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# A proposed oral health management pathway for children with orofacial cleft in New Zealand

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## Abstract

**Background:** Orofacial clefts (OFC) are the most common craniofacial anomalies in the new born with an incidence of approximately 1.79 per 1,000 live births in New Zealand. OFC represent a complex heterogeneous group of structural anomalies caused by a partial or complete breakdown in the normal early embryological formation of the face. Children born with an OFC require numerous multidisciplinary interventions aimed at restoring near normal form and function.

These treatments are coordinated and staged by dedicated multidisciplinary teams and can extend from infancy to early adulthood. Children with OFC require optimal oral health as it can impact upon some of these treatment outcomes. However, children with OFCs in New Zealand have been reported as having generally poorer oral health with a greater dental caries experience than children without cleft.

**Objectives:** This article proposes the establishment of an oral health management pathway for children with OFC in New Zealand. This was initiated in response to a recent Ministry of Health workshop which highlighted general inequities of care and poor health outcomes experienced by children with OFC.

**Conclusions:** The establishment of a clear strategy to address inequities and inequalities of care for children with OFC is long overdue. The proposed oral health pathway will ensure there is appropriate access to care that is consistent throughout the country, with provision for targeted early preventative and management measures for those OFC considered high risk.

of OFC may be associated with a genetic syndrome or other unclassified malformations, the majority are non-syndromic clefts. Rarer forms of median and oblique facial cleft, termed atypical orofacial clefts, involve the orbit and/or cranium (Tessier, 1976).

Studies have failed to present consistent findings as to the role of specific genetic or environmental factors in the aetiology of non-syndromic OFC (Cobourne, 2004; Molina-Solana et al., 2013). Certain environmental risk factors include smoking, the intake of alcohol and drugs as well as nutritional deficiencies during the early weeks of pregnancy have shown to be possible contributors. Recent chromosomal analysis, gene mapping, linkage and association studies continue to reveal additional genetic factors which play a role in embryonic development of the orofacial region (Sharp et al., 2018). This highlights inconsistencies in our current knowledge of the complexity of the interaction between genetic and environmental factors in the aetiology of non-syndromic OFC (Martinelli et al., 2020).

Cleft care in NZ is based on a multidisciplinary treatment delivery structure that is common in most other countries (McGrattan 2013). Children born with an OFC require numerous treatment procedures which are coordinated and staged from infancy to early adulthood. This care is provided by specialist clinicians working within five multidisciplinary cleft teams in NZ (Sanders et al., 2011). Core clinical services involve surgeons (Maxillofacial, Plastics and Otolaryngology), speech and language therapists and oral health professionals including those with paediatric, orthodontic, periodontic and prosthodontic expertise.

## Oral health caries risk factors common to children with OFC

Children with OFC require good oral health as poor oral health can impact upon the outcomes of other treatment and is critical to providing optimal rehabilitation of dental aesthetics and function (Peat, 1974). However, children with OFC have been reported as having generally poorer oral health with a greater dental caries experience than children without cleft (Hasslöf & Twetman, 2007; King et al., 2013; Worth et al., 2017). A recent national investigation of dental caries incidence amongst children with OFC in NZ reported a higher caries prevalence (dmft/DMFT  $\geq$  1) and mean dmft/DMFT than that reported for the general population at age 5 years, but similar at age 12 (Fowler et al., 2020).

## Introduction and background

Orofacial clefts (OFC) are the most common craniofacial anomalies in the new born, affecting 1.42 per 1,000 live births worldwide, although large geographic and racial variations of incidence have been reported (Mossey & Castilla, 2003). In New Zealand (NZ), approximately 100 children are born with an OFC each year with an incidence of approximately 1.79 per 1,000 live births. The higher incidence is in part due to a higher incidence of cleft palate (CP) among Māori, which is over twice that of European (Thompson et al., 2016).

