**Interpersonal Relationships Q & A Transcript**

**Recorded 29th March 2021 at 8pm with Kate Flanagan, CLAPA’s Communications Officer, and Kenny Ardouin, CLAPA’s Adult Services Manager**

**Kate:** Hi everyone, thank you so much for tuning in and joining us for our live Q & A on interpersonal relationships this evening. So for the next hour or so we'll be talking about some new research on interpersonal relationships in adults who are born with a cleft, going through what this means for the CLAPA community and how services can be improved in the future. So there'll be time towards the end of the session for us to take some questions from viewers so if you've got a question please feel free to write it in the live comments and we'll try to answer as many as we can later. Before we get started we'll introduce ourselves so I'll start and I'm the Communications Officer at CLAPA so I work on the charity’s social media, graphics, website, newsletters and things like this! So Kenny would you like to introduce yourself?

**Kenny:** Sure thank you Kate so yeah my name's Kenny I'm the Adult Services Manager here at CLAPA and I've been in charge of the adult services project over the last three years including doing the research which I'm really excited to share with you this evening, as well as designing and delivering the services that we put in around that came out of the research as well.

**Kate:** Great thank you Kenny and I think I forgot to say my name as well so I'm Kate the Communications Officer. So let's start with quite an important question and so what was the motivation for researching interpersonal relationships in adults who were born with a cleft?

**Kenny:** Yeah this is a really good question, Obviously we know from previous research done by our partners at the Center for Appearance Research in Bristol, so we've worked very closely with them on this project and they've helped immensely with the research side of things, but they've actually been doing this long before we have and they've found as well as international research across Europe and beyond that interpersonal relationships are a really important topic for people born with a cleft. This isn't rocket science class, we all know that our ability to have good healthy relationships with other people is fundamental to our enjoyment of life and how we view and see the world. We know from the previous research that relationships with family, friends, partners, boyfriends, girlfriends, strangers etc. can all be influenced in both positive and or negative ways by cleft and we wanted to better understand what that was looking like for adults living in the UK in the kind of late 2018 you know 2020 sort of era.

**Kate:** Great thank you for introduction. So the research paper is based on the results from CLAPA's 2018 Whole of Life Survey. Can you tell us a bit about the survey and the topics it included as well as how the results were collected?

**Kenny:** Yeah of course, so some of you who are listening and watching this tomorrow will remember taking part in the survey and if you did first of all a huge thank you because none of this would be possible without the 250 plus people who so generously gave up their time to complete the survey. And it was a very comprehensive survey as well so consisted of over 200 questions and was called the Whole of Life survey and we collected so much information from the survey that we've actually reported across five journal articles, produced four lay summaries and we'll be doing four Q and A's of which this is number three of four. We asked the obvious stuff so what treatment you had, how you found that whether you would go back for further treatment, what your experiences were, what your surgeon your dentist, orthodontist, speech therapist etc. were like. But we also asked some other things that perhaps the connection to cleft may not have been immediately obvious, so we asked you about your emotional well-being, your education experiences, your work experiences, whether you experience bullying and discrimination as well as about your relationships with friends, family, romantic relationships attitudes towards having children, those sorts of things. And people had a choice as to whether they completed the survey online or used a paper booklet, most people chose to complete it online and we had a very good spread of different ages as well so you know people write from kind of early adulthood right up to people in their 60s and 70s completing the survey so we had a real breadth of different people and a reasonably good distribution of men and women. Like it's very typical when you do this sort of survey that you get more women than men which we did find but not terribly so we had a pretty good mix so we're pretty confident that what we found speaks for a reasonable cohort of people who were born with cleft.

**Kate:** Brilliant and so the findings suggest that while adults feel comfortable in their existing friendships, engaging in new friendships is something that many did still find difficult and so many also felt inexperienced when it comes to dating and intimacy. What are some explanations for these feelings?

