expressed lower satisfaction with health professionals' support.
*Conclusions:* The experiences of Australian parents in their infant's diagnosis, management and education of ankyloglossia varied greatly. Clinical guidelines for all relevant health professionals are needed to ensure standardised diagnosis and management processes. In future, this will help guide evidence-based diagnosis and intervention for infants with ankyloglossia.

## 1. Introduction

Ankyloglossia, more commonly known as tongue-tie, refers to the limited movement of the tongue causing functional limitations, as well as a visually restricted lingual frenulum [1,2]. Ankyloglossia can result in a range of effects on both newborns and older children, and particularly significant is its connection to feeding difficulties in infants, with half of mothers with infants diagnosed with ankyloglossia experiencing breastfeeding challenges [3]. Ankyloglossia can result in ineffective infant latching, maternal pain during breastfeeding, and ultimately inadequate weight gain and irritability. Whilst these symptoms are the most commonly reported complaints in infants with ankyloglossia, they lack specificity and may be present due to other reasons [4].

A lack of clinical guidelines, diagnostic criteria and tools, pathways for the diagnosis and management of ankyloglossia, and lack of clear outcome measures has resulted in great diversity of practice among health professionals in Australia and internationally [2,5–7]. Our previous study, which explored the practices of Australian health professionals working in the field of ankyloglossia highlighted the variances in clinical practice amongst the cohort [8]. We hypothesised that these variances in clinical practice were likely a direct reflection of a lack of clinical guidelines [8]. This wide range of approaches is expected to lead to significantly varied experiences in the diagnosis and treatment of infants with ankyloglossia among parents in Australia. It has been previously established that an uncoordinated approach to ankyloglossia diagnosis and management creates health care system distrust among mothers, and parents broadly who experience breastfeeding challenges [9].

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Few studies have explored the perspectives of parents with children with ankyloglossia to date, with nil studies of this nature being conducted in Australia. Literature has highlighted the challenges faced by breastfeeding mothers of infants with ankyloglossia, including negative effects on maternal emotional and physical wellbeing [10]. In a study by Waterman et al. (2021), these negative effects were induced by physical pain during breastfeeding, and desperation, guilt and disappointment in their breastfeeding journey [9]. Despite the challenges, the women surveyed in the study demonstrated resilience by advocating and educating themselves, and persevering in their breastfeeding relationship. The Feeding Infants in Newfoundland and Labrador (FiNaL) study conducted in Canada delved into the elements contributing to difficulties in breastfeeding and the early discontinuation of breastfeeding [9]. The findings revealed that mothers who encountered breastfeeding hurdles due to ankyloglossia expressed significant frustration due to the limited availability of evaluation, diagnosis, and treatment options [4]. Additionally, the study underscored the absence of comprehensive assistance for families dealing with ankyloglossia in Canada, and an overall frustration with the health care they received. As a result of this lack of support, parents questioned the expertise of healthcare practitioners working with them and reported receiving inconsistent information from their providers [9].

A consensus statement in 2020 outlined the importance of breastfeeding parents receiving adequate support, education, counselling, and being involved in shared-decision making discussions [2]. Parents are provided with limited education on ankyloglossia the benefits and risks of frenotomy procedures, likely due to the scarcity of literature and standardised guidelines accessible to healthcare professionals [8]. Due to the current absence of defined diagnostic criteria and treatment indications for ankyloglossia, there are implications for informed consent which may impact the post-intervention perceptions of parents. Previous reports of parents of infants with ankyloglossia have described high levels of frustration with access to assessment, diagnosis and management, as well as significant inconsistencies in health care provider knowledge and acceptance of ankyloglossia, and its effect on breastfeeding [9,11].