OFC represent a complex heterogeneous group of structural embryologic facial anomalies which vary in severity and location. They reflect a partial or complete breakdown in the normal developmental mechanisms involved in the early embryological formation of the face (Mossey et al., 2009). Although a small proportion

Clinical risk factors for dental caries common amongst children with OFC include oral hygiene challenges associated with: loss of elasticity and at times, lack of sulcus depth of the surgically repaired lip, increased oral clearance times due to lodgement of food debris within the cleft site and inherent parent and/or patient fear of cleaning the cleft area post-surgery, as well as gross displacement of teeth adjacent to the cleft site, particularly if the alveolus is involved (Wong & King, 1998; Cheng et al., 2007). Other risk factors relate to: earlier colonisation of caries promoting microbial profiles in infants prescribed with pre surgical intra-oral appliances (Durhan et al., 2018), greater adherence of plaque associated with the presence of nasal discharge, particularly where a residual nasal palatal fistula is present (Richards et al., 2015) as well as possible salivary gland dysfunction associated with CLP gene *Irf6* (Tamasas & Cox, 2017). There is also an increased incidence of dental anomalies including developmental dental defects of enamel (Tannure et al., 2012), and extra and/or mal-positioned teeth (Paranaiba et al., 2013). In addition to these clinical risk factors, children with OFC have poorer dental attendance than children without cleft, which has been attributed to increased dental anxiety (Mooney et al., 2007) and there is an increased demand for dental treatment under general anaesthetic for children with OFC (Fitzsimons et al., 2014).

Although largely preventable, dental caries remains the most common chronic disease of childhood with socioeconomic status, dietary habits, ethnicity and access to community water fluoridation (CWF) remaining as key risk factors (Ministry of Health, 2010; Boyd et al., 2022). Fowler *et al.*, (2020) reported that the greater caries experience amongst children with OFC was associated with Pacific and Māori ethnicity, and those not receiving CWF. Currently, there are no established guidelines for the routine dental care of children with OFC in NZ despite their recognition as a priority group and as key stakeholders in the MOH's strategic vision for oral health (Ministry of Health, 2006). Routine dental care for children and adolescents with OFC in NZ is generally provided by the Community Oral Health Services (COHS) (Ministry of Health Nationwide Service Framework, 2018) although in some areas, there may be additional support from a specialist paediatric dentist within a multidisciplinary cleft team. Oral health care is subsequently transferred to general dental practitioners in the community, initially as an adolescent (Year 8 transition to dental practice with Combined Dental Agreements, Ministry of Health) dental benefit patients and then private practice fee-paying adults (over the age of 18 years). Prosthetic restorative procedures such as dental implants, crowns and removable dentures are often not included within the cleft service provisions and these are commonly funded by the patient, although some Health NZ districts (previously called 'District Health Boards') have some discretion to provide this care.

### Ministry of Health cleft lip and palate services workshop

Following concerns raised to the Ministry of Health (MOH) regarding varying outcomes for children with OFC in NZ, including concerns about dental caries experience, a MOH initiated workshop meeting was held in early February 2020 in Wellington. MOH and patient representatives along with clinicians from various medical, dental and allied health specialities attended to discuss the current model of cleft lip and palate services and whether improvements were required. The conclusion reached by the workshop was that outcomes of cleft lip and palate services in NZ needs to be improved significantly.

Central to all aspects of cleft care, which includes oral health care, was a desire to reduce unwarranted variation through the establishment of consistent expectations across districts and regions. An emphasis on reducing inequities in access to care and enabling evidence-based outcome-driven goals with improved outcomes, improved data collection and reporting of agreed measures was required. The group recognised the provision of care to patients with OFC is complex with the involvement of many stakeholders, and any changes would require careful consideration and consultation.

### A proposed oral health management pathway for children with orofacial cleft in NZ

A key outcome from the MOH workshop that included consultation with medical, dental and allied health specialities within cleft services across districts was that an establishment of a proposed oral health management pathway for children with OFC was required to provide a clear guidance for all oral health providers in NZ who are responsible for management of these patients.

### Development of the oral health management pathway

Following presentations on the findings of recent national studies of the dental caries experience and Oral Health Related Quality of Life (OHRQoL) of children with OFC (Nichols *et al.*, 2018; Fowler *et al.*, 2020; Fowler *et al.*, 2021) to the members of the Specialist Paediatric Dentists New Zealand (SPDNZ), a group of paediatric dentists involved in cleft care were tasked with initiating the development of an oral health management pathway specifically for children with OFC. This was evidence based with reference to current literature and overseas experiences. Consultation was made with key stakeholders including Clinical Nurse Coordinator's (CNC's) from different districts and COHS representatives prior to presentation of the proposed pathway at the MOH workshop. Further changes were made following the next phase of consultation and feedback from SPDNZ members, wider COHS representatives including Clinical Directors of COHS in different districts, consumer representatives and Cleft NZ with an emphasis placed on clinical activities that are appropriate for the current expertise and use of common reporting technologies within the COHS. The feedback and the proposed oral health management pathway was discussed and



validated at the recent interdisciplinary focus group discussions held at the NZ Cleft Conference held in Christchurch 28<sup>th</sup> October 2022 (Figure 1).