**Kenny:** Yeah so there's a lot to unpack here so just bear with me as I kind of go through because it really asking two or three questions there, but first of all it was great to see so many people reporting that they're pleased with their friendships. This is what we would hope for, for everybody. It does also make sense that people may still find it difficult to make new friendships. Cleft will be one factor in this which perhaps makes people feel a bit more introverted than maybe they otherwise would have been, but it is important to remember that people would naturally have either been introverted or extroverted regardless of whether they've had a cleft or not and that has some bearing on how you make friendships. I think though the common theme that came through here, was one of being a bit wary by making first impressions and fearing judgment or discrimination because of their appearance or their speech and sadly that can become a bit of a vicious cycle where you fear judgment so you don't approach people and therefore you're perceived as shy and then so people in turn don't approach you so then you do feel like you've been being rejected. So there is a vicious cycle when it comes to dating. You're right many people reported that they found this difficult. I don't actually know that anyone cleft or not finds dating particularly easy but it does definitely seem to be harder if you've got a condition such as cleft. I guess that romantic relationships and dating feels even higher stakes again than friendship, I mean after all you're hoping to find someone who you can be totally your whole self with and so therefore the fear of rejection is even higher when it comes to dating and I guess there's more that somebody might reject you in a kind of dating scenario than they might in a friendship scenario. It is worth bearing in mind that a lot of people, most people, have actively experienced this rejection at a younger age. Perhaps at high school where they may have been on the receiving end of some quite petty behavior and I know I've experienced that myself. Then naturally that impacts on your confidence later on in life. For most people growing up and going through adolescence you know cleft or not they will experience dating at school and you know the casual on again off again relationship development and all this awkward glory. One of the recurring themes we've seen with our cleft population is that they essentially skip that stage in their teens and then they go get straight into dating in their 20s. Now obviously when you're in your teens that rejection and incompatibility is experienced by everyone and generally speaking teenage relationships aren't quite so serious, even though they may very much feel like it at the time, but once you get a bit older these things do feel a bit more serious and so going into dating in your 20s for the first time could feel much more daunting if you don't have those other experiences to kind of put some of that you know rejection and incompatibility into perspective. I guess it can feel a lot more personal than it perhaps should and of course just kind of skipping that teenage phase also led to people reporting being quite sexually inexperienced as they've not experienced sexual intimacy in their teens either which is worth pointing out many people haven't but of course society likes to paint a picture that everyone except you is doing it all the time they're not. So some people also reported being anxious about their body's appearance or how it functions during intimacy and sex and things like kissing as well. Again these are understandable worries but they do get in the way of people being able to enjoy these things and can become a self-fulfilling prophecy if you're worrying about it all the time. Most people agree that, which I think is a really important point to make, that once they reached adulthood, once they got through those awkward teenage years, it is actually the lack of confidence or being shy rather than their appearance or their speech that impacted on their dating and I think that's quite an important distinction to make. It's very much supported by the fact that I've spoken to many partners of people with cleft including my own and they just don't see cleft as a major thing but of course in our own heads it can feel strange to think that other people see past it or don't even see it at all, but they really don't you know. Probably the best piece of advice I could give here even if it does sound a bit of a cliche is to stop comparing yourself to other people. You know it's not helpful, it's not a fair comparison anyway as you know anyone you're comparing yourself to will have their own insecurities that you don't see. The other thing of course in any relationship you know, be it a romantic relationship or you know a friendship or relationship with your family, is communication. In the romantic context if you don't ask generally speaking you don't get, so try not to be afraid of rejection. That’s quite a normal part of dating and it just takes you one step closer to finding someone who likes you as much as you like them and then once you are with a partner hopefully you trust them enough to share any concerns you might have about intimacy or your perceived inexperience. Again if they're the right person for you they will support you with this. On that note a number of people rather concerningly said that they were staying with their partner who was not ideal for them out of the fear of not being able to do any better. I mean I'm sure I don't need to spell out why that's quite problematic and obviously nobody deserves to feel or to be abused or to feel unloved in a relationship. Leaving a difficult relationship can be really hard but the evidence would certainly tell us that it isn't worth sticking out a bad relationship in the hope that it will get better. Sadly they don't tend to and you deserve better than that. Again I reiterate my point the right person for you will always have your back and will support you all the way.

**Kate:** Definitely and I’d just like to say hi again to everyone watching and thank you for joining us. I can see some nice hi's in the comments and just a reminder that if you do want to share anything or ask any questions in the comments, you're really welcome to do that. Feel free and we'll get to as many as we can later. So on to the next question. This paper raises some difficult questions and issues surrounding bullying and discrimination. Would you mind sort of expanding on the findings and implications here?

**Kenny:** Yeah I mean it does make for some sobering reading to realize that so many people experience bullying and discrimination. Sadly you know I'm not particularly surprised by this from kind of doing the work I've been doing for the last few years. You know talking to people it doesn't overly surprise me but it is a shame you know it's something that shouldn't be happening we know the world that we live in has a lot of inequities and inequalities and in recent times we've seen big groups of people who have been you know on the receiving end of bullying and discrimination for a long time and stepping up and saying that things have to change and we've seen that in big ways we've seen big protests we've seen big social movements which is really encouraging. Unfortunately though that momentum isn't quite there in the same yet same way yet for visible difference such as cleft and so in the same way that it is with some of these big other social justice movements the thing that has to change is society's attitudes. Yes there's some things that we can take responsibility for so we can do education and we can provide a lot of support to people who are, you know, the victim to bullying of discrimination. But it does really feel to me like in doing all that we’re being the ambulance at the bottom of the cliff rather than the fence at the top you know and we've got a really good ambulance we've got you know you can go to the cleft team and you can get support from the cleft team psychologist with regard to bullying and discrimination and they're excellent. They deal with us all the time and they know the supports that work and we've got a great peer support service here at CLAPA who can provide support. But I think the elephant in the room here is that we'd all like to see that these things don't happen in the first place and that it's not okay that they do. And so calling people out on bullying behaviors you know making sure your workplace and places where you might volunteer your time support and values diversity in a meaningful way and that means supporting all groups of people not just because one group is trending and has a lot of attention on them right now but supporting all groups of people because that's the right thing to do and that includes disability and difference as well. Another concern that I had when looking through our data was realizing that a number of people didn't believe that they'd been bullied or discriminated against but then they went on to describe things that happen to them which we would definitely identify as discriminatory or abusive so that raised another really important point for me that we need to make sure that people realize that they deserve better and just because something has always been a certain way it doesn't mean that it always should be.

**Kate:** Yeah definitely so on to a slightly different kind of question, the research showed that most people, or 64 percent of people, felt that having genetic testing to know their chance of having a child with a cleft was important and can you just kind of explain a bit about what genetic testing is and roughly how it works?