The likelihood of a disparity or lack of alignment between the best evidence and practice recommendations of healthcare professionals, and the information that the general public may encounter on non-peer-reviewed social media platforms is consistently highlighted [12]. Whilst health professionals have been reported to use social media to share information [12], professional advertising may not always reflect current best medical evidence, and this vulnerable patient population needs to be fully informed about the options available to them. A study by Grond, Kallies and McCormick (2021) investigated the social media posts on Twitter of parents with infants with ankyloglossia. These researchers reported that of the parents who tweeted about a previous frenotomy procedure, 92 % expressed satisfaction and 8 % dissatisfaction post-operatively. In addition, amongst the healthcare providers who stated an opinion on frenotomy, 94.4 % were judged to have a pro-frenotomy sentiment [13]. This highlights a need to explore the self-education practices of parents to understand what information is being disseminated online by parents and healthcare providers, as the sentiments expressed may be shaping patient decision making [13].

The current study, therefore, aims to contribute important information to the limited body of literature on the experiences of Australian parents and caregivers who have had an infant diagnosed with ankyloglossia. Given the significance of obtaining informed consent and providing patient-centered healthcare, this study set out to investigate the viewpoints and encounters of parents whose infants were diagnosed with ankyloglossia in Australia. The study posited the following hypotheses: (i) parental experiences would exhibit regional variations throughout Australia; (ii) a wide array of professions would be involved in diagnosing and managing infants with ankyloglossia; and (iii) parents would express dissatisfaction with the care their infant received.

## 2. Method

Ethical approval for this cross-sectional questionnaire study was granted by the University of Adelaide Human Research Ethics Committee (H-2023-010).

### 2.1. Survey design

A survey was developed to explore the experiences and perspectives of Australian parents and caregivers who have had a child under the age of two years diagnosed with ankyloglossia. All questions in the survey were categorised into four blocks that included multiple choice question formats. The four blocks explored parents' demographic information, experiences with assessment practices, management practices and the education they were provided.

The first block surveyed parents on their geographical location within Australia based on Modified Monash (MM) Model classifications [14]. The second block contained questions about factors leading to assessment of infants for ankyloglossia, the age of the infant at diagnosis and the health professionals involved in this process. The management of ankyloglossia was explored in block three using multiple choice questions for the type of treatment provided, the health professionals involved in the process, and the post-operative care their child received. A 5-point Likert scale ranging from 1 – 'Not at all to 5 – 'Extremely' was used to identify the parents' perception of the effectiveness of the treatment for ankyloglossia. Fixed anchor points were used as they have been recommended as more reliable when making quantitative comparison [15]. Likert scales were used to ascertain the likelihood of parents to consent to the treatment again. Information regarding the types and quality of education provided about ankyloglossia and frenotomy was explored through multiple choice questions and two 5-point Likert scales in block four.

### 2.2. Data collection

Data was collected from a survey developed and published using Qualtrics software (Qualtrics, Provo, UT). Australian parents who have had an infant under the age of two with ankyloglossia were invited to complete the online survey. Parents were recruited via email, professional body newsletters, interest groups and through social media groups for paediatric feeding, ankyloglossia, and related topics. The survey was disseminated through a link generated by the online survey tool. This link was not personalised to any one participant and an email outlining the study and survey was sent to moderators of the interest groups asking them to disseminate to their networks, as well as posted on relevant social media pages and professional body websites. No financial incentives were offered to participants for survey completion. Eligible participants for this study included Australian, English-speaking parents who have had a child under the age of two diagnosed with ankyloglossia.

### 2.3. Data analysis

Survey responses were downloaded into IBM SPSS Statistics For Windows (version 26) [16] for further analysis. Descriptive statistics were used to describe general trends. Additionally, Chi-squared and Mann-Whitney U tests were used to explore possible differences between groups of respondents. All p-values were calculated with a two-sided significance level of 0.05 and power was set at 0.80.

## 3. Results

### 3.1. Study sample

A total of 274 responses were collated, of which seven responses were removed due to ineligibility for the study. Responses received from

267 parents are reported.