### *Principles of care*

Engagement of specialist paediatric dentists within hospital dental services and CNC's within the districts will ensure that priority will be given to targeted caries prevention for children with OFC from an early age. This may include twice daily use of appropriate strength fluoride toothpaste (between 1,000 and 1,450ppm of fluoride), use of appropriate supplementation for those without CWF (such as the application of fluoride varnish, the recommendation of fluoride toothpastes including 5000ppm and prescription of fluoride tablets) and fissure sealants, along with child-whānau specific preventative dietary and oral hygiene advice. All children with OFC will receive treatment to ensure that their level of oral health is similar to that of their peers. Although treatment will normally be provided by locally based COHS, all patients will be able to access specialist paediatric dental advice (telehealth may be carried out where appropriate) and if required specialist level care will be provided. In addition, the establishment of a proposed oral health management pathway for children with OFC will be central for allowing future investigations to benchmark and monitor any improvements.

### *Early start caries prevention pathway for children*

The proposed pathway will be initiated with the introduction and meeting of the family by a CNC, Speech & Language Therapist (SLT) for cleft or initial contact clinician in each of the Cleft Units. These clinicians will provide information regarding early childhood oral health and its importance to overall cleft outcome during early messages to families. Families will be supported to develop good feeding habits with emphasis on delaying the introduction of free sugar eating until 2 years of age, minimizing the total sugar intake, the frequency of food intake and the discouragement of bottle feeding beyond 12 months of age (including at-will night time feeding) with the early introduction of sippy cups. Feedback from consumer representatives has highlighted that multiple messages (at times mixed and conflicting) surrounding cleft care could be given and health professionals need to be aware of the consequences and build strong connections and trust with the child, their whānau and other health professionals in the community is necessary. An information leaflet outlining the oral health habits in simple, clear, 'non-medical' language has been suggested as a useful option for parents and caregivers as a reference when needed especially when there is so much 'information upload' happening at the time of initial visit and parental concerns about receiving inconsistent health messages in the community. Cleft units across the nation are urged to come up with unique innovative ways utilising digital health applications (app based) and artificial intelligence (AI) to dissipate consistent information related to cleft care, improve access to care, support and empower children and their whānau (Dhillon *et al.*, 2021). Such work should involve partnering with

different stakeholders including university and consumer groups such as Cleft NZ and parents/caregivers of children with OFC.

The first dental visit with a paediatric dentist should ideally occur at approximately 6 months of age. Parents should be informed about the importance of the 'in-person' first dental visit with a paediatric dentist. Prior to that visit, the CNC will issue a general health status check questionnaire which will include promoting optimal oral health habits. It is recommended that cleft units across NZ work together to develop a general health status check questionnaire that could be used to survey issues and guide health related conversations and promote good general and oral health habits. At the first dental visit, the questionnaire responses will be reviewed with the parent/caregiver. Where the initial examination and the questionnaire responses indicate that the patient may be at high risk of dental caries, the patient should be scheduled to be seen at appropriate risk intervals and managed accordingly at their primary care provider, in the hospital by a paediatric or a hospital dentist where appropriate. Those considered at low risk will be rescheduled to be seen at approximately 2 years of age (or above) for their second dental visit and then arrange transition to COHS with caries prevention recommendations as required. Parents and caregivers of children with high caries risk (as identified by paediatric or hospital dentist) are encouraged to contact the CNC at the hospital should they have any concerns about their child's oral health. For those children with low caries risk, COHS remains their primary oral health care provider and parents and caregivers are encouraged to contact COHS in the first instance. Parents and caregivers of children with OFC are encouraged to be proactive in seeking routine dental visits at regular intervals with their child's primary oral health care provider (depending on their caries risk as assessed at the hospital or COHS) should there be a delay in being seen at the right time.

