

Expanding Support Services for Adults born with Cleft Lip and/or Palate in the UK: An Exploratory Evaluation of the Cleft Lip and Palate Association Adult Services Programme

Abstract:

Background: The largest group of people living with repaired CL/P are adults. Previous research has identified unmet treatment and psychosocial needs, yet few interventions exist. This paper outlines three interventions developed by the Cleft Lip and Palate Association (CLAPA) as part of its 3-year community-based Adult Services Programme; an Adults Conference, a series of panel discussions ('Cleft Talk') streamed in podcast/video format, and a Leaver's Pack of resources for adults wishing to return to cleft care.

Methods: Feedback from attendees of the Adults Conferences (2018-2019) was collected using specifically developed evaluation forms. Streaming metrics and social media interactions were extracted for Cleft Talk panel discussions (2019-2020). The Leaver's Pack was piloted in 2020, using an online evaluation form. Specialist health Professionals were invited to provide feedback or participate in a one-to-one interview regarding their perceived impact of the programme.

Results: All three interventions across the different modalities received support from participating adults, demonstrating potential to meet adults' needs across the lifespan. Health professionals also offered support for the programme, viewing the interventions as a valuable adjunct to formal medical CL/P services.

Conclusions: This exploratory evaluation indicates that peer and community-led interventions, in combination with ongoing access to specialist medical care, can have a range of positive impacts for adults with CL/P. There is scope for similar initiatives to be developed internationally, and for

individuals with other craniofacial conditions. Not-for-profit organisations are encouraged to routinely evaluate their interventions to create a stronger evidence-base for their valuable work.

Introduction:

There are estimated to be around 90,000 people living in the United Kingdom (UK) today who were born with a cleft lip and/or palate (CL/P; CRANE, 2018). Approximately 72,000 of these are aged 18 or over (CRANE, 2018), and as a result, the largest cohort of individuals affected by CL/P are adults. Cleft care has traditionally focussed on families and children, despite increasing evidence that there is unmet need in the adult population (Stock et al., 2015; Nicholls et al., 2018; Kappen et al., 2019; Ardouin et al., 2020). Issues from childhood such as unresolved medical issues, speech difficulties, the burden of ongoing treatment, and psychosocial adjustment left unattended may continue to cause difficulties in adulthood, while new challenges, such as employment, romantic relationships, and starting a family may also arise during the adult years (Havstam et al., 2011, Stock et al., 2015, Ardouin et al., 2020).

Cleft care was fundamentally changed in the UK following a commissioned report in the late 1990s (Sandy et al., 1998). The report recommendations have been implemented across the UK over the last two decades, including the incorporation of routine psychology care. In addition, the Cleft Lip and Palate Association (CLAPA) has established themselves as the leading CL/P charity in the UK, offering complementary information and support to anyone affected by CL/P. While these are positive steps, many people who are adults today would have accessed their cleft-related treatment prior to the introduction of these changes, and would not have had access to a multidisciplinary team, or to psychological services. In recent years, and in line with a growing appreciation for CL/P as a lifelong condition, CLAPA has seen an increase in adults engaging with their services and enquiring about

treatment options in adulthood. CLAPA's Facebook pages have also seen many examples of adults seeking advice regarding medical treatment or psychological support (Stock et al., 2018).

To address the unmet need among adults with CL/P, CLAPA commissioned a three-year programme of work entitled the 'Adult Services Programme', in collaboration with (*university*). To engage more fully with the adult population, CLAPA undertook a UK-wide 'roadshow' in 2018, a series of focus group events for adults with cleft, which visited 12 cities across England, Wales, Scotland, and Northern Ireland to provide adults with the opportunity to share their experiences first hand. In addition, CLAPA launched a national survey, which captured both quantitative and qualitative data in relation to adults' holistic wellbeing and support needs. These activities built upon the existing evidence base and identified treatment experiences, emotional wellbeing, interpersonal experiences, and physical health as key areas of need. More detailed findings from the survey are presented in separate papers (*references redacted for anonymity*).

Following the collation of findings from the roadshow and the survey, CLAPA set out to develop and deliver interventions that would address the needs identified. To encourage adults to meet others with CL/P, share their own experiences, and meet with academic and medical experts, a conference was launched specifically aimed at adults with CL/P and their families/partners ('CLAPA Adults Conference'). To share research findings, treatment information and guidance more widely, a video and podcast panel discussion series was developed and shared online ('Cleft Talk'). Finally, an information pack was designed to be given in clinic to all young adults across the UK at their point of departure from routine cleft care, as well as to adults who have already been discharged from routine cleft care but may wish to return in the future ('Leaver's Pack'). The aims of the current paper are to outline the development of these three interventions and to evaluate their initial impact.