**Kenny:** Yeah definitely so it's probably important to provide a bit of context actually around why we were asking that question. So we gave people the information and you know when you've been born with a cleft and there is generally then a somewhat genetic component. I'll explain a bit more about that as I give an answer to what genetic testing is but therefore you know, knowing what your likelihood is of passing cleft on could be quite important to people when they get to the point where they're thinking about having children so we did give everyone that that information. So now I'm a speech and language therapist by background so this really isn't my area but fortunately we have got an excellent cleft talk podcast with Margo Whiteford who is a retired geneticist in the Glasgow team and she explains this really well so I would encourage you now if you want to find out more information on this topic go to clap.com forward slash cleft talk and select episode 2 for more information. But to give you a brief overview genetic testing is like I said it's designed to help you understand the probability that your children might be born with a cleft and so we know that no single factor causes cleft rather it is a combination of different things and I've heard it be described like having a glass of marbles you know if you can picture a glass of marbles some are bigger some are smaller and each of these marbles in that glass is either a genetic factor or an environmental factor and your partner will also have their own glass of marbles and then when you have a child you add your two glasses of marbles together into a third glass and that third glass is your child's glass. Now if when you add your marbles together you don't fill the glass then your child doesn't have a cleft but if they do and it tips over the edge then the threshold has been reached and a cleft would occur. So basically when we think about the general population everybody's walking around with some factors for clefts, just some people will have more than others so even people who don't have cleft could actually be you know have a lot of marbles in their glass and be right on the tipping point for developing a cleft if there were another environmental or genetic factor at play. Whereas other people actually might be walking around with very low levels of marbles in their glass and that's something we just don't know about people to look at them because if they don't have a cleft then you know we can either assume it's you do or you don't but actually it's a range of different factors and that's the same with many health conditions. So you know genetic testing will then help you and your partner understand what marbles you each bring to the table. They usually do this by simple blood tests and saliva tests. The counseling side of things is then done with a clinical psychologist and it helps you understand what to do with that information and to make sense of it all because you know knowing your probability is one thing so you know if you've been told you've got a certain probability of having a child be born with a cleft what does that then actually mean for you when it comes to making decisions around having children and they'll help you be better prepared for whatever happens because obviously how you might respond to being told you have a one in four chance of having a child with a cleft could be very different to how you might prepare if you were told you've got a 1 in 50 chance for example. Does that sort of answer that that question?

**Kate:** Yeah very well I think but if that hasn't, if anyone wants to know a bit more then feel free to write a comment in the live comments. So the next question I wanted to ask was, are there any findings which you think would benefit from future research?

**Kenny:** Yeah I mean there are definitely opportunities for further research here. It would be really interesting to see you know how what we found differs across age groups, if there's any differences accounting for gender and that sort of thing. Like I said, we got a really good spread of people across ages and gender and you know different demographic points but generally with kind of 250-ish people it sounds like a lot and it would be a lot if we put them all in a room together but actually it's quite difficult to separate what people said by age or gender and then be left with a large enough group to infer that that's what people who are in their 60s think as opposed to that's what the three people who were male in their 60s for example thought. So it becomes you know harder once you make those numbers smaller so it'd be really interesting you know in a much larger study to see how these things compare and the way to do that may be to have a study that solely focuses on relationships for example, rather than in the context of a much larger study that takes up a lot more of people's time. I would also really like to see an international comparison here as well to see if there are things that are unique to the UK or if this is as common across the board. I think it's probably reasonable to see that we would expect some cultural differences there between perhaps you know the UK and maybe the US might be a bit different and then the far east as well you know and parts of Asia and things where societal attitudes are different again perhaps towards how cleft is viewed and therefore potential kind of you know bullying discrimination behaviors and stigmas that might be around relationships. You know given we're seeing a lot of this in the UK which is generally a pretty accepting country a reasonably tolerant country I think we can imagine that there are places in the world where you know we may be seeing you know an even stronger picture of people reporting that they're they believe or discriminated against or that they feel they can't get what they're after in a relationship that they've got to accept something different so I think it would be really interesting to see a comparison there. I think it would also be really interesting to find out more about people's attitudes towards having children as we really only touched on this given how large the survey already was but I think there's a lot of scope to explore that further. There's a lot of international research on this but to be honest it's mostly from the 70s and 80s and I think you know things have changed generally in the world since then and so I think it's worth revisiting.

**Kate:** Yeah definitely. I'd also just like to come to a question from the comments now someone just asked polite question but is does a cleft count as a disability and actually a few I think a few people have answered this anyway but I just wondered if you might expand on that a little bit?

**Kenny:** Yeah I mean it's a really interesting point because it depends really on how you interpret that. I think in terms of you know technically speaking in the eyes of the law you know the answer would be yes you know there's a lot of things that fall under the kind of disability category and there are certainly times in somebody's life with cleft where you know they need that sort of extra assistance particularly with things like feeding or speech and things like that where compared perhaps to somebody who doesn't have cleft. If there is an element of disability there at least at some point in time usually with cleft that get resolved I know there can be a lot of stigma about using the word so I'm quite careful to use it. I know that it empowers some people and some people choose not to be identified by it I think that's really important that people make that distinction for themselves as to whether they identify as part of the disability community or not. What I will say is that I think you know the word disability clearly is stigmatized and we see that coming through and we know actually that people in there who are in the disability community receive a lot more discrimination than any other group so that you know is a higher proportion of discrimination than you know women experience or people of color experience it's a really high proportion and that that is particularly concerning. But yeah saying technically on a legal level it would be considered a disability I know you know thinking about my own experiences I would say that comes and goes with time like there are definitely times where I feel that cleft has had more of an impact on my life and would be more akin to a disability particularly around the times where you might be having a major surgery and then there are things that you know your peer group can do that you can't do and then I would be more you know likely to I guess classes in the disability category. But then the other times of my life I'm getting on and just kind of living my life without cleft having too much of an impact I'd perhaps be less likely to consider it a disability but that is the case for many things I guess that would be referred to us as disability. So I hope that kind of answers the question I know it's a it can be kind of sensitive topic it is important to point out legally it is because that does also open the avenue for certain funding that people are eligible to apply for as well so it's really important that we give you that information but yeah I would say how you choose to self-identify is probably more important than what a legal framework says in this case.

