**Treatment Experiences Q & A Transcript**

**Recorded 14th June 2021 with Kate Flanagan, CLAPA’s Communications Officer, and Kenny Ardouin, CLAPA’s Adult Services Manager**

**Thank you to CLAPA volunteer, Ruairidh, for creating this transcript.**

Kate - Hello everyone. Thank you so much for tuning in and joining us for a live Q & A on treatment experiences this evening. For the next hour we'll be talking about some new research on treatment experiences. Sorry, I was getting a bit of a technical issue, I could hear myself being spoken back to so I'll just start that sentence again.

So for the next hour we'll be talking about some new research on treatment experiences in adults who were born with a cleft, and we'll be going through what this means for the CLAPA community and how cleft services can be improved in the future. We'll make sure there's time for questions later on, so if you do have a question or a comment feel free to write them in the live comments section on Facebook and we'll get to that later.

Before we get started we'll briefly introduce ourselves. So my name's Kate and I'm the Communications Officer at CLAPA. Kenny, would you like to introduce yourself?

Kenny - Yes, I'm Kenny and I'm the Adult Services Manager at CLAPA.

Kate - Great, so let's get on to the questions. So, what was the motivation for looking at treatment experiences in adults born with a cleft?

Kenny - Yeah a great question Kate. So we know that cleft affects a lot of areas of life, right across the lifespan - for children, families, young people and adults. We also know that in those earlier years there's a lot of necessary treatment that your parents will consent to on your behalf. So there's actually not a lot of decision making involved, or certainly not on your part anyway. However, as we get older there are treatment options and opportunities that we have to weigh up the costs and benefits of for ourselves.

So we were very interested in what people's views were of treatment once they reached adulthood; to understand the things that influence how people view future treatment and how keen or not keen they were to have future treatment, as well as some types of treatment. For example, how people viewed a surgery or dental treatment (which is quite invasive) could be quite different to how they felt about having speech therapy, for example.

Kate - Yeah, thank you for the introduction. So the research paper is based on the results from CLAPA's 2018 whole of life survey. Can you, sort of, briefly tell us a bit about the survey and the topics included? As well as how the results were collected?

Kenny - Yeah certainly. Those of you who have watched all of these in the series will be getting pretty used to this by now. But I'm sure some of you who are watching probably remember taking part in our survey. And if you did thank you very much, because none of this would be possible if it wasn't for the 250+ people who gave up their time to complete what was a very comprehensive survey.

The survey consisted of over 200 questions and we called it the Whole of Life Survey. It contained 13 different sections where we asked different questions related to different topics. So we asked the obvious stuff: what treatment you had; how you found that; whether you would go back for further treatment; what your experiences with the surgeons/dentists/orthodontists/speech language therapists etc were like. But we also asked some other things where the connection to cleft might not be immediately obvious. So we asked about your emotional well-being; your educational experiences; your work experiences; whether you'd experienced bullying and discrimination for example; as well as your relationships with friends/family/romantic relationships and attitudes towards having children.

So people had a choice as to whether they completed the survey online or used the paper booklet. Most people chose to complete it online, I guess it was a bit quicker and easier. We ended up publishing four papers on the findings from the survey on the topics of emotional well-being, physical health, interpersonal relationships and finally treatment experiences. And we've done Q and A's on all of them as well, so this is Q & A 4 of 4.

Kate - Yeah and it's good to be back again for another one. Hi if you've tuned in just now, feel free to write any questions or comments in the live comments section and we'll get to them later. Now we're going to delve into the research a little bit. So it was great to see that most people reported being happy with their surgical experiences. Were you quite surprised by this finding?

Kenny - Yeah I was pleasantly surprised by this to be honest. Obviously this is a good outcome and it's the one that we want for everybody. It's a pretty heartbreaking situation when you flip that, where someone goes through all the ordeal of a surgery and isn't happy with the outcome. So it's great that for most people that situation was avoided. And I think that’s not only testament obviously to surgical skill, but actually more importantly it’s testament to good communication between cleft teams and patients, where people end up being on the same page about what surgery or other treatments can realistically achieve, which I know is something that the cleft team psychologists work hard to achieve. Of course we have to acknowledge that there were people who completed the survey who weren't entirely satisfied with their surgical outcomes, and we need to take their experiences on board and see if there are any lessons that need to be learned from that to avoid that situation happening to other people in the future. Because that is really what we're seeking to avoid, because that's not a good outcome where someone's gone through a surgery only to feel that it wasn't worth it for them.