Demographic information about the respondents is represented in Table 1. Participants responded from all eight Australian states and territories, with over half of parents living in New South Wales (32.6 %) or Victoria (22.9 %). Based on location, 183 respondents (68.5 %) lived in metropolitan or regional cities (MM1-2), and 84 respondents (31.5 %) lived in rural and remote areas (MM3-7). The highest proportion of parents living in rural and remote areas was in Northern Territory (70 %).

### 3.2. Ankyloglossia diagnosis

#### 3.2.1. Age at diagnosis

The diagnostic phase of the respondents' ankyloglossia experiences are depicted in Table 2. Of the parents who responded to the survey, 36 (13.5 %) parents reported that their infant was diagnosed with ankyloglossia in their first day of life. Over one third of parents (35.6 %) reported their infant was diagnosed with ankyloglossia in their first seven days of life, with 45 % of infants being diagnosed before two weeks of age. Across the study participants, 262 (98 %) parents reported that their child was diagnosed with ankyloglossia before the age of one.

#### 3.2.2. Factors and symptoms that led to diagnosis

Over 80 % (n = 214) of parents reported that there was more than one factor that contributed to their infant being diagnosed with ankyloglossia, and over half of parents (520 %, n = 139) reported that there were three or more factors. The primary reason that led to a diagnosis of ankyloglossia was difficulties with feeding, as reported by 206 (77.2 %) parents. This was followed by nipple pain (53.2 %), appearance of the tongue (51.7 %) and the health professionals' opinion (47.9 %). Less common responses provided by parents were that there was no specific reason that led to their infant being diagnosed with ankyloglossia (1.1 %) and other (18.4 %). Two (0.7 %) parents reported that they were unsure of what led to their infant being diagnosed with ankyloglossia.

#### 3.2.3. Health professional involved in diagnosis of ankyloglossia

Of the parents that responded to the survey, 95 (35.6 %) parents reported that more than one health professional was involved in the diagnosis of ankyloglossia for their infant. In this study, there were five primary healthcare providers responsible for diagnosing ankyloglossia in Australia. Of these health professionals, lactation consultants issued the highest number of diagnoses in all regions of the country.

The parents of 131 infants reported their child was diagnosed by a lactation consultant, 66 diagnosed by a midwife, 61 self-diagnosed, 51 diagnosed by a doctor, 40 by a dentist, 30 by a health professional not specified in the survey (other), 14 by a speech pathologist, 11 by a nurse, and one parent who was unsure of the health professional who diagnosed their infant with ankyloglossia.

In rural and remote areas of Australia, 67.7 % of infants were diagnosed with ankyloglossia by a lactation consultant, compared to 46.6 % in metropolitan or regional cities. There was significant difference in the rate of infants diagnosed by a lactation consultant in metropolitan areas and rural and remote areas (Chi-square; $p = 0.043$). Additionally, in rural and remote areas, dentists made no ankyloglossia diagnoses, compared to 16.9 % of diagnoses in metropolitan or regional cities.

**Table 1**
Demographic information of participants.

| State or Territory | N | % |
|---|---|---|
| *NSW* | 87 | 32.6 |
| *VIC* | 61 | 22.9 |
| *QLD* | 56 | 21.0 |
| *NT* | 23 | 8.6 |
| *WA* | 20 | 7.5 |
| *SA* | 9 | 3.4 |
| *ACT* | 6 | 2.3 |
| *TAS* | 5 | 1.9 |
| Participant location (Modified Monash category) | | |
| *Major city (1)* | 146 | 54.7 |
| *Inner regional (2&3)* | 48 | 18.0 |
| *Outer regional (4&5)* | 42 | 15.7 |
| *Remote (6)* | 28 | 10.5 |
| *Very remote (7)* | 3 | 1.1 |