**Kate:** Okay thank you. Thanks for clearing that up a bit and sharing your personal views as well. So the next question is, 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 well I think this piece of research is a timely reminder of just how complex and multi-faceted cleft is as a condition and how there is much more to cleft treatment than merely treating the physical aspects of cleft and that the emotional and psychosocial side of things needs a lot of attention too and I guess that also kind of gets back at that disability question perhaps if someone is experiencing quite an adverse effect on their emotional well-being. I mean that's definitely, we know that that mental you know ill health is quite disabling for people and so although this largely sits within the domain of clinical psychologists I hope that it serves as a reminder to all health professionals to prompt and ask a few questions to make sure that we don't miss things. You know like many aspects of cleft care I think this paper goes to show the value of early intervention as well. You know if the right supports are given at an early age perhaps it lessens the need for some of the support later on in life. It's probably a really important distinction actually that I always take a bit of time now to make for parents who might be watching this your parents of young children is that actually what your child has access to now and the pathway that they'll experience is quite different to a lot of people who completed our survey because it's relatively new you know in the last 20 years or so the clinical psychologists have formed a part of cleft teams in the UK and it's quite unique to the UK as well we don't see that in a lot of other countries around the world yet even though we should. So you know a lot of these messages have been heard loud and clear and understood and now there are early interventions that happen like everybody who's born today with a cleft in the UK will have access to clinical psychology at key stages of their life growing up so some of these concerns about relationships perhaps can be addressed in that those teenage years rather than when they become a problem in somebody's twenties or thirties. We have to recognize though you know for CLAPA as an organization and particularly in the context of the adult services project which is where we've done this research that there is a very large group of people out there who have not had access to the same treatment and kind of wrap around support that is available now. And like in terms of sheer numbers so we've got around about 90 000 people in the UK who are born with a cleft 72 000 of those are over the age of 18 so by number that is the largest group of people out there. Now we did generally find you know for younger adults they reported a higher level of satisfaction with things than older adults and what we have to bear in mind is that a lot of older adults not only did they not have access to psychology but they may not have had a lot of access to any of the other allied health services so speech therapy, orthodontists those sorts of things. They may have just basically had a primary cleft repair surgery and not have had a lot of support since. They may have been told as well that there was nothing more that they can have access to which we now know is not the case and I would encourage any adults who might feel that they're in that category and that have some concerns that have been told years ago that there's nothing more that can be done to get in touch with your GP or get in touch with your local cleft team and find that the details on our website to get back in touch with them because you are eligible for treatment in the UK at any age which is fantastic but I don't think people necessarily are aware of that. So you know when we're going through this we also have to identify not only the things that you know can be done at an early age or the things that have already been done which you know we're seeing the benefit of but also recognizing that there is a large group of people out there who have been left without a lot of support. And like it's not the cleft journey is not a journey that anybody should have to do by themselves it is a tough journey and so just for people to know that there is support out there whatever age you are. But yeah equally to provide some reassurance for parents watching this that the journey that that your child is going to go through is one that you know has the benefit of many years more experience and understanding of how cleft impacts on much more than just you know the physical side of things and they're really good nowadays at providing that support early on in life so that these things don't become as much of an issue for people.

**Kate:** Thank you, and a question that lots of people might want to know the answer to here is what can friends and family members do to support a child, young person or adult who was born with a cleft?

**Kenny:** Yeah I think this is another really good question one of the most common things I hear from people when they're describing their relationships with people is they say that they appreciate being treated just like anyone else which of course makes a lot of sense. We all want to be treated like anybody else as much as we can. I'm indicating to people that you're ready to listen and have a conversation with somebody about their cleft if they want to, they're not expecting them to have to open up to you is really important. So like just being quite genuine and that being prepared to listen but not being overly curious if that makes sense. You know um people all manage this in a different way some people will want to talk about it, others won't and that's fine. And you as a support person don't get accuse or decide what is right or wrong here even if the person's decision may frustrate you. You need to let people get there in their own time and they will and I think this is especially important as well for parents thinking about their children particularly perhaps through teenage years where people have to make big decisions about future treatment perhaps and they you know a teenager has a lot on their plate as it is without having to think about kind of a major surgery or treatment option and so while it might frustrate you that they've not got there as quickly as you have, you just have to work with them and you know not try and force that upon them because that that is the point where people will start to shut down and not talk to you about things and that's where it will harm you know the relationship that they've got with you. So um just being quite genuine in that. A way that I've heard someone describe this and I would tend to agree is that living with cleft can be pretty intense and we don't necessarily expect others to fully grasp the intensity of this but an understanding from other people that this journey can be intense and being kind and supportive goes a long way and whether that be by being that listening ear that doesn't attempt to solve all the problems that rather just actively listens or whether it be offering a welcome distraction when someone is feeling a bit overwhelmed, attempting to understand and relate as best you can is really important. As a friend and especially so as a partner understanding the anxiety that people have is really important. A lot of people report feeling worried that they weren't good enough for their partner and they were worried that their partner would leave them now I'm pretty confident if I spoke to their partners they would not say anything other than that they loved the person who was born with a cleft very much and that they wish that they could see themselves in the way that they saw them. But nevertheless it's a real worry for people it's a genuine anxiety and it can be really tempting to dismiss this for people by saying something like ‘oh don't be silly’ but actually it may be really important to understand here that this is anxiety talking. Anxiety doesn't have a great reputation for being particularly rational and so that could be a really genuine fear for people, so try and talk this through with your partner or friend and understand what it is that is making them concerned and what would help to reassure them. It may well be beyond your help and again this is where the cleft team psychologist may be the best person to be involved and to support with this so gentle encouragement to re-engage with cleft service could be really useful here as well.

**Kate:** Great thank you, and we've got lots of time so I'm going to start scrolling back through the live comments now so give me one minute. Yeah lots of people saying hi that's really great. So going back to the discussion around bullying just bullying and discrimination, we've got a comment from someone saying that is very interesting about not believing they have been bullied: ‘I've just come out of counselling age 36 and talked about things that happened to me but I didn't mention at the time as it didn't feel big enough at the time’. Yeah I don't know if you want to add anything to what you've already said about that?