Kate - Yeah definitely. Moving on to another element of the research: what are some possible reasons why lots of adults who responded to the survey had concerns about visiting a dentist, and what can be done to alleviate these concerns?

Kenny - Sure, I think you just broke up a little bit there Kate. But I think what you were saying was concerns about visiting the dentist and what are some possible reasons for that? And I think for a lot of the same reasons actually that most adults and people don't like visiting the dentist, which is a fear of pain and anxiety, or worry that the dentist might not have experience. And specifically with clefts for our group, you know, people are wanting to find dentists that understand what cleft is all about and understand that someone's mouth might hurt more than that of a typical patient. Of course past traumatic experiences come into play. If you've gone to the dentist in the past and you've had a bad or a painful experience, of course that's going to make you a bit more reluctant to go in the future.

So these are all very understandable concerns, but of course we have to remember that by not going to the dentist - that's not the answer. As this will only lead to things becoming worse and then it becomes a vicious cycle, where what should be a routine appointment can become very painful if you've left it for a long time. Fortunately, most people who completed the survey had seen a dentist reasonably, you know, recently in the period before they filled out the survey. But there were some people who hadn't seen a dentist in a long time, in some cases five or ten years or more, which obviously is much too long for the cleft population in particular. We need to be seeing the dentist regularly, you know, every six months to a year sort of thing. So rather than avoiding the dentist, it's best to talk to your dentist about these concerns.

Dentists are very used to people being anxious about seeing them, and most dentists are very good at dealing with that. So if you don't currently have a dentist and are having trouble finding one that you feel is suitable and understands cleft, then it's probably worth talking to your cleft team about this. The dentist on your cleft team may have suggestions of someone who you can see. But also your cleft team psychologist may be able to work with you to make the idea of visiting the dentist less of a frightening one for you.

The other barrier that we have to mention, and it actually was the largest one that people reported in the survey, is cost. It’s worth pointing out that any cleft related dental treatment is freely available through the cleft team. Unfortunately we've heard stories from people who completed the survey that let us know they'd ended up paying thousands of pounds for treatment through private dentists that actually would have been free on the NHS. And we obviously want to avoid that and to help you to avoid that. So if in doubt, talk to your cleft team first before getting any private treatment done. So you should only need to pay for the same things that someone without a cleft would have to pay for - such as a checkup itself if you're in England, in other parts of the UK that's free, and any treatment that's not related specifically to cleft. So for example, chances are most things related to your upper teeth will in some way be related to your cleft, but things that are related to your bottom teeth are less likely to be related to your cleft. So if you need a filling on a bottom tooth you can probably realistically expect to pay for that. But if you're needing some sort of denture or dental bridge or something, because you're missing top teeth as a result of a cleft, that's far more likely to be something that the NHS cleft teams will do for you and that would be free of charge.

Kate - OK, thank you. And maybe it’s worth saying as well, a lot of what Kenny's just been saying is detailed on our website if you want to refer back to it. So if you go to clapa.com/treatment/adults and I'll add the link in the live comment section.

Kenny - We’ve also got our cleft talk podcast specifically on this topic, an episode called teething issues, episode nine I think it is. So if you go clapa.com/clefttalk or search for cleft talk on Spotify, we have a whole episode where we delve into a lot more detail on this very topic.

Kate - Yeah, so definitely worth checking out, and I'll add the links in a second into the comment section. Another question now: so common thoughts, feelings and concerns around…

Kenny - Sorry Kate, you just broke up on us there, please could you repeat the question?

Kate - Sorry, my internet is not doing well today. Would you be able to talk us through adults' common thoughts, feelings and concerns around further treatment and surgery?

Kenny - Sure. There are a lot of things that people are mulling over obviously when it comes to further treatment. First of all, like I was mentioning before, there's that cost benefit analysis. For example, having a treatment or surgery may achieve one thing, but what are the risks and side effects associated with it? Some side effects may be common and relatively minor, while others may be rarer but more severe. So people need to give consideration to these and discuss their individual circumstances with their cleft team, including other factors that make you more or less likely to experience certain side effects. For example, generally speaking with any medical treatment the younger that you are, the quicker you're going to bounce back from it; and generally the fewer complications that you would expect to experience.