Method:

Each of the three interventions and their evaluation method(s) are described below.

CLAPA Adults Conference

The CLAPA Adults Conferences were held face to face in November 2018 in London, and September 2019 in Glasgow. A third conference was scheduled for July 2020 but was cancelled due to the COVID-19 pandemic. The findings of the survey and roadshow were used to guide the content of the presentations and workshops. A wide range of topics were discussed, such as access to treatment and surgical decision-making, relationships and intimacy, building resilience and self-esteem, maintaining oral health, dealing with chronic pain, genetics and CL/P heritability, and speech concerns. Guest speakers included leading researchers, specialist clinicians from the regional UK cleft teams, and adults who were born with CL/P.

An evaluation questionnaire was given to each attendee at the end of the day to provide feedback on their experiences of the conference. The questionnaire consisted of five quantitative questions, measured using yes/no responses and Likert scales, in addition to four open-ended questions asking participants to elaborate on what they had gained from/enjoyed about the conference and what could be improved. The same form was used at both the 2018 and 2019 conferences for consistency. Attendees handed their anonymous forms to staff before leaving the venue. Responses were collated by the first author and summarised.

Cleft Talk Panel Discussions

The Cleft Talk panel discussions included a series of 15 discussions disseminated in podcast format, at a rate of one episode per month. Content for the 2019 series was recorded in person, and was also disseminated in video format (seven episodes). The 2020 series was recorded via telephone/video call due to the COVID-19 pandemic, and disseminated via the podcast only (eight episodes). As before, the

findings of the survey and roadshow were used to guide the content of each episode. Feedback on the proposed topics was also sought from the Psychology Clinical Excellence Network (Psychology CEN, consisting of all specialist CL/P psychologists in the UK). An overview of each episode including the composition of each panel is provided in Table 2.. Ahead of each podcast, a list of proposed questions was provided to all panel guests and their feedback was sought. Panel discussions were hosted by two members of CLAPA staff. Different guest panellists were invited to participate in each episode and included multidisciplinary representatives from clinical practice and/or leading UK research teams, alongside adults with lived experience of CL/P. Video and audio was recorded using a video camera and lapel microphones. Once the COVID-19 pandemic began, audio only was recorded via the video conferencing platform Zoom. The panel discussions are each between 30-60 minutes in length. Editing of the podcasts was completed by the first author using Adobe Audition and Audacity software. Editing of video content was completed by the first author using the Microsoft Photos software bundled within Windows 10. Video discussions were shared on YouTube, while podcast episodes were published on Spotify, Apple Podcasts, and SoundCloud. In all instances content was cross-posted onto the CLAPA website, Instagram, Twitter, and Facebook pages.

Evaluation data for the panel discussions were collected in a variety of ways. First, metrics from Spotify, YouTube, SoundCloud, and Apple Podcasts were collated, including number of listens, location of listens, and other demographic data where available. Data from social media posts associated with the Cleft Talk panel discussions were also collected, including the number of ‘likes/reactions’ and relevant comments. The first and second authors analysed 179 comments that were posted on the CLAPA Facebook page regarding the Cleft Talk series.

Leaver’s Pack

The Leaver’s Pack (entitled “Your Guide to Returning to Cleft Care”) is an information pack designed to be given in clinic to all young adults across the UK at their point of departure from routine cleft care.

It can also be given to any adult who has already left routine cleft care, but who may wish to return for CL/P treatment or support in later life. The contents of the Leaver's Pack are described in Table 1.

The Leaver's Pack was formally piloted between January and November 2020. The planned pilot period was extended by 3 months due to COVID-19, and data were collected online, rather than in clinic as originally planned. Ethical approval for the pilot was obtained from the Faculty Ethics Committee at (*University*). The pilot was advertised on the CLAPA website, social media, the Cleft Talk panel discussions, and in the CLAPA e-newsletter. Participants either obtained their pack directly from their UK Cleft Team or by ordering a copy from the CLAPA website. The pack was accompanied by a Participant Information Sheet and a link to complete the online evaluation survey. Upon completion of the survey, participants were able to claim a £5 voucher as a thank you for their time. The survey consisted of five demographic questions, 10 quantitative questions regarding the acceptability of the different aspects of the pack, and open-ended text boxes allowing participants to provide additional qualitative information.