### *Ongoing supervision*

Risk assessment will be reviewed each time the child is seen at the multi discipline team (MDT) cleft clinic with communication between the paediatric dentist and COHS maintained through shared information within the Titanium practice management and clinical record software that is used universally within NZ by the hospital dental services and COHS. All health professionals of MDT cleft clinic should have access to patient management software including Titanium. All children with OFC will be placed in the 'high caries risk' category when they begin treatment with the COHS so that they are seen more frequently (approximately 4-6 monthly) and provided with more frequent preventive information and treatment such as biannual fluoride varnish. Seamless access to clinical records of the child's dental status is central for communication between oral health professionals providing care for these patients. Any extractions or significant treatment to permanent teeth undertaken by the COHS or general dentist in private practice will be discussed with a paediatric

dentist or hospital dentist prior to treatment, especially if near the cleft site. Parents and caregivers should be kept informed of all patient related communications between different health professionals including copies of letter communications sent to the family.

For those children with missing permanent teeth, a formal assessment will be undertaken by the specialist paediatric dentist, in consultation with the cleft orthodontist, prior to 10 years of age. If longer term restorative provisions are planned, a consultation with a specialist restorative dentist will be arranged as part of their ongoing care. Access to a specialist prosthodontist may be limited in some districts and services should strive to involve a specialist prosthodontist in complex cases where possible. This may involve contracting specialist level work to a private practice clinician in some cases and the system should ideally be set up for this to happen. The arrival of Te Whatu Ora-Health NZ and Te Aka Whai Ora-Māori Health Authority on 1<sup>st</sup> July 2022 has been hailed by government authorities as a means to tackle existing health inequities and end the 'postcode lottery' in terms of access to health care. It is hoped that the New Zealand Health Plan currently in the making should allow us to plan and deliver equitable cleft care including oral health consistently across the country (Te Whatu Ora).

All children undergoing bone graft or secondary lip/palate surgery should receive written and verbal instructions (which could form part of an information leaflet) for maintaining oral hygiene pre and post-surgery.

The cleft team orthodontist should request a dental 'Warrant of Fitness' (WOF) from the child's primary oral health care provider prior to commencing any orthodontic treatment. Parents and caregivers are encouraged to attend this visit along with their child so their child's oral health needs and any support for home care could be made aware by the child's primary oral health care provider. The 'dental WOF' performed by the child's primary oral health care provider (normally a general dentist in the community) or a paediatric dentist may include a recent comprehensive exam, updated bitewing radiographs, preventative care strategies and oral health management plan before, during and after orthodontic treatment. Any restorative needs must be completed prior to commencement of orthodontic treatment and ongoing preventive plan put in place. The cleft team may choose to develop an oral health 'WOF' checklist or proforma which the dentist or specialist would complete upon seeing the child, with a copy sent to the CNC and family, and be uploaded in the patient file for reference. Orthodontic treatment should not be commenced for children with high caries risk until the risk factors have been mitigated, and oral health habits and support systems have been established for routine dental visits either in the community or at the hospital as appropriate. Six to eight weekly professional fluoride applications during the orthodontic visits are shown to reduce new caries lesions and is recommended to be done by the orthodontist or orthodontic auxiliary during the child's orthodontic appointment in consultation with hospital paediatric

dentist or primary oral health care provider (Flynn et al., 2022; Sonesson & Twetman, 2023). All high-risk adolescent patients receiving orthodontic treatment should receive a prescription for high strength fluoride toothpaste such as 5,000ppm F<sup>-</sup> combined with 6 monthly check ups with a dentist (Sonesson et al., 2014; Natarajan and Hallett, 2015). Routine posterior bitewing radiographs for caries diagnostic purposes are recommended during the orthodontic treatment. It is strongly recommended that Te Whatu Ora-Health NZ districts and Combined Dental Agreement (CDA) with oral health care providers should encourage and fund the general dentists in the community for subsequent dental visits in the same calendar year for each patient with cleft and this should become part of the Service Components for Standard Oral Health Services for Adolescents within the CDA. The new CDA that came into effect July 2022 fails to take an equity lens for children with OFC as a consultation fee may only be claimed once each calendar year for each patient regardless of their medical and dental comorbidities and/or existing health inequalities which means that access to care for children with OFC in the community is currently limited, with Māori children and whānau carrying the heaviest burden of care due to the increased incidence of OFC among Māori (Thompson et al., 2016) being disadvantaged. It may be that new systems may be required to tackle existing inequalities and should ideally prioritise reducing inequalities for children with special needs and medical and dental comorbidities who can be safely managed by dentists in the community.