There's obviously also the question of whether the treatment is going to achieve what you hope it will. And that sounds obvious but actually is something really important to to work through and make sure that what you expect the treatment will provide matches what the cleft team realistically think it can achieve for you. So for example, a rhinoplasty surgery will alter the shape of your nose. But no one can guarantee that it will give you more confidence, which I think is often the reason that people go into that treatment - hoping for a higher sense of confidence and self-esteem. But actually the only thing that the treatment can be guaranteed to do is change the shape of your nose. So if the goal of the surgery is to change the shape of your nose, then great. But if you were wanting it to give you more confidence, then that's obviously a discussion you need to have with your psychologist too, because there are other strategies that probably should be used either before or alongside that treatment to enable that.

Then of course people also need to think, particularly when it comes to making the decision about treatment in adulthood, what it means for them right now in their daily life. So you may have decided that you definitely want to go ahead with a treatment, but you want the timing to not interfere with work or university or child care commitments. And some procedures can impact on your daily routine for six weeks or more. So it's important to think about how you'll manage during that time. Do you have family, friends or a partner who can help you out with things? Do you need to have a conversation with your workplace or your university to get some sort of special support? Can someone prepare you suitable meals? Because of course, often you'll be on a slightly different diet to what you're used to. It can take a bit more preparation for those meals and you might just feel pretty knackered yourself. So having somebody who can help with that could be really really useful, you know. Or can you get something delivered through Ubereats or something? So just having a think about all those sorts of things that normally are part of your everyday life that you don't give a second thought to, that will become a bit harder for a period and require a bit more planning. So all those logistical things.

Whereas for other treatments this may be much more straightforward. Maybe for a dental treatment it can be done in an afternoon. You can be back at work the next day. Or maybe if you're seeing psychology or speech therapy, it's an hour a fortnight out of your routine, so much less disruptive.

Kate - OK, thank you for talking us through that. A high proportion of people who responded to the survey, that was 41 percent of people, said they weren't aware that they were eligible to receive cleft specific treatment in adulthood under the NHS. Why do you think this is and what can be done to change this?

Kenny - Yeah, that was quite high, like you say 41%, but I'm not entirely surprised. For a start, a lot of people who completed our survey grew up before the modern era of cleft care that new families will be used to. And as a result, they most likely have been specifically told that their treatment had finished, and that they weren't entitled to anything further. Then of course the system changed from the early 2000s and care is now available in the UK at any age, meaning that adults are entitled to return to cleft care, even if they've never actually seen a cleft team before and even if they've been told before that they weren't eligible for anything. So it's understandable that a lot of people haven't got the message or have been given mixed messages, but it's not really good enough.

So we want everyone to know that they are entitled to return for cleft care at any age. We've been doing our best to get the message out there including by generating our leavers pack, which is designed to be given to all adults who are born with a cleft to explain to them the material options that are available at any age, as well as our information that we've been putting out into the community via the cleft talk podcast, our adults conferences and on our website and social media. In addition to that, we've also been working hard to make sure that health professionals fully understand this too, including generating information for GPs and general dental practitioners to understand not only where they refer an adult to, where they're physically sending them to, but also the fact that adults are entitled to be referred. I think there's still a lot of GPs and general dentists who don't understand that any better than some patients do, just because they're not doing it all the time. So we've created resources to help with that, including in our leaders pack where we actually give you a letter that you can take to your GP or your dentist which outlines exactly what they need to know, where they need to go in their computer system, what they need to do to process a referral for you.

Kate - Yeah, is there any sort of timeline on the leavers pack for when that might be available?

Kenny - Yeah, I mean it's pretty imminent. So as you know, Kate, you've seen the various bits and pieces of it come into the office in the last few days, it's been a huge work in progress. And again, thank you to everybody who was involved in the trial last year. We had a pilot of it where people were able to sign up online for a trial copy, and the feedback that you all gave us during that trial has been really helpful to put into the final version. And I thought the trial one looked good, but the final version is just so much better. So thank you for the feedback that you've all given to enable that to happen. So it's just the case really, as you can imagine and as Kate knows first hand, it takes a lot of work to put a lot of bits of paper together into a folder when you've got to do that, you know, a thousand times over. So it's really a case now of how fast our team can put that together and get them sent out.