Health Professional Feedback

The views of Health Professionals working within NHS Cleft Teams regarding the CLAPA Adult Services Project were also sought through email feedback ($n = 5$) and one-to-one interviews ($n = 2$). Clinicians from a variety of disciplines were asked the following questions: "What do you think the CLAPA Adult Services Project has contributed or complemented to the services already provided by the NHS?", "What impact do you think the Adult Services Project is having/will have on adults who were born with cleft?", and "Are there any other comments that you would like to add?"

Results:

CLAPA Adults Conference

Thirty-four adults with CL/P attended the two conferences, in addition to 16 health professionals, and three family members/partners. A total of 27 attendees completed the evaluation form. Of these, 17 participants reported this was their first time attending a CLAPA event (62.9%). Participants were asked what they had gained from the conference. Common responses included meeting others with CL/P, sharing and hearing stories, discussions about the psychological aspects of cleft, and learning about treatment options. The two conferences were held in geographically distant parts of the UK to maximise reach, and therefore none of the participants attended both conferences. However, 89% stated they would attend a similar event again in future.

Cleft Talk Panel Discussions

Cleft Talk panel discussions were released monthly from June 2019 to December 2020 (except for a three-month hiatus from May-July 2020 due to COVID-19). At the end of February 2021, Cleft Talk had reached a combined total of 3,131 people. Of these, 2,051 streamed the podcast, while 1,080 streamed the same content in video format. The most popular episodes to date were those on the topics of self-esteem, friendships and romantic relationships, and living with cleft palate only. Cleft Talk was most popular in the UK and the United States, with other European countries, Australia, and New Zealand making up the remainder of the top ten locations. The most popular platform by which to access Cleft Talk was Spotify. As of the end of February 2021, 54 people had subscribed to the podcast on Spotify. According to Spotify data, 74% of people who accessed Cleft Talk were female. The majority of listeners on Spotify were aged between 28 and 44 (53%), with 36% of listeners aged under 28%, and 12% of listeners aged 45+.

In response to the Cleft Talk panel discussions, 18 adults posted on the CLAPA Facebook page that they were grateful that these topics were being raised and discussed. The Cleft Talk series also prompted adults to share their own experiences of living with CL/P in adulthood. These discussions included concerns about: feeling different ($n = 8$), speech/sounding different ($n = 7$), self-esteem ($n =$

6), appearance ($n = 6$), anxiety ($n = 5$), bullying ($n = 4$), food aversion ($n = 2$), hearing ($n = 2$), and relationship issues ($n = 1$). Adults also posted about the importance of good psychological care ($n = 7$) and comprehensive medical care ($n = 8$) during adulthood.

Leaver's Pack

A total of 55 adults with CL/P received a Leaver's Pack, and 27 participants completed the evaluation survey (49.1% return rate). Of those who completed the survey, most were female (74.1%), White (92.6%), and born with a cleft lip and palate (51.9%). Participants' age was categorised as 20 years or younger (33.4%), 21-29 years (25.9%), and 30 years or above (40.7%).

Participants indicated that the Leaver's Pack covered key topics of interest and importance (100.0%), and that the content was very (88.9%) or mostly (11.1%) easy to understand. Participants also responded that the pack had helped them to learn a lot (77.8%) or a little (18.5%) more about the treatment and support options available to them, and had considerably (81.5%) or moderately (18.5%) increased their confidence about accessing CL/P treatment. Relatedly, participants reported they were very (77.8%) or moderately (18.5%) more likely to access CLAPA's information and support services in future. Participants found the map illustrating the location and contact details of UK cleft teams to be very (85.2%) or moderately (14.8%) useful. Participants also reported the flowchart outlining the cleft team referral process to be very (85.2%) or moderately (11.1%) useful. Participants responded that the letter addressed to General Practitioners and General Dental Practitioners had made them considerably (66.7%) or moderately (29.6%) more confident about visiting these health professionals in future. Participants also stated they were likely to revisit the Leavers' Pack should they need information in future (96.3%). Finally, a total of 42.3% of participants indicated they would like an online version of the pack to be made available in future.