**Table 2**
– Ankyloglossia diagnosis experiences among Australian parents.

| | N | % |
|---|---|---|
| Age at diagnosis | | |
| *Less than 1 day* | 36 | 13.5 |
| *2-7 days* | 59 | 22.1 |
| *8-14 days* | 26 | 9.7 |
| *Between 2 weeks and 2 months* | 65 | 24.3 |
| *Between 2 months and 1 year* | 76 | 28.5 |
| *Between 1 year and 2 years* | 4 | 1.5 |
| *Over 2 years* | 0 | 0 |
| *Unsure* | 1 | 0.4 |
| Who diagnosed the ankyloglossia | | |
| *Lactation consultant* | 131 | 49.1 |
| *Midwife* | 66 | 24.7 |
| *Self-diagnosed* | 61 | 16.6 |
| *Doctor* | 44 | 16.5 |
| *Dentist* | 40 | 15.0 |
| *Other health professional* | 30 | 11.2 |
| *Speech Pathologist* | 14 | 5.2 |
| *Nurse* | 11 | 4.1 |
| *GP* | 7 | 2.6 |
| *Unsure* | 1 | 0.4 |
| Location of diagnosis | | |
| *Hospital* | 75 | 28.1 |
| *Community health clinic/community service* | 55 | 20.6 |
| *Dental clinic* | 32 | 12.0 |
| *General practitioner's office* | 17 | 6.4 |
| *Other* | 88 | 33.0 |
| What led to diagnosis of ankyloglossia | | |
| *Difficulties with feeding (difficult latch, difficult suck, other)* | 206 | 77.2 |
| *Nipple pain* | 142 | 53.2 |
| *Appearance of the tongue (heart shaped tongue or other)* | 138 | 51.7 |
| *Health professional's opinion* | 128 | 47.9 |
| *Other* | 49 | 18.4 |
| *No specific reason* | 3 | 1.1 |
| *Unsure* | 2 | 0.8 |
| Other health professionals involved in diagnosis | | |
| *Lactation consultant* | 84 | 31.5 |
| *Dentist* | 67 | 25.1 |
| *None* | 53 | 19.9 |
| *Midwife* | 50 | 18.7 |
| *Other health professional* | 49 | 18.4 |
| *Doctor* | 47 | 17.6 |
| *Nurse* | 27 | 10.1 |
| *GP* | 19 | 7.1 |
| *Speech Pathologist* | 10 | 3.8 |
| *Unsure* | 3 | 1.1 |

#### 3.2.4. Location diagnosis occurred

The diagnosis of ankyloglossia was provided in a hospital setting for 75 infants (28 %), community health service for 55 (20.6 %), dental clinic for 32 (12.0 %), GP office 17 (6.4 %) and other for 88 infants (33.0 %) See Fig. 1.

In rural and remote areas of Australia, over half of parents (51.6 %) reported their infant was diagnosed with ankyloglossia in a hospital setting, 32.3 % in a community health setting, 3.2 % in a physician's office, and 12.9 % in an unspecified location. In metropolitan and regional areas of Australia, a quarter of parents (25.0 %) reported their infant was diagnosed with ankyloglossia in a hospital setting, with dental clinics (13.6 %) and community health settings (19.1 %) also being key locations where ankyloglossia was diagnosed.

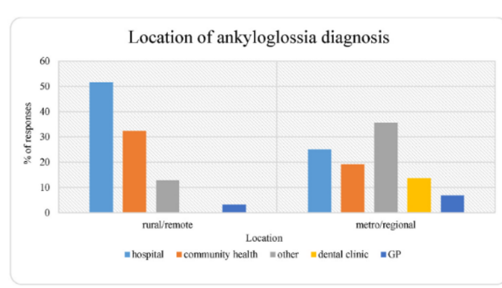


**Fig. 1.** – Location of ankyloglossia diagnosis.

### 3.3. Ankyloglossia management

Of the 267 parents that responded to the survey, 22 (8.2 %) reported that their infant did not receive any management for their ankyloglossia. Conversely, 112 (41.9 %) parents reported that their infant received both non-surgical management and surgical management of their ankyloglossia See Fig. 2.