We do have some orders from cleft teams which we're prioritizing in this kind of first batch of them that we've ordered, so you may be able to very soon ask for one through your cleft team. But then we will also move to a general rollout where you'll be able to request your own copy online, which would be very important for people who haven't engaged with a cleft team before to be able to get them.

Also in the pipeline, although there's no time frame on it, is an online version of the pack. so, the idea being you can go to a website that'd be quite interactive with you: so you put in what your concerns are and it will hopefully help direct you to the right piece of information. Something like that takes a lot of time to put together, so our focus now is on getting the physical pack out there. But yeah, hopefully it'll not be too long before you can order those online. And I would really encourage you to, because they're really cool for anyone who's leaving the cleft service.

I might just put a caveat on that because I know a lot of people watch these Q and A's who are not adults with cleft who might be earlier in the journey, so families and things like that. And thank you very much for joining us, it's always great to have you with us and I think there's a lot of applicability of the things we discussed. But I would just ask you guys to hold off on ordering a leavers pack because we're kind of foreseeing that we'll be inundated and that the idea will very much be that you will receive one at the appropriate point in your cleft care.

Kate - Yeah it's very exciting, it's such a fantastic resource to have. Going back to the research, are there any findings which you think would benefit from future research?

Kenny - Yeah definitely, I think like all research there's always scope to do more. I think one of the key things that we do see/that we're starting to see in our research is the difference between younger adults who have accessed cleft treatment more recently and older adults who accessed treatment a long time ago, when treatment was much more limited. Obviously there's a lot of individual variation within that but generally there seems to be some differences in the experiences of those two groups. But it is very hard in our study to determine the difference in experiences between the groups other than to talk in very general terms.

There's generally a trend if you had your treatment more recently you will generally report that you are happier with it, that you'd have more access to treatment and that you felt less need for follow-up treatment, and you might have had less anxiety or concerns about future treatment. Whereas the older group typically have had less treatment, have had a lot more misinformation, have some unresolved health care needs, but unfortunately also may feel very reluctant to re-engage because either they've been told they can't or they've had a lot of past trauma, pain and bad experiences that they understandably don't want to repeat.

So there's been only limited studies looking at the experiences of older adults with cleft, in fact I'm only aware of one study that specifically looks at that. And it does happen to be a UK study done by our friends at the Center for Appearance Research, but it was done with quite a small group. So it would be really good to kind of feel that out a bit more and get a bit more information from the older adults to understand their experiences. So I think it would be very valuable for someone to do a larger study specifically looking at older adults.

Kate - Great, thank you. How can this paper be a useful tool for health practitioners to improve care for adults born with a cleft lip and or palate?

Kenny - Yeah, I mean I would certainly encourage the health professionals to have a read of the paper. I think it is a really useful paper to understand how past treatment experiences impact on people's attitude for further treatment. Also I think any paper that examines treatment experiences is very poignant to the people who are delivering that treatment, and realizing of course that we don't do anything in healthcare in a silo that, you know… Yes someone might come in to some extent as a number with their NHS number, but they're far more than that - they're a person with a unique set of experiences, goals, ambitions. And we mustn't lose track of that ever when we do any sort of treatment on somebody for any reason. We've got to be cognizant of where it fits in that person's goals and ambitions.

And health professionals get this, I'm probably preaching to the choir there, but I do think it's important for health professionals to understand that there are two distinct groups of adults, that's probably a bit of a new finding. So those who had treatment a long time ago, and those who've had it more recently and therefore they have experienced a very different level of care. The paper reminds health professionals who may be more generalist that adults with cleft are entitled to receive care through the cleft team and to proactively ask and tell adults about this, because adults themselves may not know that information. It also reminds all health professionals working with adults with cleft that they may come to the appointment quite apprehensive or unsure. And therefore, you know, like everything a kind, calm and empathetic demeanor can make the world of difference for patients. And it's just good practice generally to be nice to the people who you're working with.

Kate - Yeah, absolutely. That's actually all the questions that I'd planned to ask, so I'll take a look at the live comment section and see … We've got a few questions. Did I break up again?

Kenny - Yeah, it's strange because we can see you but the audio keeps cutting out. I don't quite know why, it's usually the other way around.

Kate - Sorry everyone. I was just saying: there's a few comments but I think a lot of them might not be necessarily treatment experiences focused. I'll read them out anyway.