Feedback from Health Professionals

Five specialist health professionals responded to CLAPA's request for email feedback and two participated in one-to-one interviews. This included five CL/P Specialist Psychologists, one CL/P Surgeon, and one CL/P Specialist Speech Language Therapist. Feedback from Health Professionals was grouped by theme (including benefits for adults with CL/P and Health Service) with exemplar quotes provided. These are presented in Table 3.

Discussion:

The aims of this paper were to outline the development of three new interventions to expand information and support for adults with CL/P and to evaluate their impact. These interventions were designed in response to recent literature highlighting the challenges that adults with CL/P may experience, in addition to extensive engagement with the adult community and a national survey of adult wellbeing in 2018. The resulting interventions included an Adults Conference, a series of 'Cleft Talk' panel discussions, and a Leaver's Pack containing information for both young and older adults about returning to CL/P should they wish to in future.

Evaluation Summary

Overall, all three interventions received positive feedback from adults with CL/P, health professionals, and other stakeholders. The Adults Conference proved popular among both adults with CL/P and their partners/family members, and was a place for attendees to meet others affected by CL/P and share experiences. Research in the field of craniofacial conditions, as well as broader areas of health, has previously demonstrated the importance of peer support and its lasting effects on feelings of social isolation and wellbeing (e.g. Tiemens et al., 2006; Lauckner and Hutchinson, 2016). For example, Bogart and Hemmesch (2016) found support conferences to increase social comfort and companionship in adults with Moebius Syndrome, while also reducing stigma, anxiety, and depression. The conferences also gave adults a chance to learn more about the psychological support available in the

UK, a feature of care they would not have had access to while growing up, and direct access to multidisciplinary health professionals within an informal setting. The conferences also provided the opportunity for patients and health professionals to come together in a neutral space and learn from one another. This was valued by health professionals who reported these events had been good for their own professional development, and as a reminder of the different experiences of older and younger groups of adults.

One of the main aims of the Cleft Talk panel discussions was to take the informative content offered at the two conferences and to share this information on a much wider scale. The potential of this approach was demonstrated by the geographical reach of the podcasts and video, which far exceeded a UK-based audience. This also suggests there is need for information and psychological support for adults living in other countries around the world. Interestingly, and despite the general perception that podcasts are predominantly favoured by younger listeners, 12% of all listeners were aged 45 or over. Currently, two other podcasts focused on CL/P exist, but these are dedicated to research and a paediatric population respectively. Given the growing popularity of podcasts as a medium and the accessibility of this type of content, podcasts could provide a promising route to information dissemination. This was also favoured by cleft specialist health professionals, who stated that one of the key benefits of the Adult Services Programme was the confidence it gave them knowing that adults would have access to accurate, reliable information once they left the CL/P service. The CL/P teams were also invested in the podcast given they had lent their clinical expertise to each episode.

Initially, the Leaver's Pack was intended only for young people about to leave routine cleft care, and was due to be handed out in clinic. However, with the need to advertise the pack online instead due to COVID-19, older adults also took part in the evaluation survey. The results suggest that the pack may not only be helpful in preparing young people for adulthood, but also for adults of all ages thinking of returning to cleft care. Recent research has identified that adults with CL/P may have difficulties

regaining access to specialist treatment after they have left routine care (Stock et al., 2018; Ardouin et al., 2021). The inclusion of practical information, flowcharts, a map of UK cleft teams, and template letters for GPs and Dentists appear to have provided adults with tangible resources and authoritative support when seeking a referral, and have boosted adults' confidence to do so. Further, although some participants stated the Leaver's Pack was not something they currently require, they could see themselves using it in the future. Health Professionals could also see the benefit of the Leaver's Pack, commenting that it was something which validated adults' experiences, as well as providing them with the means to re-engage with the CL/P service in later life. One health professional reflected on how the programme had assisted patients to receive the care they were entitled to, without needing to pay for private treatment. Providing all adults affected by CL/P in the UK with access to the Leaver's Pack should continue to progress patient and health professional knowledge of adult entitlement to NHS care.

Benefits and Limitations

The CLAPA Adult Services Programme sought to develop and deliver a variety of new interventions, based on need. While many health-related charitable organisations introduce interventions in response to a perceived need, such organisations seldom have the time, expertise or resources to evaluate the efficacy of their interventions (Norman et al., 2015). Dedicated research funding and partnership with (*University*) allowed for the development of interventions based on scientific evidence and the pragmatic evaluation of the utility of these interventions. Further, the interventions were directed by the community's feedback from the outset, creating a sense of collective ownership of the project.