**Kenny:** Yeah I mean that that is a really interesting scenario and I think it is often only when we reflect back that we can identify some of these things and I mean the story that this person tells is certainly not unusual you know to kind of discover these things in their 30s 40s or you know even later in life. I think you know bullying and discrimination like we were saying, it takes its toll in different ways. I mean I certainly look back on my own experiences as well and I think there were things that at the time I probably should have been more concerned about or should have sought support on but you just don't necessarily have the knowledge to identify that's what's happening to you or have the skills to know how to deal with it. I think the thing is though it can have that impact later on in life and making sure that if it is something that's bothering you later in life that you do see some support for that and talk that through with somebody because it can start to get in the way of things if it's kind of left unaddressed and if you're feeling you know particularly upset or aggrieved by an incident that happened earlier in life. I mean there are a couple of things actually that came up in the survey that were of particular concern which I wrote about in the lay summary as well. Where we you know somewhat people we ask people to describe what happened to them in terms of bullying and discrimination um and there were a couple of instances which we would as authors of the paper identify as sexual assault but obviously that had gone unreported because the person hadn't used those words themselves but it was just the very explicit description of what had happened that was how it would be interpreted. So you know there are there's obviously a big under reporting issue here as well and we know that generally with you know things that people are victim to in society particularly you know things like sexual abuse or assault often doesn't get reported. It was just really sad to see that happening in our community and that people hadn't identified necessarily that's what had happened to them or if they had they didn't feel comfortable to use those words to describe it and I think that probably is indicative of an unmet psychological need there as well as well as of course you know the need the desperate need for society to change this attitude.

**Kate:** Yeah definitely. Another question: ‘for the speech therapy session I was 35 years old, mine was done at the Birmingham children's hospital. How come I was not referred to as adult speech language therapy?’

**Kenny:** That is a good question and I know that different cleft teams do this differently. I mean the most likely reason I can think of is because even as an adult when you're going back for speech therapy you want to be going through the cleft team and seeing the cleft team speech therapist it may well be in this case that just happens to be based at the children's hospital. I believe actually in Birmingham that a lot of the adult services are done through the children's hospital because it's where the cleft team is based and you want to have access to those expertise. A lot of cleft teams do a clinic in the adults hospital and move between them but I know there are regions of the UK where because they've got everything set up in the children's hospital because the majority of patients are children that they do see you in that same area. I know that's happened for me in London as well when I went in to see the actual cleft team that was done through that Evelina children's hospital but they give you a kind of a separate place to wait and things like that, but it is where the cleft team are based and they've got their offices. So it's quite useful if that happens and it's far better to be going through the cleft team speech therapist than a general one who doesn't have that cleft experience. So I do get though it can feel a bit uncomfortable having to go into a children's hospital as an adult um it's not ideal and it's something that we have said back to the cleft teams as well.

**Kate:** It looks like it's the same in Manchester as well, we've just got a comment from someone saying that adult services are at the children's hospital in Manchester too. I'm just going to find some other questions. So going on to the genetic testing kind of area of the findings, we've got a comment from someone saying ‘myself and my mum have both got a cleft they told me it was probably my mum being on a certain medication. I have three daughters and none with it but my daughters have a 10 chance.’ I don't know if you can shine any light or reply to that or yeah?

**Kenny:** I mean great so that's an example of someone who's gone through genetic counseling by the sound of things and they've worked out that probability of someone I think is as well you know what's been touched on. Sorry Kate did they say both them and their mother had a cleft?

**Kate:** Yeah.

**Kenny:** Yeah so I think what's probably happened here is we've touched on a really classic example of genes plus environment, you know like the fact that that mum had it you know so there's obviously some genetic component there but then the question around the medication as well is an environmental factor and this is quite typical of what happens with cleft. It's one thing plus something else or plus multiple things and then obviously if that environmental factor, you know if it was indeed the medication had a role to play here, that by removing that in terms of this lady having her own children then that's reduced the risk by you know down to ten percent or whatever. I think you know risks around the sort of 10 mark are not uncommon, it can really sit somewhere around one and fifty ish but it you know it can be quite a bit higher than that and you know one in ten is not hugely higher than that really in the grand scheme of things. But yeah it is why I would encourage people to look at the option of genetic counselling.

**Kate:** And while on this topic there's a few really nice comments I just want to read out. So we've got one saying, ‘me and my son were both born with a bilateral cleft lip and palate I was never told the percentage but I wouldn't have it any other way. I feel like he was hand-picked just for me.’ And then someone else has said, ‘love this, I feel exactly the same about my daughter who was born with a unilateral cleft lip and palate’. Then oh another lovely one, might as well read out all the lovely comments! Um someone said, ‘hi I'm also a cleft lip baby. I was bullied at school, of course I didn't take it well but that made me stronger and embraced my beautiful smile more.’

**Kenny:** Yeah that is a really good point and thank you all for sharing such lovely feedback, it's really nice to know that what we found and talk about resonates with people. But that is something I haven't spoken a lot about in here is that you know a proportion of people, a reasonable proportion of people, did report a sense of resilience you know in the longer term. So that things were difficult perhaps early on in life and they maybe didn't you know, like we're saying before, have the skills perhaps to deal with it or feel that comfortable to deal with it but they reported that it set them up better you know better in later life to deal with things as they came up. I have certainly seen a lot of people say that and I've seen a lot of examples of that where people who are born with clefts or other you know health conditions that require quite a lot of difficult stuff early on in life and then seem to be a little bit better at taking other things that life throws away in your stride. That's of course the reason I haven't stated it particularly loudly is it's really important to recognize that's not the case for everybody and I don't want to set an expectation that you should become resilient just because you've gone through something difficult because we know that doesn't happen for a lot of people and that that's why those ongoing supports in adulthood are really important so just to validate however you're feeling is fine. There is support available like so if you feel you know like you've dealt with cleft and kind of have put it in some sort of perspective that works for you and you've developed a sense of resilience and that you don't need further support, that's great we're not saying that you're denying something or that that you need support you know that that's excellent and ideally we'd like more people to feel that way. But equally if you're feeling like you know you've had quite a rough time and that you know things are quite difficult we'll know that there's a lot of other people who have felt that way too and that is why the support is there is to support, you know, when you're feeling like that and to hopefully make you feel you know in better steps to kind of work through these things as they come up. But yeah thank you again for those those comments, it's really nice to hear.