So we've got a comment saying, ‘My daughter is waiting for speech therapy. She was born with a microform cleft.’ So I guess to that person it would be to check in with your cleft team?

Kenny - Yeah, I think the first half of that broke up but from what I got there it was that someone was waiting for speech therapy related to a microform cleft?

Kate - Yeah, someone's daughter.

Kenny - Okay, yeah I mean it would be checking in with the cleft team. Particularly given that it’s a microform cleft, generally speaking there's less need for speech therapy specifically related to that if the palate isn't involved. But yeah, definitely discuss individual circumstances with the cleft team. I know that because of covid and things like that there have been some delays on this unfortunately, but make sure that it's very much still on somebody's radar.

Kate - Yeah, so hopefully that helps that comment. Then we've got someone else, again I think this is quite specific but I'll read this out anyway, if you can hear me hopefully. So Laura says, ‘My daughter is due her operation this summer, we've not got a date as of yet but she's already two and a half. It's a submucous cleft, the muscle that closes up against the wall of the throat I believe. She's a redhead like me and I've been told that we tend to take longer to heal. Is that true? Also what other problems have people found they have with a cleft? My daughter is also under the genetics team.’ That's an interesting fact about redheads because I myself am one.

Kenny - No, that's not something I've read in the research. Yeah, I would go back and ask for more information as to where that comes from because it implies some sort of, kind of, something different with the immune system would be my only guess there? And I just don't know enough about the genetics that lead to somebody having red hair and how that predisposes them to other things. It kind of makes some sense in the sense that, you know, we do have different things that give us predispositions to other things, but it's not something I'm particularly aware of, sorry. What was the second half of the question?

Kate - Okay, it’s ‘What other problems have people found they have with a cleft? My daughter is also under the genetics team.’

Kenny - Right, I wonder if that's specifically getting at what other conditions related to… yeah given the question about genetics. And to that, I would probably respond with directing you to one of our panel discussions which is on genetics, which was the second one in our series. So again if you go to clapa.com/clefttalk or look it up on Spotify as well. It kind of goes over some of the more common things that are associated. It’s worth pointing out that for most people cleft is an isolated thing and there's not other things involved. But there are certain things that you might be more at risk of in the future such as the chance of having children with cleft. We do know that once someone in the family has cleft the chances of somebody else having cleft, assuming there's no other conditions, goes up from about 1 in 700 (which is your general population average) to about 1 in 50. So still very low odds in terms of, you know, absolute likelihood, but still quite an increase from the 1 in 700 hundred. So in terms of genetics I would encourage looking there.

If the question is also more around other sorts of things that you might expect alongside cleft, I mean typically, you know, the difficulties with speech can be quite common, difficulties with dentition as well are quite routine. But there's a lot of support and services available which will come up at the appropriate time in your child's life to kind of work through these as and when or if they arise, because they don't for everybody.

I think also at the very start of her question she touched on something that we haven't actually covered a lot in this Q & A, which is the impact of Covid. And it probably is worth talking a little bit about this. This paper is based on the Whole of Life Survey that I was mentioning, which we did in 2018. So this was long before anybody had the word Covid in their vocabulary. But of course it has come to affect everybody's life in so many ways, and that includes cleft care. We know that the NHS has had to have quite different priorities for the last 18 months or so, and so a lot of routine treatment has been deferred, and now we're going to, you know… As we start to come out of the pandemic there is obviously a huge backlog to clear there. And we're not entirely sure at this stage exactly what that will look like and what the time frames around that will be. I know that the cleft teams have been doing a lot of really good work on kind of highlighting the impact of delayed cleft care and doing a lot of lobbying on the cleft community's behalf to ensure that it doesn't kind of fall off the radar.

But I think it's probably reasonable to expect, particularly for adults, that there will be some delays to treatment for a while to come. Adults were already the group that generally got deferred. Even before Covid came along they would have to wait longer than anybody else. And unfortunately I think with Covid we'll probably see that happen again, but on a longer sort of scale. And so, you know, my colleagues at the Center for Appearance Research have been working hard to pre-empt this as well, and those who are a part of the adult's Facebook page will see some of the work that they've been being concerned about, in terms of the impact of Covid. So it will be something that CLAPA and others keep an eye on and we'll keep flying the flag for us as and when issues arise. But yeah, I think it's realistic to expect that things won't be quite perhaps what we were used to for a wee while yet.

