

Transitioning from child to adult cleft lip and palate services in the United Kingdom: Are the NICE Guidelines reflected in young adults' experiences?

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Abstract

Cleft lip and/or palate (CL/P) is one of the most common congenital conditions worldwide. Individuals born with CL/P will embark on a long-term treatment pathway throughout childhood and often into adulthood. As they grow older, young people become more involved in medical decisions. The National Institute for Clinical Excellence (NICE) has published guidance for health professionals on how transitions of responsibility should be managed in health services. The aim of the current study was to examine the extent to which the NICE recommendations are currently being implemented in UK CL/P services according to young adults' first-hand accounts. Semi-structured interviews were carried out with 15 young adults with CL/P aged 16-25 years. Interview questions were designed to map onto the NICE guidance. Data were analysed to assess whether each guideline was met, partially met, or not met for each individual participant. Overall, findings suggest that further consideration is needed as to how best to implement the recommendations effectively. The introduction of assigned transition workers in CL/P services to co-ordinate transition to adult care offers one possible solution. Focusing on the provision of holistic, patient-centred care, this aspect of the CL/P service could include giving patients access to medical history documentation, liaison with key health professionals including GPs and dental

practitioners, and the development of age-appropriate resources to facilitate the transition process.

Keywords: cleft lip and palate, adolescent, transition, policy, NICE

Introduction

Cleft lip and/or palate (CL/P) is a common craniofacial condition which occurs when the lip, nose, and/or palatal structures fail to form typically in the early stages of fetal development (NHS, 2019). In the United Kingdom (UK), the prevalence is thought to be around 1 in 660 live births (Medina et al., 2020). The aetiology of CL/P is complex, with a combination of genetic and environmental factors being indicated (Dixon et al., 2011). Infants born in the UK with CL/P are placed on a centralised evidence-based pathway of treatment provided free of charge to families by the National Health Service (NHS; NHS Commissioning Board, 2019). According to the prescribed pathway, primary lip/palate repair operations are typically carried out in the first 13 months of life. However, children with CL/P will also receive input from a multidisciplinary team, such as clinical nurse specialists, speech therapists, audiologists, geneticists, psychologists, paediatric dentists, and orthodontists throughout childhood and often into early adulthood (Hodgkinson et al., 2005; NHS Commissioning Board, 2019). The UK treatment pathway offers a lifespan approach; adults with CL/P are therefore entitled to return to specialist care at any time. This is typically carried out via a referral from their General Practitioner (GP) or General Dental Practitioner (GDP; NHS Commissioning Board, 2019).

There is a growing body of evidence highlighting the psychosocial challenges for adults with CL/P, including difficulties with low self-esteem, employment, intimate relationships, and fear of negative evaluation (Ardouin et al., 2020; Costa et al., 2021; Stock et al., 2015). Young adults have reported being unhappy with their physical

appearance despite having been discharged from their CL/P team, sometimes to an extent where being seen from certain angles or smiling in a ‘natural’ way is avoided (Moi et al., 2020). Concern about the appearance of one’s lips and nose, in particular, is common from age 16 (Cadogan et al., 2021). Although adults can be referred back to CL/P treatment, recent studies indicate that many are not aware of this, or perceive access to treatment to be challenging due to past trauma or a lack of support (Ardouin et al., 2021). Providing appropriate support from an early age is therefore crucial to prevent difficulties from escalating, and to facilitate positive adjustment and build resilience.

One way to ensure that adults can *and* feel able to access treatment is to ensure that shared decision making (SDM) practices are implemented surrounding CL/P treatment during childhood and adolescence. SDM can be defined as a “collaborative process whereby patients and providers work together to find a mutually agreed upon treatment plan” (Boss et al., 2016). This encourages patients and (for young patients) caregivers to feel involved in treatment, and to share their hopes and worries about treatment and outcomes. This, in turn, promotes patient autonomy and involvement, increasing young people’s confidence in making decisions, and encourages their healthcare providers to listen to and respect them (Beacham & Deatrick, 2013; Wogden et al., 2019). Appropriate implementation of SDM should ensure that by the time an adolescent reaches adulthood, they feel equipped to take control of their medical care, and are aware of the options available (Ambresin et al., 2013; Voorheis et al., 2020). In the UK, a child under 16 may consent to proposed treatment if deemed mature and competent enough to understand it. However, in instances of a child refusing, overriding consent can be sought from caregivers when the treatment is in the child’s best interests (General Medical Council, 2018; The Medical Protection Society, 2020). From age 16,

adolescents are presumed to have the capacity to make medical decisions (General Medical Council, 2018). For patients with CL/P moving into adulthood, this means that choices to have further surgery lie for the first time entirely with the patient.

