

Spring Survey 2014 Report - ADULTS

RESPONDANTS

Responses from the 'ADULTS' section of our Spring Survey 2014 came from **108** (out of 668) participants who said they were born with a cleft and were over 18.

Of these, **65.3%** were born with cleft lip and palate, **17.7%** isolated cleft palate, **17%** with cleft lip.

GENERIC HEALTH PROFESSIONALS

40% said in their experience generic health professionals **didn't fully understand** how to treat patients with a cleft. **39.5%** weren't sure, only **20.4%** said yes. There was little variation by age, though older patients were the most likely (**66%**) to respond that they weren't sure.

Most of the issues reported were with GPs/Doctors (**31.8%**) and Dentists (**29.7%**).

Particular problems reported:

Patients having to **explain themselves** and their particular issues to health professionals who are unaware or uneducated about these, and the lack of age-appropriate information about cleft lip and palate can make explaining how the condition affects them difficult.

Patients are sometimes **ignored** when trying to explain there may be a problem, which can cause serious issues with things like teeth-pulling, or taking impressions of a mouth where the patient has a cleft palate. Problems are also reported with treatment for ear infections not taking a cleft palate into account and occasionally doing "**more harm than good**".

Ignorance about cleft-specific issues can lead to patients **receiving conflicting advice** about how best to deal with these issues, which can make them **lose faith** in these services. Patients can also be given **inaccurate advice** about what is available on the NHS which can lead to them being referred to the **private sector for expensive treatments** for cleft-related issues, when they should be referred to a cleft specialist. This was especially disappointing for one patient, who remarked "*why are we treated as a normal patient with regards to dentistry when we reach 19? We don't ever stop having a cleft.*" This can put patients off attending regular appointments, which will only hurt them in the future.

Patients being asked to do things which they are **unable to do** (e.g. peak flow tests for asthma can be difficult or impossible for those with a cleft palate), which can be frustrating, especially when the doctors do not fully understand why the patients can't cooperate.

General **lack of sensitivity** or consideration of a patient's own wants and needs with regards to their treatment. **Rude or insensitive** comments also frequently reported, including:

- "My dentist told my mum that it was a shame that I wasn't a boy because when I was an adult I could grow a moustache."
- Many remarks about appearance and a feeling that patients were treated like a "canvas that could be 'improved' and not a person"

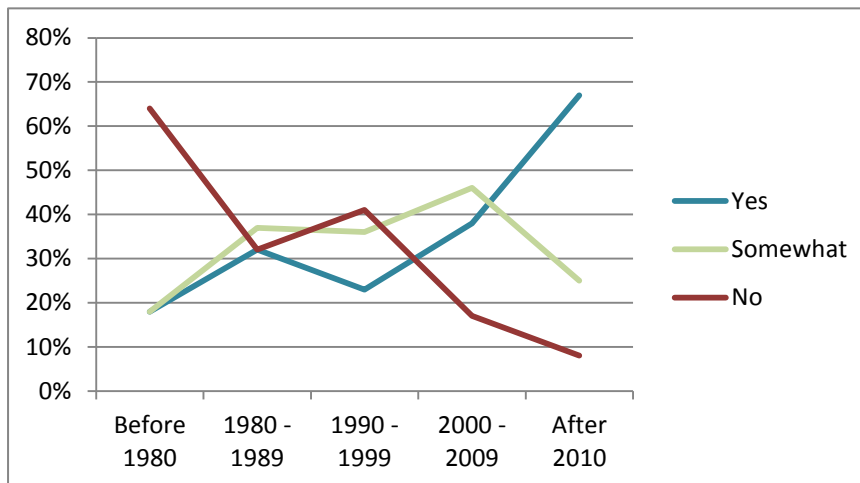
- “I keep getting offered treatment to make me look pretty, but nothing practical has been offered to address the problems I’m having.”
- “Dentist refusing to treat me as I’m too complex”
- “In my experience, GPs don’t know how to respond and get awkward when the subject is broached. It can feel a little patronising.”
- “It’s very hard to get treatment as an adult, it would be nice to know I could call and just have a chat with the cleft nurse, sometimes it’s not an appointment you need just some advice, or help from someone in the know. Lots of people assume that once the hole is mended you’re done, but it’s just the tip of the iceberg.”
- “When I was discharged nobody ever mentioned that I could ask for or have further treatment in future, I thought I had had all the treatment I was ever going to get and that I just had to live with how I looked.”

CONCLUSIONS: In general, there is a lack of information aimed at health professionals about the effects of a cleft on an adult patient, and also a lack of information aimed at adults which can lead to them not feeling confident enough to challenge health professionals about their treatment.

While educating health professionals is an important goal, in the short term it would be more helpful to ensure the information adults need is readily available to help them understand what they are entitled to on the NHS. This will give adults with a cleft the tools they need to confidently explain their condition, point their health professional in the direction of further information if necessary, and to understand what they should and should not expect.