Kate - We've actually got a question about Covid specifically. So someone here had Covid actually in October and really struggled with her breathing. She also said that she's struggled before because of her cleft. Are there any specific breathing exercises for anyone with cleft?

Kenny - Yeah, well first of all I'm sorry to hear that you're unwell with Covid - that's pretty nasty. I mean, it's interesting, you know… You raise the concerns generally about breathing, and again unfortunately the line broke up there, but from what I gathered this person had breathing difficulties even before contracting Covid. And this is something that we did find in the survey, and it's not something that there's a lot of previous research on. We spoke about it in more detail in our physical health Q & A that, you know, it does seem that there are issues for some people in the cleft community with breathing that perhaps have gone unaddressed. I wouldn't want to give any medical advice here about strategies for breathing, particularly given you've had Covid. I think that also will change the advice that's given. But I would say definitely raise it with your GP and your cleft team who can refer you to a respiratory physician if required. I think the unique combination of having had breathing difficulties because of cleft, but we also know that there's research that having Covid also impacts or can impact on your breathing longer term. And so I think having some strategies quite specific to that recovery would be quite important.

Kate - Thank you Kenny. Another comment, hopefully the line won't break up but let me know if you can't hear me. Fiona says, ‘For those of us with PRS having treatment in the 1970s and 80s, I've had a lifetime of professionals who either disregard the issues or don't understand them. They don't appear to know how to refer to the cleft team, I've been asking for four years. GDP and GP knowledge is incredibly poor in my experience.’ Did you catch that?

Kenny - Yeah, so I mean that is very disappointing to hear. They are certainly not alone. We found it, but also that older adult study that I was referencing from the Center for Appearance Research from a few years ago found the same thing. And actually, people got quite exasperated with having to explain to every health professional that they were coming into contact with what cleft was and having to tell the story over and over again. I think GP and general dental practitioner knowledge is very hit or miss at the moment, and it is something that we identified quite early on after doing this research, that needs to change. Obviously logistically how you go about that is very difficult,you know.

We're trying to do what we can do in terms of empowering adults with cleft, giving them the resources they need to go to the GP or general dental practitioner, but also encouraging the cleft teams to take this research on our behalf and disseminate it through their professional networks. Because of course they're all part of a professional network. So your cleft team dentist will also be part of, you know, the overarching dental body for the UK and they will go to conferences and things like that perhaps from time to time, so helping spread the word in that way. We've also been involved and CLAPA has been involved for a long time with clinical education where, you know, the next generation of students for different practices and disciplines, so you know speech therapy, orthodontics, dentists, psychologists, often receive some information either from us or through a another guest lecturer on cleft; and that provides the information there at that point.

So there's a lot of hope that the next generation going in has this knowledge and then it kind of filters its way up. But we do acknowledge that there are a lot of practitioners who just don't know a lot about this, and it is frustrating when they don't use the tools that we and others have provided to help find out this information. But I would encourage you if you are going to see the GP or the dentist and you're worried about this, to get in touch with us. You can email us at adults@clapa.com and ask for a copy of our letter for GPs and dentists, because it does make it very clear. And the feedback I've had from people has been that that's been very helpful for them and also for their GP or their general dentist, because it just outlines very clearly what they need to do.

Kate - Thank you Kenny. And just to follow up, she had coronavirus and she's just added that she doesn't know who … her respiratory and said everything they said …

Kenny - sorry can you repeat that?

Kate - So yeah, the lady with coronavirus just followed up with another comment and said that she doesn't know who her cleft team is. But she has been to respiratory and they said everything's okay.

Kenny - Right, I mean it’s difficult to comment obviously on specific cases. But in terms of the cleft team, I mean, certainly worth attending there to get a second opinion, and you can find the information for all the cleft teams on our website. So I tend to find actually, if you just google ‘NHS cleft teams’, the first thing that comes up is our website with all the contact details. Otherwise, get in touch with us - if you let us know which part of the country you're in we can also direct you to the right place.

I'm sorry to hear that you feel that people have been dismissive of your concerns. That is incredibly frustrating. But as I say, particularly and maybe what they've done is they've evaluated the impact of Covid and have decided that's fine, you know, and within normal limits which is good. But then you maybe need someone looking more specifically at the impact of cleft on breathing. Because, I mean we found, and you can hear me talk about it in another Q & A, but we found the rate of asthma for example was three to five times higher in the cleft population than it was the UK average. So, you know, our instinct would tell us there's something in there.