In 2016, the National Institute for Clinical Excellence (NICE) published a set of recommendations entitled “Transition from children’s to adults’ services for young people using health or social care services” (NICE, 2016). These recommendations constitute five sections, summaries of which are displayed in Table 1. In CL/P services, the treatment pathway documents the need for an appropriate transition process to promote autonomy and minimise the likelihood of “non-adherence to treatment”. However, protocols for how to achieve this are lacking, leaving it up to individual CL/P teams to manage patients’ transition.

Transition experiences among adolescents with CL/P is a relatively unexplored area of research. In the UK, one study reported that adolescents with CL/P felt ill-equipped to make treatment decisions, due to professionals ‘talking over’ them or ‘leaving them out’ of discussions (Wogden et al., 2019). Additionally, some young people across UK and US samples have reported feeling pressure from caregivers to have, or not to have, surgery (Vallino & Louw, 2017; Wogden et al., 2019). Within the broader health literature, research on transition is more prevalent and presents similar findings. For example, young adults with diabetes and asthma have reported feeling apprehensive and unready to transition into adult services (Archibald & Ashford, 2018; Butalia et al., 2020; Patel et al., 2019; Withers, 2012; Withers & Green, 2019).

The aim of this study was to explore the extent to which NICE recommendations regarding transition from child to adult care appear to have been implemented, from the perspective of young adults with CL/P. This work sought to offer insight into areas

where young people felt supported in their transition, as well as areas for potential development.

Method

Ethical considerations

Full ethical approval for the current study was granted by the Research Ethics Committee at The University of the West of England, Bristol, UK. The ethical recommendations set by the British Psychological Society were also followed.

Design

This study utilised a qualitative approach involving individual semi-structured interviews to capture young adults' experiences in their own words. The NICE Recommendations for Transition from Children's to Adults' Health Services (Table 1) were used to develop a semi-structured interview schedule (Table 2). This was drafted by the first and last author, with questions mapping onto each recommendation. Feedback from a patient representative, a CL/P specialist surgeon and 4 CL/P clinical psychologists were incorporated into the final interview schedule. Where the language used in the NICE recommendations was not relevant to participants or difficult to access, questions were rephrased appropriately and the interviewer was able to prompt to facilitate responses.

Procedure

Participants were recruited using social media adverts posted by (*Research Centre*) and leading UK charity, the Cleft Lip and Palate Association (CLAPA). Adverts contained brief information about the study and a weblink to an eligibility survey. Young adults were eligible to participate in the study if 1) they were aged 16-25

years, 2) born in the UK, and 3) had a CL/P diagnosis. Participants were sent a Participant Information Sheet via email detailing the aims of the study, and key ethical considerations, such as the participant's right to withdraw. Demographic information (outlined below) was also collected online. A convenient time to carry out the interview was agreed with each participant by email.

Individual, one-to-one interviews were carried out by the second author between February and March 2021 using Microsoft Teams. Each interview began by reminding the participant of the aims of the study, providing an opportunity for the participant to ask questions about the research, and building rapport. Verbal consent was obtained and recorded prior to the interview. All interviews were audio-recorded and transcribed verbatim by an external transcriptionist.

Participants

Of 20 who expressed interest, 15 young adults (mean age: 21.40 years; 11 female) met the eligibility criteria and gave their consent. Participants were representative of 8 of the possible 12 UK CL/P networks. Nine participants had a diagnosis of cleft lip and palate, four had a cleft lip only, and two had a cleft palate only. Twelve reported having no additional syndromes. Fourteen identified as 'White British' and one as 'Mixed Race'. Five were university students, two were at school, and all others were in either full- or part-time employment. Interviews lasted an average of 69 minutes.

Analysis

Transcripts were divided between the first and second authors and were initially coded according to which NICE guideline was being addressed. A decision was then made about whether each guideline was met, partially met, or not met for each participant. The 'partially met' classification was used when the participant indicated inconsisten

experiences (e.g. participants perceived some CL/P team members to have been more sensitive to their needs than others). These decisions were cross-checked and agreed by the first and second authors. Frequencies were then recorded for each category.