At 12 years of age the specialist paediatric dentist will aid in transition of the child with OFC to the Adolescent Oral Health dental services in the community through the CDA. This will include a specifically designed proforma for the accepting dentist with treatment history and any guidance for management as appropriate (Figure 1).

#### *Contemporary baseline of dental health status*

A specifically designed proforma/base chart within Titanium or other validated system will be used to record data for caries, missing teeth, supernumerary teeth, enamel hypomineralisation and tooth development at age 3 years, 5 years, 12 years and 17 years. The age at which baseline data is recorded can be a range for example – at 2-3 years or 5-6 years or 16-17 years. Recording dental health status at age 3 years would help capture data on the number of children affected with early childhood caries and hypomineralisation; age 5 and 12 years would allow comparison of caries status (dmft/DMFT) to non-cleft dmft/DMFT data from MOH; recording baseline at 17 years would help with identifying any restorative treatment needs before the child's 18<sup>th</sup> birthday when the publicly funded dental care currently ends in NZ. These baseline recordings will also help determine the risk assessment of the individual patient and provide an indication of oral health projection for both clinician and family. CNC's should work alongside Hospital Dental Services and COHS to ensure recordings are carried out in a timely manner. This should be added to the CNC's checklist along with other health indicators that are carried out at regular intervals.