#### 3.3.1. Ankyloglossia management – non-surgical

Of the parents who responded to the survey, 135 (50.6 %) respondents reported that their infant received non-surgical treatments for the management of their ankyloglossia, including treatments such as feeding support and equipment changes.

Parents were asked in the survey to specify the non-surgical treatments their infant received, with most parents receiving support with positioning changes (80.7 %) and support with latching (79.3 %). Other non-surgical treatments received can be found in Table 3.

#### 3.3.2. Ankyloglossia management –surgical

Of the 267 parents who responded to the survey, 222 (83.1 %) parents reported that their infant received surgical treatment for the management of their ankyloglossia, and 45 (16.9 %) parents reported that their infant did not receive surgical intervention.

Fifteen (6.8 %) of these parents reported that their infant received more than one surgical treatment, with 13 (86.7 %) having received both a frenotomy performed with scissors or scalpel, as well as a frenotomy with laser.

Frenotomy using scissors or scalpel was the primary treatment that respondents' infants received, with 121 (50.6 %) parents selecting this option. This was closely followed by 115 (48.1 %) parents selecting laser frenotomy as the surgical treatment their infant received. Three (1.3 %) parents reported that their child received a frenuloplasty (plastic surgery) procedure.

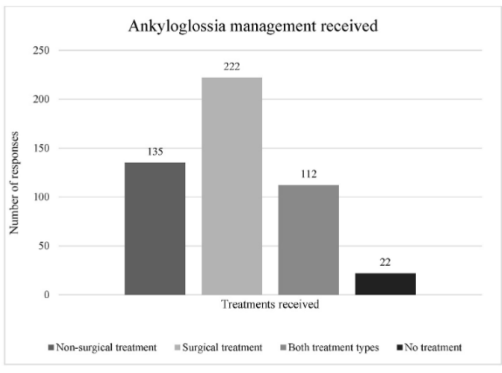


**Fig. 2.** – Ankyloglossia management received.

**Table 3**
– Management of ankyloglossia.

| | N | % |
|---|---|---|
| Non-surgical treatments received | | |
| *Positioning changes* | 109 | 80.7 |
| *Support with latching* | 107 | 79.3 |
| *Equipment changes* | 79 | 58.5 |
| *Supply support* | 35 | 25.9 |
| *Other feeding methods* | 28 | 20.7 |
| *Other* | 22 | 16.3 |
| Surgical treatments received | | |
| *Frenotomy (cut with scissors or scalpel)* | 121 | 54.5 |
| *Laser frenotomy* | 115 | 51.8 |
| *Frenuloplasty (plastic surgery)* | 3 | 1.4 |
| *Other* | 0 | 0 |
| Location of non-surgical treatment | | |
| *Private clinic* | 37 | 27.4 |
| *Community health centre* | 28 | 20.7 |
| *Hospital* | 27 | 20.0 |
| *At-home service* | 26 | 19.3 |
| *Dental clinic* | 7 | 5.2 |
| *General practitioner* | 6 | 4.4 |
| *Other* | 4 | 3.0 |
| Location of surgical treatment | | |
| *Dental clinic* | 105 | 47.3 |
| *General practitioner's office* | 38 | 17.1 |
| *Private clinic* | 38 | 17.1 |
| *Hospital* | 29 | 13.1 |
| *Community health centre* | 9 | 4.1 |
| *ENT clinic* | 2 | 0.9 |
| *Other* | 1 | 0.5 |
| Post-surgical aftercare recommendations | | |
| *Wound stretching* | 155 | 69.8 |
| *Breastfeeding support* | 122 | 55.0 |
| *Pain medication* | 117 | 52.7 |
| *Breastfeeding/expressed breastmilk/colostrum* | 110 | 49.6 |
| *Oral exercises* | 105 | 47.3 |
| *Skin to skin* | 86 | 38.7 |
| *Sucrose* | 23 | 10.4 |
| *None* | 18 | 8.1 |
| *Speech therapy* | 9 | 4.1 |