The intention of the project to deliver multimodal interventions appeared to increase its overall reach. For example, a considerable proportion of participating UK adults were engaging with CLAPA for the first time, while others were accessing the programme content internationally. The ability for people to listen or watch panel discussions at a time and place of their choosing seems pivotal to its success.

Listening to a podcast or watching a video could be considered a less anxiety-provoking way of obtaining information when compared to attending an event in person, particularly given that levels of social anxiety are raised in the CL/P population (Berk et al., 2001; Ardouin et al., 2020). Further, it is likely that a significant group of people who would not ordinarily have the time, resources, or capacity to attend an in-person event would find the podcasts and videos more accessible. Meeting members of the CLAPA team, UK cleft teams, and other members of the cleft community in a virtual setting, may also encourage people to engage at a face-to-face setting in the future should the opportunity arise. However, while online forums can offer support to those affected by CL/P (Stock et al., 2018), and while COVID-19 restrictions may impact the way future events are run, the benefits of in-person events should not be overlooked.

One limitation of this exploratory evaluation is the difficulty of monitoring the reach of interventions delivered online. For example, the Cleft Talk panel discussions were advertised across various social media platforms, via e-newsletters, and word of mouth. Such online engagements are difficult to track and measure in a meaningful way. Similarly, episodes were made available through different streaming services. While this maximises reach, the statistics that can be publicly accessed vary between services, making them difficult to collate and compare. For the purpose of the current paper, only Spotify data could be reliably presented. Given the wide variety of podcast material available and the relatively specialist focus of Cleft Talk, it is difficult to compare the popularity of our podcast with that of others. Additionally, it is not possible to track the true number of people who watched or listened to a podcast, since 'one' stream could have been viewed by an entire family, a school group, or a group of clinical trainees. As an example, the Cleft Talk panel discussions have recently been used as recommended 'reading' in clinical education programmes in both the UK and in New Zealand, recognising the value of providing learning materials in multiple modalities that are effective for today's students.

A further challenge is that adults with CL/P are a heterogeneous group with markedly varied treatment pathways and experiences, and therefore have different needs and levels of engagement. Furthermore, adults present with a variety of cleft types, and those with isolated cleft palate are noticeably less likely to engage in CLAPA's services generally (CLAPA, 2018), despite being the largest proportion of people affected by the condition. Further consideration needs to be given to how to best engage groups that are typically less likely to interact with research and intervention, and to ensure such activities are appealing. Indeed, adults with CL/P are a difficult group to reach more generally, given their anticipated lack of engagement with both hospital and community CL/P services since they were discharged. Nonetheless, the interventions designed as part of the CLAPA Adult Services Programme are an example of support which bridges the gap between previous practice (whereby UK CL/P services were disjointed and incomprehensive) and current practice (which is centralised and holistic), and CLAPA will continue to work toward services which are accessible and relevant to all adults with CL/P.

Conclusions:

Research has long demonstrated the need for ongoing support for adults affected by CL/P, yet few interventions exist. The exploratory evaluation of the CLAPA Adult Services Programme demonstrates the value of peer and community-led interventions, in combination with ongoing access to specialist CL/P medical care in later life. The multimodal information and support mechanisms introduced by the CLAPA Adult Services Programme has provided a starting point and has demonstrated acceptance by a wide range of stakeholders. There is scope and potential for similar initiatives to be developed internationally, and for individuals and families with related craniofacial conditions. Charities and not-for-profit organisations are encouraged to routinely evaluate the efficacy of their interventions wherever possible to create a stronger evidence-base for their valuable work.