Preliminary findings were shared with members of the UK Cleft Psychology Clinical Excellence Network and their feedback was incorporated into the report.

Results

Table 3 displays frequencies indicating which recommendations were met, partially met, or not met according to participants' narratives. In total, 14 out of the 18 applicable NICE recommendations were 'not met' for the majority of participants (where the 'not met' frequency equalled more than the sum of 'met' and 'partially met'). The recommendations that were not met included recommendations for preparing, planning, and reviewing the transition process, involving primary care practitioners, assigning a named worker, and ensuring young people knew what adults services were available. The remaining four recommendations which were reported to have been mostly 'met' related to holistic, goals-orientated SDM practices.

Discussion

This study aimed to explore the extent to which the NICE recommendations on transition from child to adult health care in are implemented within CL/P services, according to young people's narratives. Overall, participants' responses indicate that further consideration is warranted to ensure NICE recommendations are being implemented comprehensively and consistently. Yet, current areas of strength were also identified. Findings are discussed in more detail below.

A person-centred and holistic service

The majority of questions corresponding to the ‘Overarching principles’ section of the recommendations were met with positive responses, with young people reporting that, they felt that their strengths and goals were considered in treatment planning. This is encouraging, in light of broader health literature which indicates that adolescents who have felt involved in their treatment are less likely to experience decision conflict, feel more empowered, and feel more able to take part in discussions (Boss et al., 2016; Jordan et al., 2019). In turn, this perpetuates SDM and health autonomy. According to the young people who participated in this study, CL/P services are offering a service which is guided by patient-centred values, and which have been shown to improve SDM processes across health settings.

Knowledge is (em)power(ing)

Many operations and interventions in the CL/P pathway are performed before the age at which adolescents preparing to take control of their own treatment could be expected to recall. For example, primary lip and palate repair operations typically happen in the first 13 months of life, followed by speech investigations and further surgery in early childhood (NHS Commissioning Board, 2019). One of the NICE recommendations which was unanimously unmet for the participants in the current study was the provision of documentation outlining their medical history and treatment plan.

Condition- and treatment-specific knowledge have been suggested as key enablers of patient empowerment during adolescence (Acuña Mora et al., 2020). This existing literature, combined with the present finding that most participants reported plans or wishes to have further treatment, indicates that helping adolescents to understand their treatment history may be empowering for the young person and facilitate SDM in future.

Appropriate resources for adolescents with CL/P

In the current study, participants' experiences of the information provided during transition points and the communication from healthcare professionals were variable. Eight of the 15 participants did not believe their transition had been developmentally appropriate. Within SDM literature, it has been indicated that SDM is less likely to have happened successfully in adolescents' care in instances where a patient-doctor power imbalance has been perceived by the patient (Boland et al., 2019). This highlights the importance of effective communication between professionals and adolescents, and also of ensuring treatment options are presented in a way that is appropriate and accessible to the patient. Some transition resources are in use for other health conditions, such as the 'Ready Steady Go' booklet, used to help prepare adolescents for managing their healthcare independently (Transition and Patient Empowerment & NHS, 2018). However, not all aspects of these resources apply to CL/P, and no centralised, CL/P specific resource currently exists for young people in the UK. In the US, a transition model for CL/P care has been proposed, which aligns closely with the current study recommendations for the UK. This proposed model includes the use of resources, specifically aimed at young adults, and informed by CL/P literature around the primary concerns for this age group, such as appearance, changing caregiver dynamics and decisions around further treatment (Vallino & Louw, 2017). Given the specialist input that is required across all aspects of CL/P care, this type of resource could be a positive step toward ensuring NICE recommendations are reliably implemented.

Involving general practitioners and dentists in CL/P care

In this sample, no participants felt confident that their GP or GDP would be able to support them in seeking further CL/P care. Existing literature has demonstrated that

individuals with CL/P may struggle to re-access specialist treatment in adulthood for a variety of reasons, including not realising that they are still entitled to support (Ardouin et al., 2021; Stock et al., 2015). Although any adult with CL/P can be referred to a CL/P team at any point, this process relies on both the individual and the practitioner being aware of this entitlement and how to action it. Similarly, previous literature has shown that adults with CL/P may experience difficulties accessing appropriate dental care, due to a lack of knowledge of CL/P among GPs, or related to the individual's own hesitancy due to prior 'traumatic' or ineffective treatment experiences (Ardouin et al., 2021; Stock et al., 2018). Involving GPs and GDPs in the transition process, and maintaining open communication between the CL/P team, the patient, and their GP/GDP would strengthen the expertise within the team and help to facilitate any future treatment.