When parents were asked to select the health professionals involved in the surgical management of their infants, 49.5 % (n = 110) parents selected that more than one health professional provided surgical management to their infant. One hundred and twenty-two (55 %) parents reported the surgical procedure was completed by a dentist. Other health professionals involved in the surgical management of ankyloglossia, as reported by parents, were lactation consultants (39.6 %), general practitioners (20.7 %), midwives (12.6 %), paediatricians (9.9 %), paediatric surgeons (5.9 %), nurses (5 %) and ENT (2.7 %). Four parents reported that were unsure which health professionals were involved in their child's ankyloglossia surgery, and 24 (10.8 %) parents reported that an 'other' health professional was involved.

Parents were asked to report on the aftercare recommendations they received from the health professional performing their infants' surgical procedure. Of the 222 parents whose infants received surgical treatments, only 18 parents (8.1 %) did not receive any aftercare recommendations following their infant's surgical treatment. Over two thirds of parents (69.8 %) were instructed to stretch the frenotomy wound after surgical treatment. Speech pathology intervention was recommended to 4 % of parents for their infants following surgical management of ankyloglossia. Other post-surgical aftercare recommendations received can be found in Table 3.

### 3.4. Education

When asked whether parents received education from health

professionals regarding the diagnosis or management of their infant's ankyloglossia, 222 (83 %) parents reported that they received education about their infant's diagnosis of ankyloglossia. Forty-five parents (17 %) did not receive any education regarding ankyloglossia.

Verbal information about diagnosis and management of ankyloglossia were the most common types of information provided to parents, with 208 (93.7 %) and 168 (75.7 %) responses respectively. Written information about diagnosis and management of ankyloglossia were received by 124 (55.9 %) and 106 (47.7 %) parents respectively. Other forms of education provided to parents were video information (25.7 %), web pages (26.6 %) and social media pages (13.1 %). Five (2.3 %) parents reported receiving 'other' forms of education, and two (0.9 %) parents reported that they did not receive any of the aforementioned forms of education regarding their infants' ankyloglossia diagnosis or management.

Parents were asked to rate their satisfaction of the education they received from health professionals on a Likert scale from 1 to 5. On this scale 1 indicated 'extremely dissatisfied' and 5 indicated 'extremely satisfied'. The mean level of satisfaction among parents regarding the education they received from health professionals was 3.7 (SD ± 1.26, min-max 1–5).

### 3.5. *Satisfaction of parents*

Parents were also asked to rate how effective they believe the treatment for their child's ankyloglossia was on a Likert scale of 1–5. On these scales 1 indicated 'not at all' and 5 indicated 'extremely'. Parents reported that surgical treatments were significantly more effective than non-surgical treatments (mean 4.36, SD ± 0.86 vs 2.71, SD ± 1.12; unpaired *t*-test; $p < 0.001$).

When asked whether they would consent to the treatment their infant received again, on a Likert scale of 1–5 (1 indicating 'extremely unlikely' and 5 indicating 'extremely likely'), parents reported being significantly more likely to consent to surgical treatments again compared to non-surgical treatments (mean 4.61, SD ± 0.77 vs 3.83, SD ± 1.34; unpaired *t*-test; $p < 0.001$).

Parents were asked about their satisfaction with the level of support they received from the health professionals involved in their infant's tongue-tie treatment. On a Likert scale of 1–5, where 1 indicated 'extremely dissatisfied' and 5 indicated 'extremely satisfied', on average, parents reported their satisfaction as 3.9 out of 5.

The satisfaction level of parents regarding the education they received from health professionals did not correlate with their likelihood to consent to the treatment again ($p = 0.271$). Additionally, parents who their own research on ankyloglossia rated their level of satisfaction with the support they received from health professionals as lower.

## 4. Discussion

This study proposed several hypotheses: (i) regional variations in parental experiences would be evident across Australia; (ii) diagnosing and managing infants with ankyloglossia would involve a diverse range of professions; and (iii) parents would articulate dissatisfaction with the care provided to their infants. These hypotheses were investigated through the parent survey, and further explored in data analysis.