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Table 1: Contents of the CLAPA Leaver's Pack for Adults with CL/P

Item	Information contained
Leaver's Pack Folder	<ul style="list-style-type: none">• CLAPA's contact details and social media info (inside left cover)• QR code to access relevant online information via the CLAPA website (inside right cover)• A map showing the locations and names of the UK Cleft Teams (back cover)
Introduction Sheet	<ul style="list-style-type: none">• An introduction to the Leaver's Pack, including who it is for and how it was produced• A table of contents of the pack
Cleft Talk Panel Discussions Leaflet	<ul style="list-style-type: none">• An introduction to the Cleft Talk Panel Discussions• A list of podcast/video episodes and how to access them
Cleft Team Contact Information Sheet	<ul style="list-style-type: none">• A map showing the locations of the UK Cleft Teams• Names and contact details of the UK Cleft Teams
Adult Returner Referral Pathway	<ul style="list-style-type: none">• A flowchart outlining the process of how to return to the CL/P service for treatment or support in later life• A detailed explanation of each stage of the process, including details of potential barriers to referral and how to resolve these issues if they occur
Advice for GPs and GDPs	<ul style="list-style-type: none">• A single page A4 letter printed on a CLAPA letterhead addressed to GPs and GDPs outlining the process for making a referral to a UK Cleft Team• Links to the latest online referral eligibility criteria
CLAPA Peer & Parent Support Service	<ul style="list-style-type: none">• An outline of CLAPA's peer and parent support service, which links individuals and families affected by CL/P with others with lived experience• Information on how to access the service and what to expect
FAQs Booklet	<ul style="list-style-type: none">• A comprehensive booklet informed by the Roadshow and Survey findings, and current literature, and designed in collaboration with the Psychology CEN. The booklet contains detailed

	<p>information and guidance on the issues that may occur in adulthood, in addition to signposting to relevant sources of further support. Topics include:</p> <ul style="list-style-type: none">○ Accessing UK Cleft Teams○ Psychological Services○ Mental Health and Wellbeing○ Considering Surgery & Recovery○ Speech and Hearing○ Dental and Orthodontics○ Private Treatment○ Genetics○ Bullying and Discrimination○ Additional Resources
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Footnote

CEN – Clinical Excellence Network

CLAPA – Cleft Lip and Palate Association

GP – General Practitioner

GDP – General Dental Practitioner

UK – United Kingdom

Table 2: Cleft Talk Panel Discussion Episode Detail

Episode Title & Name	Release Date	Format	Panellists
Improving self-esteem and self-confidence	June 2019	Podcast & Video	<ul style="list-style-type: none"> • Cleft Team Psychologist • Adult born with a cleft* • CLAPA Adult Services Manager* • CLAPA Adult Services Officer
An overview of genetics and decision making about having children	July 2019	Podcast & Video	<ul style="list-style-type: none"> • Cleft Team Psychologist • Cleft Team Geneticist • CLAPA Adult Services Manager* • CLAPA Adult Services Officer
Relationships – Friendships and Romantic Relationships	August 2019	Podcast & Video	<ul style="list-style-type: none"> • Cleft Research Psychologist • Cleft Team Psychologist • Senior Research Fellow • CLAPA Adult Services Manager* • CLAPA Adult Services Officer
Treatment Decision Making	September 2019	Podcast & Video	<ul style="list-style-type: none"> • Cleft Surgeon • Cleft Team Psychologist • CLAPA Adult Services Manager* • CLAPA Adult Services Officer
Kissing, Sex and Intimacy	October 2019	Podcast & Video	<ul style="list-style-type: none"> • Cleft Team Psychologist • Visible Difference Research Psychologist • CLAPA Adult Services Manager* • CLAPA Adult Services Officer
Jaw Surgery – should I get it done? What can I expect if I do?	November 2019	Podcast & Video	<ul style="list-style-type: none"> • Cleft Surgeon • Cleft Team Orthodontist

			<ul style="list-style-type: none"> • Cleft Team Psychologist • Adult born with a cleft* • CLAPA Adult Services Manager* • CLAPA Adult Services Officer
Christmas Special: The Best of 2019	December 2019	Podcast & Video	<ul style="list-style-type: none"> • CLAPA Adult Services Manager* • CLAPA Adult Services Officer
Imposter Syndrome: Life with “just” a Cleft Palate	March 2020	Podcast	<ul style="list-style-type: none"> • Cleft Team Psychologist • Adult born with a cleft* • CLAPA Adult Services Manager* • CLAPA Adult Services Officer
Teething Issues: All you need to know about dentistry	April 2020	Podcast	<ul style="list-style-type: none"> • Cleft Team Restorative Dentist • General Dental Practitioner • Adult born with a cleft* • CLAPA Communications Officer • CLAPA Adult Services Officer
Q&A on Emotional Wellbeing Paper (Ardouin et al., 2020)	May 2020	Podcast	<ul style="list-style-type: none"> • CLAPA Communications Officer • CLAPA Adult Services Manager*
Q&A on Physical Health Paper (Ardouin et al., 2021a)	August 2020	Podcast	<ul style="list-style-type: none"> • CLAPA Communications Officer • CLAPA Adult Services Manager*
Cleft & COVID-19 Special	September 2020	Podcast	<ul style="list-style-type: none"> • CLAPA Adult Services Manager* • CLAPA Adult Services Officer
Managing Bullying & Discrimination	October 2020	Podcast	<ul style="list-style-type: none"> • CLAPA Adult Services Manager* • CLAPA Adult Services Officer