Kate - Yeah and we've got another comment from someone. Her son's dentist makes a point of showing his trainees her son's mouth whenever he visits.

Kenny - Yeah. I mean this is a really interesting point and one that, you know, we have to look at from both sides really. On the one hand yes, you know, trainee dentists don't don't see a lot of cleft and it is important, you know, for all the reasons we were mentioning before that they are exposed to cleft during their clinical training. Because it does now make them more likely to know how to deal with that when they see it in their practice, to know when to refer on. But of course it's got to be done in the context of what you consent to and feel happy with. And it is feedback that I've seen before that people get very fed up of kind of being paraded around, you know, for the purposes of clinical training.

I think any good practitioner should ask your consent for that and obtain that. And do feel free to, you know, to refuse that. That is your right as well. So while I generally encourage people to support that, because clinical education is really important, and for me personally I've kind of figured that people do need that training so for me it's an easy consent, but I also get there are points in your treatment where you just don't feel like that or you're not up to it. And it's okay to refuse it at that point, you know. They will see a few people and I'm sure they will get enough experience from other people.

Kate - And this mum has just clarified and said that the dentist .. that's good ..

Kenny - So sorry that broke up …

Kate - The dentist, yeah, apparently the dentist does ask.

Kenny - Yeah, so that's good, cool, excellent. I mean that's the key one. But also, do feel empowered , you know. This is actually a really key thing while we're talking about treatment experiences in general: you can say no to anything. And I think, you know, don't feel like … The health professionals are not trying to pressure you either. They generally want to present you with the options and hear what you have to say on it, and so while they may have an opinion of what they feel is most appropriate for you, they will ultimately support whatever decision you take and help you to make the best of it.

So don't feel like you ever have to agree to something because you think it's what the health professional wants. At the end of the day, and I can speak to this from being a health professional as well, like, we just want what's best for you. And what's best for you... you are going to know all the other things going on in your life far better than we do, so let's have a conversation. You know, that's what consultations are all about is kind of figuring out, ‘Okay, well here's what we can offer, but actually what's important to you? What are your priorities?’ And if something isn't a problem for you right now, then we're probably not going to suggest a treatment to fix it even if one exists. Because if it's not a problem, the general feeling is, you know, let's not fix something that isn't broken.

Kate - Yeah and I think that might be … I'll just double check the questions that we've had come in. Yeah, so if anyone has anything else to add feel free to write it in. But otherwise I just wanted to mention that as Kenny said earlier, this is the fourth and final Q &A in this series on research. And you'll find previous Q & A's and this video soon on our website at clapa.com/treatment/adults and I'll add the link in the comments section now.

And before we head off we just wanted to highlight that there are a number of other research opportunities that you can get involved with. They're all listed on our website at clapa.com/news and as one example, there's a great opportunity for children and young people born with a cleft (and that's a cleft palate with or without a cleft lip) and their parents to discuss the outcome measures used in speech and language therapy at Great Ormond Street Hospital. So if the child or young person is currently a patient with the GOSH speech and language therapy service they're invited to attend engagement sessions in July and the team would love to hear from you. So I can put some information about signing up in the live comments now. Kenny I don't know if there's anything else you wanted to add or talk about before we wrap up?

Kenny - Yeah I mean, just to encourage you to participate in research because it is really helpful and it's effectively helping us to help you. And so I understand that that study that you were discussing there, I don't have all the details as I only learnt about it earlier today, but it's looking at patient reported outcome measures. And they're really important because that is your way of making sure that clinicians and patients are on the same page as to what, you know, treatment can achieve, and in the context of treatment on younger children and also a parent reported outcome measure, because it makes sure that, you know, children, parents and clinicians are all on the same page. Because I think, you know, often that's where one of the big discrepancies can come up and that's what can lead to that situation that we were mentioning before about, you know, where somebody went for a treatment and perhaps wasn't happy with the outcome. Often it's as a result of actually they're not all being clear about what treatment can achieve. So those patient reported outcome measures are a way that really help to make sure that everyone's on the same page.