A named transition worker for adolescents with CL/P

A large proportion of the NICE recommendation document focusses on a 'named transition worker'; a named adult who acts as the liaison between an adolescent and their health team, who often already has a role within the care team. Most of the recommendations identified by the current study could be coordinated by this one transition worker, such that adolescents have a comprehensive transition package *and* an individual to build a trusting relationship with. No participants in the current study were familiar with the concept of a named worker, nor could they identify anyone in their team who had fulfilled this role. In other long-term health conditions, clearly defined transition workers have been associated with a multitude of benefits, such as shortened waiting times for consultations, greater healthcare provider satisfaction, improved access to care, better treatment engagement and understanding, greater caregiver satisfaction, and a more positive overall patient experience (Betz & Redcay,

2005; Fair et al., 2012; Haze & Lynaugh, 2013; Rearick, 2007; Rideout, 2007). A named transition worker situated within CL/P teams, who has the capacity to spend time getting to know the adolescents and families may allow for a more personalised transition. In turn, this could enable adolescents to voice their concerns and opinions in a way that is relevant and useful to them, which could further strengthen patient-clinician relationships, as seen in other health conditions (Haze & Lynaugh, 2013).

A comparative role in the context of CL/P is that of the Clinical Nurse Specialist (CNS), who is assigned to new caregivers shortly after they receive an antenatal or postnatal CL/P diagnosis. The CNS supports new parents through initial consultations and primary operations, while providing information, practical support, and reassurance to help parents adjust to being responsible for making treatment decisions for their child (Martin et al., 2020). Parents have described their CNS as trusted mediators between themselves and clinicians, and value them as a highly important member of the CL/P team (Searle et al., 2018). This provides an interesting parallel with the current findings, and suggests that a similar role working with adolescents and families prior to, during, and following the transition to adult care could be of benefit.

Methodological considerations

This study offers an examination of young adults' experiences of transitioning from child to adult CL/P services in the UK, with specific reference to current NICE recommendations. The findings offer unique insight into the transition process and highlight areas of current strength, as well as areas for future focus.

Although the sample is an acceptable size for qualitative research, it cannot be assumed to be representative of the CL/P population. Additionally, most participants were female, so results may not be transferable to individuals of other genders. Future research should seek to build on this work with a larger, varied sample size, which may

be aided by a quantitative design. Potential trends in relation to cleft type, the presence of additional syndromes, and other variables of interest could then also be explored. Building on the current study by exploring the perspectives of other members of the CL/P community (for example, healthcare professionals and caregivers) could also provide interesting opportunities for triangulation, and a more comprehensive assessment of CL/P services for young adults.

Conclusion

Young people born with CL/P may require significant support in the lead-up to and after they become responsible for their own medical decisions. This is recognised within the prescribed pathway of care for individuals with CL/P, and by the broader NICE recommendations on transition to adult care. Drawing upon the perspectives of young adults with CL/P, the current study indicates that further consideration is needed with regard to how to implement these recommendations effectively in CL/P care.

Subsequently, the introduction of assigned transition workers in CL/P services to coordinate transition to adult care is suggested as an option for future work to consider. This aspect of the CL/P service could focus on the provision of holistic, patient-centred care, and include access to medical history documentation, liaison with key health professionals including GPs and dental practitioners, and the development of age-appropriate resources to facilitate the transition process.

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Table 1 – Summary of the NICE guidelines (NICE, 2016)

