



CLAPA Adult Services Project



Year 2



Background to the project

There are an estimated 75,000 people over the age of 16 living in the United Kingdom who were born with a cleft. CLAPA recognises the unique needs and experiences of adults affected by cleft and ensuring services that work are available for the entire cleft community. From March 2018 until February 2021, CLAPA is undertaking an exciting project funded by the VTCT Foundation aimed at improving services for adults who were born with a cleft. 2019 is the second year of this project.

What we've done so far

Here's a quick recap of some of the things that we did in 2018:

Survey

We undertook the biggest survey of adults affected by cleft in the entire world.

Our Whole of Life survey asked adults born with a cleft to share their thoughts and experiences about medicine, health, emotional well-being, work, bullying, discrimination, dating and relationships, genetics and more.

We're using this valuable information to help guide our future endeavours. Thank you to everyone who participated in the survey.

Roadshow

We had the incredible opportunity to meet with many of you all across the UK in the Summer who told us what was important to you as an adult.

We're keeping this front and centre in our minds as we deliver Year 2 and Year 3 of this project.



Read the report here: www.clapa.com/roadshowreport Do the findings resonate with you?

Conference

We also had the wonderful opportunity to meet with many of you again at our annual Adults Conference on Saturday 17th November 2018 in London. This day was directly informed by the roadshow, with the topics discussed being many of those that you told us were important to you.

What we're doing in Year 2

Reporting back to the community

Although we've already reported back on the roadshow and preliminary survey findings, we have a lot more detailed information from the survey yet to come. We know that this information is of interest to different people for different reasons, and we aim to make it as accessible for everyone as we can. This will mean working with our colleagues at the Centre for Appearance Research to publish our findings in academic journals which the health professionals working in the field of cleft can access, presenting at cleft conferences, but also reporting back to the cleft community using simple plain English. Watch this space!

Striving to make referrals to the cleft team easier

We hear you. Making a referral to the cleft team can be really difficult for some. We want to make this easier for everyone. We'll be exploring options at how best to do this, but suspect it will be a multi-pronged approach of delivering information to the cleft community, encouraging NHS to accept self-referrals wherever possible, as well as providing education to GPs and General Dentists to help them to make the right referral, first time.

Developing a Leavers Pack

We also realised that many of you aren't aware of what services are available to you, or what happens if you move to a different part of the UK or overseas. Let's make that right. CLAPA wants to work with the NHS cleft teams to develop a UK wide "Leavers Pack" which contains information about your access to treatment as an adult, a list of all the cleft teams across the UK, treatment options you may consider in adulthood, answers to commonly asked questions, a letter you can take to your GP to get a referral and more. A version would also be online which would be kept up to date.

Access to high quality information

You told us that you're not fans of crystal ball gazing. Neither are we. You want access to high quality information that you can use to help you make those all important decisions. It is frustrating to be told one thing, only to have it contradicted by somebody else. CLAPA will work with the NHS to develop some additional content for our website, including videos and panel discussions with those in the know. We will encourage primary health care providers (e.g. GPs, dentists, midwives etc.) to ensure that they are providing accurate information with regard to cleft.

Developing a register of dentists who understand cleft

Not many people like going to the dentist. However, many of you have told us that you are afraid of going to the dentist. That's not a good situation and will likely impact negatively on your oral health in the long run. There are many reasons why people feel this way, but the common denominator is that many dentists don't understand some of the unique cleft related needs. We endeavour to develop (and update) a list of recommended dentists on our website who are recognised to have both experience working with cleft, and a genuine sense of empathy and understanding for people who are anxious about visiting the dentist.



Adult Representation Committee

We have a new group which provides advice to CLAPA on its adult direction, as well as being involved in external research opportunities. To find out more about this group, check out www.clapa.com/arc.

Continuation of the Peer Support service

You told us that having access to trained psychologists as part of the NHS are super important. You also told us that no-one quite gets it like someone who's walked in your shoes. CLAPA's peer support service has been around for a while and is one of our most valuable services for adults. We'll be ensuring that you continue to have access to this vital service, and encouraging more people to volunteer their time as a peer supporter.

Adults Conference

We're excited to be holding another conference in the second half of 2019. The conference will be held in Glasgow. Check out www.clapa.com/ac2019 from mid-2019 for more information.

What can I do to help?

As an adult born with a cleft, there are a few things that you can do to help! We want to spread the word about the Adult Services Project as far and wide as we can, and there's a few ways you can help us to do that:

- ✓ Let other adults with a cleft in your circles know about the project and the upcoming conference in Glasgow – share our information about the project on social media, put up a poster at your local supermarket, spread the word at your workplace etc. Remember, since cleft affects 1 in 700 people in the UK, chances are that everyone knows someone who knows someone with a cleft!
- ✓ Consider volunteering for CLAPA – you may like to join the Adult Representation Committee, or become a Peer Supporter.
- ✓ If you're considering or currently having further treatment, talk to your cleft team about the project too!
- ✓ Consider doing a fundraiser for CLAPA to enable us to continue our work. This could be something as simple as organising a collection tin in your office, or it could be as involved as seeking sponsorship to sail a yacht across the Atlantic. Whatever floats your boat (real or metaphorical), the CLAPA fundraising team can help – fundraising@clapa.com.
- ✓ Join the CLAPA Community (it's free!)

You can connect with the project by:

Visiting our website at:

www.clapa.com/adultservicesproject/

Joining our Facebook community at:

<https://www.facebook.com/groups/CLAPAadults/>

Contacting our Adult Services Coordinator, Kenny Ardouin at:

kenny.ardouin@clapa.com or by calling 020 7833 4883