**Kate:** Yeah and we've got a few people agreeing now as you were just saying that about resilience. Let me find another question for you. We've got a few people sharing experiences, you know you were talking about like differences internationally, areas for further research, and so someone's unfortunately had some bad experiences going to the US and they were shouted out while on holiday and they've said ‘I guess there are mean people everywhere’ and yeah I think that's definitely true. Someone else said, ‘cultural issues are huge for all of us as an old adult in the US it's interesting to see what exists my family was superstitious which brought shame to me’ and so I guess that reiterates the point you're making that actually that is something that should be looked into more, like more research could definitely benefit.

**Kenny:** Yeah I mean definitely. I mean what we're seeing there is probably a combination of different cultural practices perhaps but also that the age thing. I mean unfortunately I've not got a lot of experience with the US system I've not lived there myself but I do know that the way that healthcare for cleft was managed was very different to that of the UK and therefore the support that might be available to someone is quite different you know. From the little I know about how the US works I know it's an insurance-based healthcare system so it's not like the NHS where it's kind of you know available to everybody free of charge like it's you know depending on your level of coverage what you'll be able to access and so I think this is where those you know international studies are really important because I wouldn't want to pass judgment on what that might mean for somebody growing up with a cleft but it certainly will have an impact which is different from systems like the UK you know and other countries where healthcare is free at the point of access.

**Kate:** Yeah and I think the same person's just commented saying that they've done well, they've retired after 47 years as a nurse and 30 years as an advanced practice nurse and nurse practitioner, in a wonderful marriage which is lovely.

**Kenny:** That is lovely to hear and look, they will have far more expertise loyal about the US healthcare system in that case so again thanks very much for tuning in and joining us. I think actually this highlights and it's something we found with cleft talk as well, that actually there's not a lot of this internationally happening like this adult services project that CLAPA has done is kind of a world first really and I think the engagement we're seeing not only within the UK but from around the world is testament to how important this piece of work is and how overview the support for adults is so it's really nice to be opening the dialogue and to have people joining us from all over the world to share their experiences because there is far more that unites us than divides us on this journey depending on where we are in the world and so I think it's nice to have this collective voice be quite strong.

**Kate:** Yeah absolutely and when you were talking about, I think this was at the point you were talking about like accessing further support and everything, we've got someone just saying that's really good to hear, they haven't been to their local cleft team in about 15 years and they were told that they didn't have access to them so they'll talk to their GP now they've said, which is really great.

**Kenny:** Just on that note we've got resources that like you know you are very much entitled to go back to the cleft team but it's important for me to point out and I think I pointed it out in a previous Q & A on physical health and it will certainly come up again in our next Q & A on treatment experiences. Just because the you are entitled to it, unfortunately it doesn't mean it's necessarily easy to get that first appointment and that is where we we're here to help. We've put together an actual letter that you can take to the GP that outlines the part of the NHS, it's called the service specification, which highlights in black and white, in plain English that anybody of any age is entitled to care. The cleft teams all know this, that it can be a bit hit or miss as to whether your GP or your dentist knows this and they have certainly been instances of people being referred to the wrong place. So if you ever do if anyone listening to this in the UK contacts your GP or your general dentist and has difficulty getting a referral or says you're not eligible for a referral do get in touch with us. Email us at adults@clapa.com, we will send you through the letter template that you can take with you to the GP and like the response I've had to that from GPs is that actually that's a very useful tool because it's just you know closed a gap in their knowledge that they just weren't aware of. Because your average GP probably doesn't see a lot of adult cleft patients to be completely honest. So yeah anything we can do to support that you know that is what we're here for, because it's it can be a little bit difficult sometimes. Your other option of course is you'll find all the cleft team details on our website by all means phone them and have a chat with them about getting back in. They'll also tell you what you need to do and support you to get back into to see them as well.

**Kate:** Great thank you Kenny. I'm not actually sure if you've already kind of answered this question so I'll read it out just in case. Someone said, ‘I had speech and language therapy at age 28 at Birmingham children's hospital. How come I wasn't referred to adult speech and language therapy and because I was an adult there was no support and limited for small sessions.’ So I'm not sure if you've already touched on that when you're talking about the adult services at children's hospitals before?

**Kenny:** I think there may be also getting a second issue here which is worth talking about particularly also at the moment is very relevant in the context of Covid which is a service provision issue. So yes you are entitled to return and to have an assessment. How the treatment that is then offered to you is obviously somewhat at the discretion of the cleft team. Different cleft teams have different priorities as to kind of where things sit for them and for what you know get seen more quickly and things I know like some areas you know prioritize adult psychology for example for the reasons we've mentioned that there's actually a very large group out there people who aren't supported or haven't had that support. I should say yeah in terms of the limiting to a number of sessions it is disappointing obviously if you feel that that hasn't been enough and that you need more. You can always seek a second opinion, that's something that everybody is entitled to do and the way to do that is to phone any other cleft team and say that you would like to come in for a second opinion and they will assess you. They won't necessarily agree to treat you, that they will certainly give you an assessment and provide recommendations as to whether they agree or disagree with what your cleft team has recommended for you in terms of treatment. It is also worth mentioning with Covid at the moment unfortunately a lot of cleft treatment is on hold and unfortunately that concerningly to me obviously it's disproportionately affecting adults. Like adults is the thing that seems to have gone on the back burner with coronavirus, they've had to kind of make some difficult decisions about what's priority and like of course nobody wants to take anything away from children but I would like to make sure that we don't end up kind of not getting back to where we need to be as a result of Covid. I think it's some work that CLAPA will work very closely with the cleft teams too to make sure that that adult voice continues to be heard and that adult treatment continues to be available for all those who need it.