So if you are eligible for that study I would encourage you to participate. But also other studies, you know, that you see advertised. Obviously this one and these four Q & A's were quite unique in the sense that, you know, as far as I'm aware it's the first piece of research that CLAPA have commissioned ourselves and kind of taken the lead on. But there are a lot of other things going on with, you know, the Center for Appearance Research and the Cleft Collective as well, which many of you will have been involved with. So, you know, thank you to everyone who does participate in research because it is having a big difference. And it's quite an exciting time for cleft because I think it's finally actually getting a lot of attention that perhaps is long overdue. And I think you know the fact that so many people willingly give so much of their time to participate in the research indicates to me that actually this is something that people feel is really important and really valuable.

Kate - Yeah for sure, yeah and it's a great way to make a difference to the future of cleft care as Kenny was essentially just saying. We've also had a comment just come in from someone saying …

Kenny - Sorry, can you repeat that again?

Kate - Of course. ‘Has the incidence of PTSD or complex PTSD been investigated in adults who were born with a cleft?’

Kenny - Yeah, what was the question? What is the incidence? or is it, has the incidence been investigated?

Kate - Has the incidence been investigated.

Kenny - Yeah, a really good question. Not specifically with PTSD because it's quite hard to measure if somebody hasn't had a formal diagnosis. But what we did do in the adult survey was we took… we had some standardized measures in there, including measures of depression and anxiety so that they were actually … we asked questions that were very similar to ones that you might get asked to fill out if anyone's ever done something like talking therapies or gone to see a counselor or psychologist, you probably recognize some of the questions that we asked because they give information about whether someone has had depressive or anxious thoughts. We also explicitly asked you, ‘Have you received a diagnosis of depression or anxiety or another mental health condition?’

What we found was that around about 40 percent of adults had, which is quite a bit higher than the general population. So there does seem to be evidence, and this is also backed up by international evidence of the cleft population - other research has found the same thing, that adults with a cleft are more likely to have been reported as having depression or anxiety.

Now on the surface of it that sounds quite concerning, but there are a couple of things to bear in mind. So first of all, I mean I think it's fair, I do think it stands to reason that, you know, the experiences that someone goes through with a cleft would make you more likely to experience depression or anxiety. That's unfortunate and it's not something we would hope to have found, but I think most people can see that's probably not entirely surprising given the stuff that people have to go through at times.

But I do think that perhaps the figure that we found and the difference, more importantly, the difference between the figure we found and the general population figure, I think that's probably bigger than the reality. And the reason for that, I think probably our figure is reasonably accurate but I think probably the general population figure is under-reported. Because we were only looking at formal diagnosis, as was the general population figure, and so I think what you probably will find is that because all of the cleft population in the UK are seen by a psychologist, they are going to, you know… If there is a mental health condition there, it's going to be picked up because they've been seen routinely by a psychologist.

The general population isn't. So for the general population, to be diagnosed with anxiety or depression it has to get to the point where they take themselves to the doctor about it. Or, you know, or something else happens that causes it to be diagnosed. So I think probably what we're seeing is a lot more of the mild end of the spectrum is being reported and diagnosed which actually probably makes up the bulk of the cases will be mild anxiety and depression rather than more severe. And they're just getting reported more in our population. Whereas I think in the general population, a lot of that gets missed. SoI hope that kind of makes sense. But yeah, specific to PTSD I'm not aware of it, but it would be a valuable thing to explore. And certainly for psychologists working within the cleft team to be aware of.

Kate - Thank you Kenny. I think that's all we've got on the live comments at the moment. So yeah, I guess we'll wrap up now unless there's anything else you wanted to add about the research or anything?

Kenny - No, I think that that's all for now. Thank you very much for tuning in as always, really appreciate the opportunity to come and talk about the research we've done and to feedback to the community who, as I said earlier, was so giving of their time to enable this to happen. So just a big thank you from me.

Kate - Yeah, so thank you very, very much everyone for tuning in and I've been sharing a few different links on the live comments as we've gone on, so hopefully you can find a lot of the things we've been talking about. But if not you can always reach out to us by emailing info@clapa.com and we can send you the relevant links or refer you on to the right places on our website etc. And so yeah, thank you very, very much for joining us and good night from both of us. Thank you.

**Thank you to CLAPA volunteer, Ruairidh, for creating this transcript. If you have any questions about this recording or this research paper, please contact** [**adults@clapa.com**](mailto:adults@clapa.com)**.**