Regional variations in parental experiences of ankyloglossia diagnosis and management were evident across Australia. In this study, dentists did not provide ankyloglossia diagnoses in rural and remote areas of Australia, while the occurrence of diagnoses by lactation consultants was notably higher compared to metropolitan regions. As previously noted in the existing literature, Australian dental practitioners who administered laser frenotomy procedures were predominantly concentrated in metropolitan areas [8]. Prior research has established that remote health services commonly experience frequent staff turnover, have fewer specialist physicians available, and depend more on generalist health professionals [17–19]. This study reaffirmed this previously stated observation, as the procedures performed on infants in these geographically distant areas notably omitted laser frenotomy as a treatment option. This underscores the restricted availability of laser surgical interventions for infants residing in rural and remote regions of Australia, and the reliance on frenotomy procedures performed by other health professionals such as lactation consultants.

Our study sheds light on the considerable diversity among health professionals engaged in diagnosing and managing ankyloglossia in Australia, as previously noted in Australian literature [1,8]. This diversity in health professionals corresponds to variations in clinical practices related to ankyloglossia diagnosis and management, indicating a lack of standardized guidelines, evident in both Australia and internationally [8,20]. Considerable variations were identified in the post-treatment aftercare recommendations provided in this study, underscoring a lack of uniform protocols for after care practices. In this study, only 8 % of parents whose infants received a frenotomy procedure reported that they were not recommended any aftercare treatments. This varies from recent literature where 40 % of health professionals reported not recommending any aftercare treatments [20]. Wound stretching was recommended for over two thirds (69.8 %) of the infants represented in this Australian study, compared to reports from 38 % of American otolaryngologists on providing recommendations for stretching the frenotomy wound. The frequency of parents receiving recommendations to stretch their infants frenotomy wound is concerning, as there is no current evidence demonstrating the efficacy of such stretches [20]. It has been reported that providers of laser frenotomy procedures commonly instruct parents to perform post-procedure wound-stretching exercises multiple times daily for several weeks to help avoid wound reattachment during healing [21]. Further, stretching of surgical wounds is not recommended as it prolongs healing time and increases risk of scarring and infection [22]. The lack of a scientific reason for carrying out these stretches is a medico-legal risk for clinicians who recommend and use this approach, further highlights the lack of standardised guidelines. This study contributes substantively to the ongoing discourse surrounding the urgent need for evidence-based guidelines for all health professionals involved in ankyloglossia management.

The satisfaction of parents regarding the ankyloglossia diagnosis and management their infant received was explored in this study. It has been previously established that breastfeeding parents require adequate support, education, counselling, and being involved in shared-decision making discussions [2]. When health professionals provided information about ankyloglossia in general to parents, it resulted in heightened levels of parental satisfaction and overall contentment with the service they had received. When parents were provided with information about surgical treatments, their satisfaction levels increased, and they reported being more inclined to provide consent for future interventions of the same nature. Conversely, when parents were provided with information regarding non-surgical treatments, their satisfaction levels did not demonstrate a substantial rise, and their inclination to give consent for subsequent interventions was not evident. Parents expressed a favorable perception of the effectiveness of frenotomy and indicated their willingness to provide consent for it in the future. This aligns with existing literature, which reports a high concurrence rate, with 97 % of parents expressing a desire to opt for frenotomy in comparable situations [23]. This suggests a general preference for surgical treatments among parents, with educational efforts having limited influence on their treatment preferences.