**Kate:** All right thank you. Let me just find another one. So we've got someone saying, ‘would you say having a cleft contributes to diversity?’ and they put diversity in quote marks.

**Kenny:** Yeah I mean it's a really interesting question. Again I think there's people's self-perceptions that are at play here. I mean definitely visible difference is something that we've spoken about and we know that you know appearance differences and speech differences do impact on how people can be perceived by others. So in terms of like I would encourage anybody when they're thinking about diversity particularly in like a workplace context for example and that these are things you need to consider you know people who may have you know an appearance difference or who may sound different and think about the kind of discrimination that that they might face or the harassment that they might endure as a result of these things and what are you doing as an employer or as an event organizer or as a school to safeguard people from that you know to minimize the risk of that. The other really important thing to mention here which I think fits nicely with diversity is kind of the cumulative effect of differences. So for example you know having cleft is one thing but if you also are you know identify as a person of color or you know are a woman or are part of the LGBTQIA community, you will also face prejudices by being part of those groups and parts of the community as well and that unfortunately it adds on top of you know other differences as well. So I think you know there's often real issues for people when you kind of have two or three things start adding on top of each other and you know it harps back to my earlier point of how society's attitudes need to change for a lot of us to be addressed in a really fair and meaningful way. But being aware of those for people, like not assuming that you know one person will experience one type of discrimination just because of one factor, recognizing that you know people with multiple factors it's likely that and it's very unfortunate but it is likely that they will experience multiple types of discrimination. So you know those people would be more at risk than say someone who's got one risk factor. So like me for example being born with a cleft but you know otherwise being a straight white male that's a lot of things going in my favor, but perhaps if some of those other factors were different for me I would expect to experience more discrimination on top of the discrimination I was experiencing for being born with a cleft. Does that kind of make sense? Kind of a roundabout answer.

**Kate:** Yeah and I think that's a really important point that you just made so yeah thank you for that. We've got a comment from someone, going back to the section on bullying, and they've said ‘I don't think we see bullying clearly as young children, it's later when we figure out that the mean kid was a bully and get the implications’ and I think that really echoes a lot of what you've been saying actually throughout this Q & A.

**Kenny:** Definitely, definitely and I think there is a lot of you know and particularly I mean I'm looking back to my own kind of adolescent and pre-adolescent years and I think we've got a word for a lot of the behavior that that happens now and the word I would use would be gaslighting where you're kind of made to feel that you know there's something wrong with you or that you're not good at something or not as worthy of as other people. It comes back to that you know if everybody treated each other as we would like to be treated you know the world be a better place but I think that it's a real issue because you can particularly if you're you know if it's happening to you often enough you can start to believe that and then this belief cycle that you don't deserve all the things that you deserve and then that manifests itself in different ways later in life. So I think you know the person who's written that is absolutely right, it is often when we reflect back later on that we identify what we experienced was bullying and like I now look back at the people who are doing the bullying and kind of can identify some of their own risk factors for you know that kind of made them fall into that perhaps you know make them fall into that that category. You know things like a lot of them didn't have great relationships with you know peers and family and things like that and so I think that also helps back to the point of you know what can everybody do to support people with cleft it's like you know making sure that we're supporting every child growing up and making sure that as a society we value that people have the necessities of life because you know people who don't are not only at risk of being bullied but also of becoming bullies themselves.

**Kate:** Yeah definitely. We've now got a question about support that you can get from your cleft team, so someone's asked, ‘does the extra support extend to dental care? My dentist said clefts are associated with weaker enamel which would explain the dozens of fillings inlays crowns etc. I've had over the years and it gets expensive. I don't think I've ever had a cleft team, I only had one operation at three months old back in the 1970s.’ Again echoes what you've been saying about, this Q & A.

**Kenny:** Yeah a really good question and one that we will cover in great detail in the next Q & A in May about treatment experiences. To answer that quickly, yes it does extend to dental care and yes the observations that your dentist has made are very much supported by the evidence. The issue can be getting that referral. Again your dentist can make a referral to the cleft team dentist and probably should if they believe that the dental issues you're having are as a result of cleft and there's a lot of restorative dentistry that can be done and it's available free of charge from the NHS if it is related to cleft. Making that distinction can sometimes be hard. We do have another resource which could be very useful to you um which is our teething issues episode of our cleft talk podcast so if you go to clapa.com/clefttalk I think it's episode nine it'll be very clear anyway on the website where we actually speak with a general dentist and also a restorative dentist who's working in the cleft team as well about what you can expect your general dentist to do and what you can expect to be referred to the cleft team for. So I would really encourage you to have a listen to that if you are having some difficulties with the dental stuff and getting those referrals, but also tune into our next Q & A towards the end of May where we'll talk about this in more detail yeah.

**Kate:** A similar comment from someone else, well not similar it's a different issue, but that they've asked and emailed and called her dental practitioner to ask for a referral to the cleft team, they look as if they're really confused and as yet haven't done that and and they've been asking for years and they've just said it's fascinating to hear about the possibility to get into like the system via other routes. So I guess everything that you've just said kind of answers that question as well hopefully.

**Kenny:** Yeah I mean definitely in that scenario for that person I would encourage them now to just phone the cleft team and explain they've been trying. Your other option of course is you can go to your GP and get your GP to do it. It doesn't matter who does it, if it's your GP or your dentist either of them can refer for any service and then if you continue to get stuck drop us an email adults@clapa.com and we'll see what we can do to help.

**Kate:** Yeah and there's lots of lovely comments on here about cleft teams being amazing and things like that and then we've got one, ‘where do I go to get my genetics tested? I'm the only one in my family to have one, so while it hasn't been genetic so far, does that mean it might be now?’

