

Appendix 1: Survey Questions

Ankyloglossia Diagnosis and Treatment in Canada

General Information

1. In which jurisdiction do you work?

- Alberta
- British Columbia
- Manitoba
- New Brunswick
- Newfoundland and Labrador
- Northwest Territories
- Nova Scotia
- Nunavut
- Ontario
- Prince Edward Island
- Quebec
- Saskatchewan
- Yukon
- Federal Health Program (such as, Indigenous Services Canada, Canadian Armed Forces, Correctional Service Canada)
- Other (please specify) (Free Text)

2. What is your profession or role? In addition to your occupation or title, please describe your role as it relates to assessing and diagnosing ankyloglossia and/or providing treatment for patients who have ankyloglossia (i.e., frenectomies). (Free Text)

3. Are you currently involved in any capacity with assessing and diagnosing ankyloglossia and/or providing treatment for patients who have ankyloglossia (e.g., frenectomies)?

- Yes; please describe the nature of your involvement (Free Text)
- No; if no you will be redirected to the end of the survey

4. What best describes the type of facility you work in? (select all that apply)

- Regional health authority
- Government office (e.g., ministry-level)
- General hospital, facility, or clinic
- Specialized hospital, facility, or clinic with an emphasis on maternal/newborn/children health
- Breastfeeding clinics
- General dental office
- Specialized dental office with an emphasis on children
- Dental association
- Speech language facility
- Rural health care setting
- Remote health care setting

- Urban health care setting
- Other (please specify)

5. Please describe the type of facility you are representing and in which you predominantly practice (e.g., name and description of type of facility). (Free Text)

6. Do you work in one or more of these geographical settings? (Please select all that apply.)

- Urban
- Rural
- Remote

(Please self-identify based on your local understanding of the criteria for remote. As an example, Health Canada defines various levels of remote, ranging from remote isolated = no scheduled flights or road access and minimal telephone or radio service, through to non-isolated remote = road access and less than 90 km away from physician services)

- Other (please specify) (free text)

Assessment and Diagnosis

7. Are there any policies, frameworks, guidelines, or other guidance documents in use in your jurisdiction to guide the assessment and diagnosis of ankyloglossia?

- Yes (e.g., please list the title, year, and link if available, option to upload multiple links)
- No

Selection for Treatment

8. Are there any policies, frameworks, guidelines or other guidance documents in use in your jurisdiction to guide the selection of patients for frenectomies?

- Yes (e.g., please list the title, year, and link if available, option to upload multiple links)
- No

9. Are there specific criteria that a patient must meet?

9a. To be assessed and diagnosed for ankyloglossia? (Free Text)

9b. To obtain a referral for a frenectomy (also known as tongue-tie release)? (free Text)

10. Similarly, are there any criteria that would exclude patients from gaining access to a frenectomy? (Free Text)

Ankyloglossia and Frenectomy Trends

11. What is the current incidence of ankyloglossia in your jurisdiction (i.e., rate per population)? Please specify what year the statistic is from. (Free text)
12. What is the current rate of frenectomy procedures performed in your jurisdiction (i.e., rate per population)? Please specify what year the statistic is from. (Free text)
13. Has there been a noticeable change in the rate of frenectomies performed in your jurisdiction? If yes, can you provide reasons why there might be an increase/decrease?
- Yes (Increase); Please describe (Free Text)
 - Yes (Decrease); Please describe (Free Text)
 - No Change
 - Unknown
14. Have you observed any trends related to performing frenectomies in your jurisdiction?

For example, does the frequency of frenectomy procedures differ in breastfed vs formula-fed babies, or in firstborn versus later-born children, or based on other criteria? (Free text)

Barriers and Facilitators

15. What are the barriers to optimal diagnosis and treatment of ankyloglossia? (select all that apply)
- Lack of guidelines on how to assess and diagnose ankyloglossia
 - Lack of guidelines on the treatment of ankyloglossia
 - Lack of funding (e.g., frenectomies performed in private dental offices and not covered by public funding)
 - Lack of access to specialized medical expertise (e.g., breastfeeding specialists; lactation consultants)
 - Lack of dedicated facilities for newborn/pediatric care and breastfeeding
 - Lack of rural and/or remote care
 - No consensus across clinical specialities regarding how to manage patients with ankyloglossia
 - Other (please specify) (Free Text)
16. What are the facilitators (or enablers) of optimal diagnosis and treatment for ankyloglossia? (select all that apply)
- Awareness of guidelines on how to assess and diagnose ankyloglossia
 - Adherence to guidelines on how to assess and diagnose ankyloglossia
 - Awareness of guidelines on ankyloglossia treatment
 - Adherence to guidelines on Ankyloglossia treatment
 - Availability of funding (e.g., frenectomies performed in private dental offices and covered by public funding)
 - Availability of specialized medical expertise (e.g., breastfeeding specialists' or lactation consultants)