In this study, the sources of information that parents received, and their subsequent satisfaction regarding their infants care were explored, as it has been established that healthcare information provided shapes patient decision making [13]. Parents who independently researched ankyloglossia rated their level of satisfaction with the support they received lower, however, their perception of the procedure's effectiveness was not affected. This phenomenon may be attributed to a belief that they possess a deeper understanding of the subject matter or a

tendency to have preconceived notions regarding their preferences [24]. Dentists and medical practitioners consistently received positive feedback from parents regarding the care they provided to infants, however, it was noted that they showed relatively lower levels of involvement in educating parents. This observation highlights the relationship between parental awareness, education, and satisfaction. It suggests a need for further investigation into whether the lack of education and information leads to parental contentment, especially when the procedure's ultimate outcome is perceived as positive.

Although parents generally expressed satisfaction with the assistance offered by health professionals, it is crucial to highlight that this satisfaction did not consistently align with their willingness to grant consent for the intervention again. This aligns with a study by Ray and colleagues [10] exploring maternal perspectives of frenotomy, as reported by mothers in social media groups such as breastfeeding forums. Overall, more posts expressed positive experiences in the diagnosis and treatment of their child's ankyloglossia, compared to negative or neutral ones [10]. This differs from findings in Canada, where parents reported a low level of satisfaction with the support provided by health professionals for their child's ankyloglossia [9]. Health professionals involved in ankyloglossia diagnosis and management should use these parental reports to guide their education practices, informed consent procedures and improve shared decision making.

It has been widely established that informed consent and shared decision making are fundamental principles in medical ethics and the cornerstone of patient-centered care [25,26]. It upholds the principles of autonomy, transparency, and shared decision-making, ensuring that patients are fully informed and able to make choices that align with their values and preferences [27]. Including parents in all stages of their infants' ankyloglossia journey and upholding informed consent in healthcare facilities are paramount. This helps reduce decision conflict and promotes shared decision-making in the absence of robust clinical guidelines for diagnosing and managing ankyloglossia.

Limitations of this study included the small sample size of participants, given the national reach of the research study. This also highlights the possibility that participants may not be representative of their respective groups, as the responses in this study are representative of the parents who are willing to participate in research studies. Secondly, the closed questions in this study were designed to facilitate a short survey response time for each participant, however, this led to a lack of clarity in some questions where parents were unable to provide further information.

The reasons leading to the diagnosis of ankyloglossia in our study closely mirror those documented in the existing literature, corroborating the previously established association between ankyloglossia and a spectrum of effects on feeding, encompassing challenges such as latching difficulty, feeding struggles, and maternal pain [4,10,28–30]. This agreement confirms the reliability of existing knowledge and reinforces the understanding that ankyloglossia is a complex condition affecting both infants and mothers during breastfeeding.

## 5. Conclusion

Findings from this study highlighted the multifaceted nature of the diagnosis and treatment of ankyloglossia, and its tangible impact on both infants and mothers during breastfeeding. Notably, variations in clinical practices, from diagnosis to aftercare, underscore the lack of standardized guidelines in the field. This emphasizes the pressing need for comprehensive and uniform clinical protocols for the diagnosis and management of ankyloglossia. The geographical concentration of laser frenotomy procedures in metropolitan areas, parental satisfaction with surgical interventions, and the importance of informed consent and shared decision making in healthcare emerge as critical themes in our findings. Findings from this study signal the need for the development of evidence-based guidelines to ensure consistent and optimal care for infants with ankyloglossia across diverse healthcare settings in Australia. This research sheds light on regional variations, underscores the importance of ethical healthcare practices, and emphasizes the need for uniformity in the care provided to infants with ankyloglossia nationwide.

## CRediT authorship contribution statement

**Donna Akbari:** Writing – review & editing, Writing – original draft, Visualization, Validation, Software, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Hans Bogaardt:** Writing – review & editing, Validation, Supervision, Project administration, Methodology, Formal analysis, Data curation, Conceptualization. **Kimberley Docking:** Writing – review & editing, Validation, Supervision, Resources, Project administration, Methodology, Investigation, Formal analysis, Data curation, Conceptualization.

## Declaration of competing interest

The authors declare no conflicts of interest in regards to the research and outcomes presented in this manuscript. This research has not received any financial support or other benefits from a commercial entity or organisation.

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