Succeeding in the Workplace	November 2020	Podcast	<ul style="list-style-type: none"> • Adult born with a cleft* • Cleft Team Speech Language Therapist • Cleft Team Psychologist • CLAPA Adult Services Manager* • CLAPA Adult Services Officer
Christmas Special / Season Finale	December 2020	Podcast	<ul style="list-style-type: none"> • Cleft Research Psychologist • CLAPA England and Wales Manager • CLAPA Adult Services Manager* • CLAPA Adult Services Officer

* - Has lived experience of cleft

Table 3: Outcomes of the CLAPA Adult Services Programme According to Multidisciplinary Health Professionals

Outcome	Exemplar Quote(s)
Benefits for Adults with CL/P	
Adults with CL/P have been given a platform to express their unique needs	<p>“I believe [the Adult Services Programme] has given [adults with CL/P] a voice”</p> <p>“The [Adult Services Programme] has championed the voices [of adults with CL/P].”</p>
Adults with CL/P have access to accurate information	<p>“The [Adult Services Programme] has allowed adults with CL/P to have much easier and wider access to information”.</p> <p>“The fact that adults with CL/P can be directed to a key reference place is invaluable... Having a central place where they can ask their questions and receive accurate/informed answers is key.”</p>
Adults with CL/P feel more empowered	<p>“Adults feel genuinely cared for and they feel more in control of their treatment... It also allows some adults closure in their CL/P pathway.”</p> <p>“The Adult Services Programme has provided much needed recognition for adults with a history of CL/P. Prior to accessing or being made aware of this project, older adults expressed feeling forgotten about.”</p> <p>"The [Adult Services Programme] has provided an invaluable forum to help adults feel entitled to/worthy of follow-up care.”</p>
Adults with CL/P are re-engaging with the specialist CL/P service	<p>“[The Adult Services Programme] is validating adults’ experiences, and encouraging and helping them to re-engage/seek re-referrals back into the CL/P service.”</p> <p>“The support and advice provided has meant that a lot of adults who had [sought private treatment] or given up on some aspect of their care have successfully returned to the specialist pathway and received appropriate care.”</p>
Benefits for the Health Service	

<p>The NHS has access to greater information regarding long-term outcomes in CL/P.</p>	<p>“It has provided helpful insight into the experiences of adults born with CL/P and will be valuable in ensuring NHS services are able to continue to provide person-centred care.”</p> <p>“This project has helped develop understanding of the needs of adults, especially those who last accessed CL/P care many years ago, and how we can build our services around meeting those needs.”</p>
<p>Opportunities for health professionals and adults with CL/P to learn from one another</p>	<p>“I had the privilege of attending a workshop carried out as part of the Adult Services Programme and this highlighted to me that the experience of care that older adults had is very different to what we hope patients experience today.”</p> <p>“Very good initiative, I enjoyed being able to lend support in partnership with CLAPA. Delivering a presentation at the event was a chance to do extra reading, develop my skills, and a networking opportunity.”</p>
<p>Community-based interventions can reduce the need for formal NHS support</p>	<p>“Adult services are generally limited within the NHS, especially access to psychology... The [Adult Services Programme] provides another way to get treatment or care, and in fact in some cases can obviate the need for that care.”</p>
<p>The interventions developed provide an important adjunct to the services offered by NHS CL/P teams</p>	<p>“The Adult Services Programme has been a very important addition to the services already provided by the NHS. It has helped to raise awareness of the regional specialist services and how to access them...and has provided a supportive space for adults to consider whether they might like to explore further input from the CL/P team.”</p> <p>“The Adult Services Programme provided the opportunity [for adults with CL/P] to develop peer support networks separate from the “medical” space.”</p> <p>“The Adult Services Programme provided the important ability to be able to speak to people outside of the clinic setting, and for information to be accessible to people.”</p>