- Availability of dedicated facilities for newborn/pediatric care and breastfeeding care
- Availability of care in rural or remote health care settings
- Other (please specify; e.g.,) (Free Text)

Guidance Needs

17. Please indicate your level of agreement with the following statement:

There is a need for further guidance (e.g., guidelines, frameworks, policies, clinical pathways) to provide direction regarding the **diagnosis** and **assessment** of ankyloglossia.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

18. Please indicate your level of agreement with the following statement:

There is a need for further guidance (e.g., guidelines, frameworks, policies, clinical pathways) to provide direction regarding the **treatment** of ankyloglossia.

Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Permission to Contact

19. Would you be willing to be consulted further on this topic, either through an informal phone call or by email?

- Yes
- No

20. Can you suggest any others who would be willing to be consulted further on this topic, and/or complete this survey?

- Yes (Free text - insert contact info)

- No

Appendix 2: Information on Survey Respondents

Table A1: Jurisdictions and Organizations

Province/Territory ^a	Organization Represented by Survey Respondents
British Columbia (n = 2)	College of Midwives of British Columbia BC Women’s Hospital & Health Centre
Alberta (n = 1)	Clinicians in private practice
Saskatchewan (n = 3)	The Berry Breast Support Private practice
Manitoba (n = 2)	University of Manitoba Baby Sleep 101
Ontario (n = 18)	Pediatric Oral Health & Dentistry International Breastfeeding Centre Kindercare Pediatrics Birth and Baby Needs Mother’s Nectar Lactation Consultation Services Little Bird Pediatric Dentistry Halton Healthcare East Ottawa Midwives Midwives of Mississauga Midwives of Muskoka CHEO—Children’s Hospital of Eastern Ontario Canadian Paediatric Society Kensington Midwives Black Creek Community Health Centre Clinicians in private practice
Quebec (n = 4)	Health E-Learning CLSC de Benny Farm CIUSSS du Centre-Ouest-de-l’Île-de-Montréal Clinicians in private practice
Nova Scotia (n = 3)	Nova Scotia Health Authority Clinicians in private practice
Prince Edward Island (n = 1)	Health PEI
Newfoundland and Labrador (n = 1)	Eastern Health
Nunavut (n = 1)	Qikiqtani General Hospital

^aNo responses received from New Brunswick, the Northwest Territories, or the Yukon.

Table A2: Occupations and Settings

Occupations and Occupational Settings of Respondents	Number of Respondents (%) ^c
Occupation^a	
Pediatrician	5 (13.8%)
Pediatric otolaryngologist	1 (2.8%)
Pediatric dentist	3 (8.3%)
Registered nurse	5 (13.8%)
Public health nurses	2 (5.6%)
Midwife	6 (16.7%)
Clinic director	2 (5.6%)
Clinical dietitian	1 (2.8%)
Lactation consultant	11 (30.6%)
Occupational Setting^b	
Regional health authorities	8 (22.2%)
General hospitals, stand-alone facilities, or clinics	6 (16.7%)
Specialized hospitals, stand-alone facilities, or clinics with emphasis on maternal, newborn or child health	11 (30.6%)
Breastfeeding clinics	10 (27.8%)
General dentist clinics	2 (5.6%)
Specialized pediatric dental clinic	3 (8.3%)
Community settings	3 (8.3%)
Home care settings	7 (19.4%)
Midwifery clinics or off-site care	1 (2.8%)
Public health offices	1 (2.8%)
Private practice	6 (16.7%)
Education centres	1 (2.8%)
Speech language pathology clinics	0 (0%)
Dental associations	0 (0%)
Geographic Setting^b	
Urban	34 (94.4%)
Rural	16 (44.4%)
Remote	2 (5.6%)
Remote management (e.g., telehealth)	2 (5.6%)

^aRespondents selected one option; six individuals were lactation consultants in addition to their primary occupations.

^bRespondents could select more than one option.

^cOut of a total of 36 respondents.