Overarching principles	<ul style="list-style-type: none"> - Involve young people and their carers in transition-related service design, delivery and evaluation (including co-production of transition policies and strategies) (1.1.1) - Ensure transition support is developmentally appropriate (1.1.2) - Ensure transition support is strengths-based and that goals are set for the young person (1.1.3) - Use person-centred approaches such that the young person is an equal partner in their care and treatment (1.1.4) - Ensure primary care (i.e. GPs) are in place for the young person (1.1.8)
Transition planning	<ul style="list-style-type: none"> - Ensure transition takes place at a relatively stable time in a young person’s life (1.2.3) - Ensure the transition planning takes into account each young person's capabilities, needs and hopes for the future (1.2.3) - Hold an annual review meeting to review transition plans with the young person and their health/care team (1.2.4) - Involve all practitioners providing support to the young person and their family or carers, including the GP (1.2.4) - Help the young person to identify a single practitioner – who should act as a 'named worker' – to coordinate their transition care and support. This named worker should support the young person and their family throughout the transition period for as long as is felt appropriate. (1.2.5-1.2.9) - Offer young people opportunities to access peer support, coaching or similar to help them engage with their transition into adult care (1.2.11) - Ensure young people are supported to manage their condition through assessment of self-confidence and readiness to take control of health and care decisions. (1.2.17) - Ask young people how, and to what extent, they want their guardians to be involved in their transition to adult care. (1.2.19) - Speak to guardians about transition such that they know what to expect and what support is available. (1.2.20) - Help young people develop confidence in working with adults' services by giving them the chance to raise any concerns and queries separately from their parents or carers (1.2.21)
Support before transfer	<ul style="list-style-type: none"> - Service managers to ensure that the young person meets someone from their adult team before they officially transfer from their children’s team (e.g. in a joint appointment) (1.3.1) - Contingency plan to be in place in case of the named worker leaving their role (1.3.2) - Consider working with the young person to create a ‘personal folder’ including information about themselves and their treatment, any care plans and any needs, that the young person keeps and takes with them to adult appointments. (1.3.3) - Young people and their guardians should be given information about what support is available to them from adult services and how to access it. (1.3.4)
Support after transfer	<ul style="list-style-type: none"> - If a young person has moved to adult services and does not attend meetings or appointments, attempts should be made to contact the young person and re-engage with them by the named worker. (1.4.1) - Ensure that the young person sees the same healthcare practitioner in adults services for the first 2 attended appointments after transfer from children’s services. (1.4.4)

Supporting infrastructure	<ul style="list-style-type: none">- One senior executive and one senior manager should be appointed in each health and social care organisation to develop and oversee the implementation of transition protocols (1.5.1)- Consider establishing integrated forums for young people to provide feedback on current transition protocol and highlight any gaps. (1.5.5)
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Table 2 – Summary of semi-structured interview guide. Questions are mapped onto each NICE recommendation

Question	NICE Recommendation
How much were you involved in your care while you were growing up?	1.1.1, 1.1.2, 1.1.3, 1.1.4
What – if anything - do you feel the cleft team did to involve you in your care while you were growing up?	1.1.3, 1.1.4
How much are you involved in your care now?	1.1.2, 1.1.3, 1.1.4
If applicable - what are the main differences between the involvement you had as a child and the involvement you have now?	1.1.2, 1.1.3, 1.1.4
What – if anything - do you feel the cleft team do to involve you in your care now?	1.1.3, 1.1.4
Do you feel like you have enough information and support to manage your own cleft treatment moving forward? If you need any more information in the future do you know where to get it? Where would you go?	1.1.3
How old were you when you felt like you became more involved in your cleft treatment?	1.2.1
Did you feel prepared to manage your own treatment at that time? If no, why not? If yes, what helped you to feel prepared?	1.2.3
Has anyone ever asked you how you feel about making these decisions? If yes, who, when, how? Was this reviewed at any point?	1.2.4
What has been your experience of other health professionals outside of the cleft team during this time in your life, for example your GP, your dentist?	1.2.4
Have you ever been allocated a named person (a nurse, for example) to be your port of call if you have any questions or concerns about moving from child to adult cleft care?	1.2.5
Would having a named person have been helpful for you? What would they have been useful for?	1.2.5
Did anyone else support you with your move to adult care? (e.g. GP)	1.1.8, 1.2.5
Have you ever been offered support from CLAPA or another young adult with cleft to help you move to adult care?	1.2.11
Has anyone ever helped you to share your views at moments when you found it difficult to understand your care or found it difficult to speak up?	1.2.11
Have you been given the option of using mobile technology, apps or email to stay in contact with your cleft team?	1.2.12
When you move/moved from child cleft services to adult services, will you be/were you given a way to stay in touch with key people and/or networks you had growing up?	1.2.13
Has your cleft team/CLAPA mentioned any peer support opportunities to you (chances for you to speak with other young adults impacted by cleft about the transition process or treatment in general)?	1.2.15, 1.2.16
Have you ever been asked if you're comfortable with your parents being involved in your treatment choices/coming to appointments with you? How do you feel about your parents' involvement?	1.2.19
Have you been given the opportunity to ask questions or raise concerns without your parents being in the room with you?	1.2.21
Do you feel your wishes about your parents' involvement has been listened to and respected?	1.2.22