## A proposed oral health pathway for children with Orofacial Cleft Lip and Palate in New Zealand

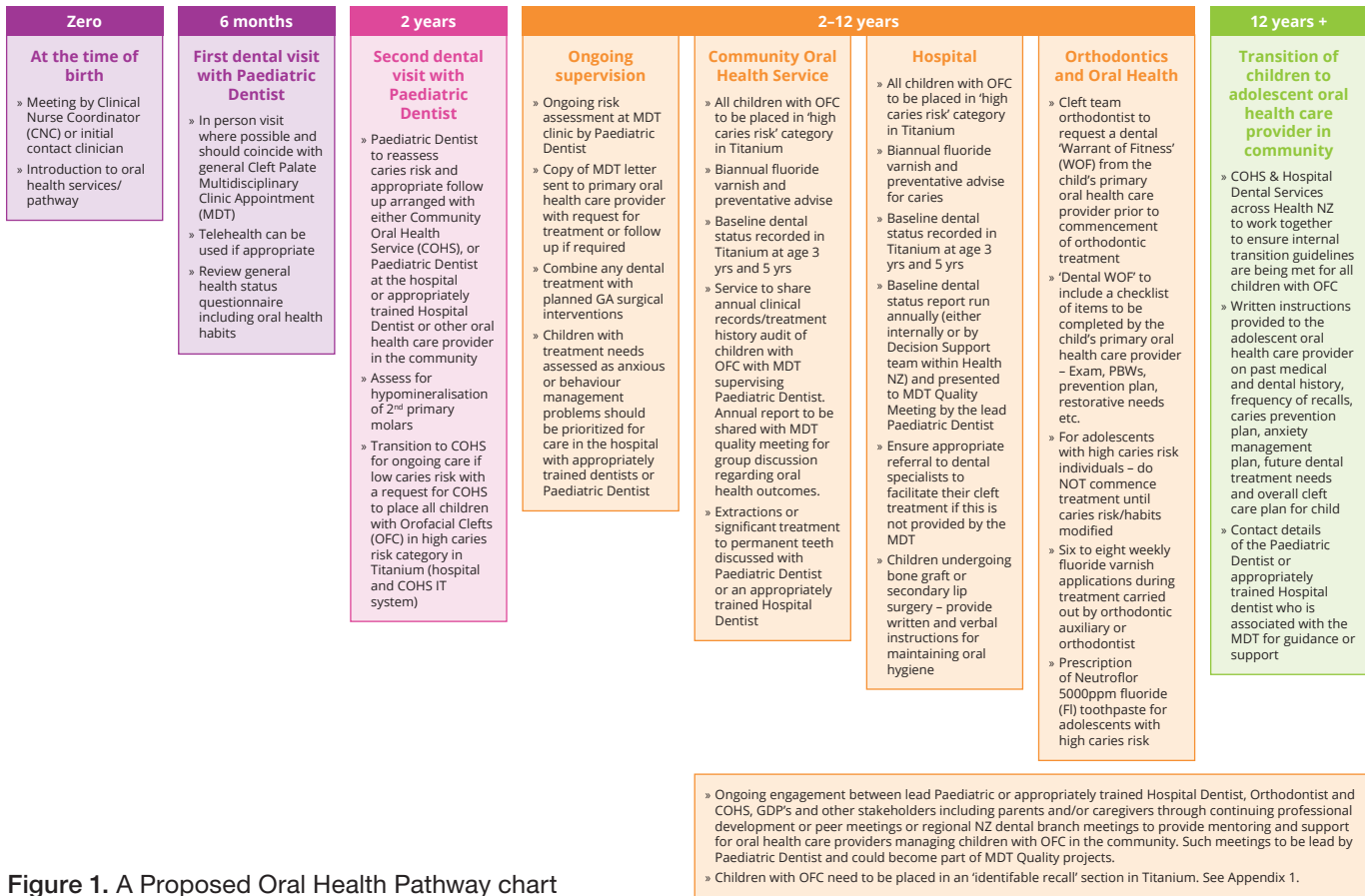


Figure 1. A Proposed Oral Health Pathway chart

It is well recognised that the surgical and non-surgical interventions associated with cleft care place a heavy burden of care on the child and responsibility on the parents. There is an increased incidence of failed outpatient appointments for children with cleft (Rodd et al., 2007). To ensure that no child is disadvantaged by non-attendance, any child who misses 2 successive dental appointments previously confirmed with a parent/caregiver will be flagged for a cleft team discussion. After all the internal measures to contact the family have been exhausted (for example, ringing from CNC's dedicated work mobile phone, sending e-text or text from CNC's mobile phone, sending letters after confirming appointment date/time with family over the phone, contacting school where appropriate), referral to social agencies such as Partnership Community Workers (PCWs) or Kaiawhina, or Oranga Tamariki or local Māori/Pacific health navigator services, or through a local child health services channel will be initiated by the CNC as appropriate. Health services should have exploited every possible avenue in the community to engage with the whānau before choosing to delist them from their service. A copy of all communication should be posted to the family's General Medical Practitioner (GMP) or Paediatrician and a copy made available in electronic medical notes.

### Discussion

The United Kingdom has reported on its cleft service which shares similarities with NZ in regard to dental health outcomes (Fitzsimons et al., 2014). Their experiences highlight the need for enhanced preventive dental care for patients with OFC, and this should be initiated from an early age (Sanghvi et al., 2019). Central to the proposed dental management pathway for children with OFC in NZ is the leadership from specialist paediatric dentists whose involvement with the respective MDT clinics is essential. Clear communication between the specialist paediatric dentist, the supporting COHS, the CNC and the patient/whānau are essential, and this will be aided by the use of standardised information pamphlets, appropriate technology, accessible Titanium notes and regular communication with stakeholders involved. Feedback from multiple stakeholders and consumer representatives informed expectations from different oral health service providers seeing children with OFC at different ages and that of consumers/whānau. Parents of children with OFC would like a cleft specific oral health related information leaflet developed with information regarding 'who does what' within the cleft team, shared model of care between hospital and community with respect to cleft care and such leaflet to be developed in an infographic form, clear (non-medical terms), concise information regarding timeframes/milestones to follow up on actions.

It is hoped the proposed pathway would improve access to care for all children with OFC and reduce the impact of postcode lottery access to health care in NZ. Feedback from parents/caregivers have been that services develop an information leaflet outlining the good oral health habits to be handed at the time of initial family meeting. This is often seen as having the option of referring to the information leaflet as a reminder to follow up on actions and such leaflet developed in clear, non-medical terms, information on contact details for CNC who would be acting as a liaison between families and clinicians.

An aspiration for the future OFC dental workforce includes increasing the number of oral health therapists, dentists and specialists of Māori and Pasifika descent to aid in reducing health inequities in this group. This also includes consideration for extending this pathway to other non-OFC children who present with equally challenging circumstances, such as multiple missing teeth.

## Conclusion

The establishment of a clear strategy to address inequities and inequalities of care for children with cleft is long overdue. The proposed oral health pathway will ensure there is appropriate access to care that is consistent throughout the country, with provision for targeted early preventative and management measures for those considered high risk. The engagement of specialist paediatric dentists, CNC's, COHS and those dentists committed to adolescent oral health services with a commitment for clear communication will ensure consistency of care. A dedicated benchmarking of dental health status at age 3 and 5 years of age will allow for review and adjustment of the pathway over time.

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