**Kenny:** Yeah I mean that's a really good question, exactly what the genetic counseling is for. What it does seem to be is that there's an element of truth in that, that once you have a cleft your chance of your child having a cleft even if there's no other kind of factors at play is higher than it would be had you not had a cleft. So if you don't have if no one's got a fact that the average is about one and seven hundred and if you do have a cleft and no other factors that rises to about one and fifty so again like we're talking very small numbers but actually it's a reasonable jump. In terms of where you can go to get genetic testing, you organize that through your cleft scheme so usually the genetic counseling side of things is something you'll be sent somewhere different in the hospital to have because they're kind of, they are part of the cleft team but they also are part of many other teams so they kind of sit on the periphery of it. But get in touch with your cleft team and ask that. If you don't have a cleft team get in touch with your GP and ask for a referral to the cleft team for genetic counselling and they should be able to organize that that for you. Again I would encourage everyone watching that cleft talk episode twoexplains a lot more about how if you have had a cleft and no one else in your family has kind of what that that means for you going forward and it's mostly reassuring good news. Like that you know like I don't want to worry anyone necessarily like the general thing is like it's a slight increase but actually it's still around that 1 and 50 mark which is probably not enough to get too worried. But um yeah do seek out genetic counseling if it's something you're interested in. I know for me personally it would be something I would want to know.

**Kate:** Thank you Kenny. Someone's asked can you get a second opinion from any other cleft team in the UK regardless of where you live, which is a really interesting question.

**Kenny:** Yes you can. Obviously the thing with that is if you choose one that's you know if you're in um Salisbury and you want to go and get the Glasgow cleft team you're going to have to travel for that so generally we would recommend you go for the neighboring cleft team simply because it's easier for you to get to. But if you would rather go to another one for a second opinion that is your right to do so.

**Kate:** Thank you. Then we've got a few comments saying things like a lot of work is being done in primary schools now about bullying so hopefully children with cleft now shouldn't experience this like they used to which is really great and yeah hopefully that is the case. A few people are asking if this will be available to you later. Yes and so when we do a live video it should save to our Facebook page and can be watched later and we'll also upload it to our website as well, a recording, and so you will be able to watch later. Another really interesting question someone's asked, ‘are there any articles or resources to show a partner of someone with a cleft? My partner has never really come into contact with cleft affected people and while I talk about my own experiences it would be useful to show more.’ I guess a starting point for this question would be all the stories that have been shared by lots of wonderful people from the CLAPA community, like adult stories that we have on our website and I can put a link in the chat now, but Kenny do you want to add anything if you know any?

**Kenny:** Yeah I mean I would also direct them to the CLAPA website, there's a lot of resources on there. I think depending on what specifically they would like to find out more about, I think the cleft talk episodes are really good as well like we very much design them with a more broad audience in mind so not only adults with cleft but actually the people around those are adults with cleft. I think as well I mean if it's kind of they want to read research this stuff obviously the articles themselves delve into this quite a bit, particularly the one that this paper, that this lay summary is based around, but also yeah I mean we haven't seen a lot of this go through our peer support service but it would be something that if someone had particular questions that they wanted to ask a member of our cleft community I can't see a reason why that wouldn't be available. But yeah start on the CLAPA website, have a read through people's stories, but yeah if there's kind of a specific question or set of questions in mind you might be best to get in touch with us and kind of we can point you in the direction of specific information.

**Kate:** Yeah I've put a few links on there now but as Kenny said if you do have any difficulties finding anything just let us know and anyone can always email info@clapa.com anytime, so yeah definitely let us know. Let's see if there any more because I'm also aware that it's been over an hour so let's have a look. A few people saying thank you. So I'm just going to read out a comment here someone said, ‘I'm 46 and spent most of my life with bullies as I have ginger hair but nothing was worse than the stuff said to me about my looks.’ They had a cleft, a cleft lip and palate. They said, ‘you would not know now. People tend to think I've been in a fight and got bottled. I've become a strong-hearted person due to what I was born with and what I had to go through yet people tend to forget what my parents and brother went through on this journey with me. They made me so strong.’ That’s nice, awful that this person has had these experiences but also an important point they've made about like friends and family and how they're part of that journey too and how best that they can support.

**Kenny:** Yeah and that is a really good observation they've made there and something that actually I haven't spoken a lot about in the Q & A today because it was a really kind of positive and pretty ubiquitous finding that people reported receiving a lot of support from family and friends but family especially. That is something that seems to be reasonably widespread among the cleft community that people feel that the support they've had from their family has been really good and absolutely you know people's families have gone through a lot with them as well and it's not easy on anybody and parents and siblings you know go through this journey together. So it's key to people's developing that sense of resilience I think is having those positive environments at home and the support there.

**Kate:** Yeah absolutely. Someone said that they're 44 and they only discovered CLAPA last year, hi and welcome we're really glad you're here! There’s a lot of appreciation for cleft teams and surgeons and everything going on in the comments which is really great but I think probably given that it's been over an hour I'm conscious of time I think we'll probably wrap up here. So yeah I guess we'll just say thank you so much for joining us tonight and for tuning in and for sharing your experiences and asking questions. It's always really great doing these Q & As because everything that everyone contributes kind of makes them what they are so we really really appreciate it. Thank you to everyone who will be watching this video later on as well. I'll add the link to the research summary again in the comments just in case anyone wants to recap there and we've put the cleft talk link there as well and as Kenny said it's really worth checking out. We hope you found this session really interesting and thank you very much for joining us! Kenny I don't know if you want to say any last words?

**Kenny:** Yeah I can say echo that really. Thank you very much, it's a real privilege to be able to come and talk about the research with you guys because like and again you know my appreciation to all the people who took part in the research and who have enabled us to open this conversation and like I say it's really nice to get the feedback that what we're sharing resonates with people and it lets us know we're on the right track and we'll keep moving forward in the right direction.

**Kate:** Absolutely. So from both of us thank you so much for joining us and good night. We hope you enjoy the rest of your evening. Thank you, bye!

**Kenny:** Bye