If the child team is different from the adult team, did you meet anyone from the adult team before you moved?	1.3.1
Were you given any information about your past treatment, your medical records or your cleft 'journey' in preparation for you moving into adult cleft services?	1.3.3
Did anyone ever discuss with you what the main differences are between child cleft services and adult cleft services? (E.g. signing your own consent forms, making the decisions around treatment yourself, being 'in control' of what happens to you and when, being in a different hospital)	1.3.4
If applicable, since you have 'transitioned' to adult care (turned 16), would you say your care has been consistent? Have you seen the same people each time?	1.4.4, 1.4.5
If you've missed any appointments, have they followed up with you? Has your named worker (if applicable) ever been in touch?	1.4.1, 1.4.2, 1.4.3
<i>If the participant has not engaged in any cleft services since they 'took control', ask</i> Has anyone been in touch with you from the cleft team to check that you do not want any further treatment, and to let you know how to contact them in the future?	1.4.1, 1.4.2, 1.4.3
Overall, do you feel like the move from child to adult cleft care has been successful for you?	Rounding off
What advice would you give to a young person approaching the age at which they can make their own decisions about treatment?	
Overall, do you think there is anything that could have been done better? What advice would you give to health professionals who would like to help make the move from child to adult cleft care easier?	

Table 3 – Summary of results: which of the guidelines relevant to CL/P care were met, partially met or not met?

NICE Recommendation	Met	Partially met	Not met
Overarching principles			

Involve young people and their carers in transition-related service design, delivery and evaluation (including co-production of transition policies and strategies)	1	0	14
Ensure transition support is developmentally appropriate	4	3	8
Ensure transition support is strengths-based and that goals are set for the young person	7	5	3
Ensure transition support uses person-centred approaches such that the young person is an equal partner in their care	7	5	3
Ensure a GP is in place for the young person	10	5	0
Transition planning			
Ensure transition takes place at a relatively stable time in a young person's life	N/A ¹		
Ensure the transition planning considers each young person's capabilities, needs and hopes for the future	5	4	6
Hold an annual review meeting to review transition plans with the young person and their health/care team	0	3	12
Involve all practitioners providing support to the young person and their family or carers, including the GP [and dentist]	0	0	15
Help the young person to identify a single practitioner – who should act as a 'named worker' – to coordinate their transition care and support.	0	0	15
Offer young people opportunities to access peer support to help them become involved in their transition planning	4	0	11
Ensure young people are supported to manage their condition through assessment of self-confidence and readiness to take control of health and care decisions	0	0	15
Ask young people how, and to what extent, they want their guardians to be involved in their transition to adult care	1	0	14
Speak to guardians about transition such that they know what to expect and what support is available	N/A ²		
Help young people develop confidence in working with adults' services by giving them the chance to raise any concerns and queries separately from their parents or carers	7	0	8
Support before transfer			
Children's and adults' service managers should ensure that a practitioner from the relevant adult services meets the young person before they transfer from children's services. This could be by arranging joint appointments or running joint clinics.	7	0	8
Contingency plan to be in place in case of the named worker leaving their role	N/A ³		
Consider working with the young person to create a 'personal folder' including information about themselves and their treatment, any care plans and any needs, that the young person keeps and takes with them to adult appointments	0	0	15

Young people and their guardians should be given information about what support is available to them from adult services and how to access it	4	0	11
Support after transfer			
If a young person has moved to adults' services and does not attend appointments, adult care should follow up with the young person.	0	0	10 ⁴
Ensure that the young person sees the same healthcare practitioner in adults' services for the first 2 attended appointments after transfer from children's services	2	4	7 ⁵

¹This was N/A as participants could not identify a time where 'transition' had happened

²This was N/A as parents were not interviewed. Young adults were unsure if their parents had been spoken to about transition

³This was N/A as no participants had a named worker

⁴for 5 participants, this question was not applicable, as they were currently in active contact with their cleft teams at the time of interview

⁵For 2 participants, this question was N/A as they had never attended appointments as an adult