TRANSITION FROM CHILD TO ADULT PATIENT

Did you feel as though you had a smooth, well-supported transition from child to adult patient?



Those answering ‘Yes’ increased from **13.33%** for those turning 18 before 1980 to **61.54%** for those turning 18 since 2010.

‘Somewhat’ increase from 13.33% for before 1980 to 23.08% after 2010

‘No’ decrease from 46.67% before 1980 to 7.69% after 2010

Conclusion: Things are definitely improving as far as the transition goes, hopefully this trend will continue with the wider availability of information and a greater focus on supporting patients.

RETURNING TO TREATMENT

53% returned to treatment for cleft-related issues after turning 18, and **91%** of these rated their experiences as good or very good. **71%** reported they were happy with their experiences the last time they sought treatment from their cleft team, with only **13%** saying they were unhappy.

Statements About Treatment

"I understand what treatment options are available for over 18s with a cleft"

28% agreed, **50%** disagreed.

"I understand how I might access these on the NHS for any issues relating to my cleft."

23% agreed, **51%** disagreed

"I feel able to approach my GP/dentist/other healthcare professional with any concerns I might have related to my cleft"

46% agreed, **40%** disagreed

"I am confident that any generic health professionals (i.e. not cleft specialists) I deal with in the future will understand any specific treatment needs I have because of my cleft"

19% agreed, **40%** disagreed, **41%** unsure

There was very little variation on these answers with regards to age, though older patients were more likely to say they were unsure.

CONCLUSIONS: Things are definitely improving, and young people with a cleft now can expect to be much better supported during their transition to adult patient than they would have been in the past. Patients who have returned for treatment were largely happy with their experiences, but just over half of the adults we surveyed did not know what treatment they are entitled to or how to access this treatment on the NHS, so there is still a need for better and more accessible information about this.

40% of adults with a cleft do not feel that they can approach their GP or dentist about any concerns they have about their cleft, nor do they think that most health professionals understand their particular needs as a patient with a cleft.

GENETICS

Passing on their cleft to any future children was a concern for **67%** of respondents, but only **9%** indicated that this would stop them from having children, with **35%** firm in their desire to have children. The degree towards which having a cleft affected an individual's desire to have children decreased in younger generations.

While **55%** indicated that they asked for further information to help them make this decision, **40%** felt that they were badly supported and didn't get what they needed, which was a particular problem in Northern Ireland. However, **35%** said the support was 'okay' and **24%** said it was 'excellent'.

Conclusion: It is clear that adults with a cleft need more information about this to be readily available to help them to make an informed decision with all the support they need.

SPEECH

55% of adults with a cleft said they considered themselves to have some kind of speech disorder or difficulty caused in whole or part by their clefts. When just considering adults with a cleft palate, this rose to **64%**.

Of those that had received **treatment** for this (**91%**), **79%** only received treatment as a child patient, even though **70%** said it still negatively affected their personal lives, with only **5%** saying it didn't affect them at all.

Only **7%** said there was enough support for this at their place of work or education, while **59%** said there was not.

34% said they would like further treatment, but **65%** of these did not know how to go about this.

When asked for examples, respondents reported a wide range of the effects of speech issues:

- **Public speaking** was the top concern, followed by **talking on the phone**. Both of these were reported as things respondents actively tried to avoid.
- **Meeting people for the first time** was a source of anxiety for many respondents as they often did not know whether or not they would be understood, and may have to shout or speak very slowly. It is especially difficult when people with a speech issue got frustrated or flustered at not being understood or having to repeat themselves over and over, as this can make their speech even harder to understand. This can even be an issue with close friends, family and spouses
- Remarks such as people asking 'if you have a cold' came up often, or being **treated like a child** or like they were unintelligent because of the way they sounded, which is something that was also a problem at schools. Some individuals with jobs that required a lot of contact with others reported that **networking and meetings could be very difficult**, as they do not feel they make a good first impression.

Conclusions: While information should be made available on further treatment, it could be more helpful to signpost individuals to other organisations or support groups to help them gain confidence with their speech.

VISIBL E DIFFERENCES

97% of respondents with a cleft lip considered themselves to have a visible difference. When asked if this negatively affected their personal life, **72% said yes**, with **31% of these people saying it affected them ‘a lot’**. Only 7% said it didn’t affect them at all.

When asked the same question about their professional lives, **49% said yes** with only 14% of these saying it affected them ‘a lot’. This is a disparity that wasn’t present when it came to speech issues, where the effects on personal and professional lives were judged as roughly equal.

When asked if they were or would be seeking any treatment for this, **22%** said yes with the hopes of changing their appearance, 12% said only for functional reasons, **28%** said they didn’t know they could get treatment for cosmetic issues, and 19% said they did not want any.

Particular concerns

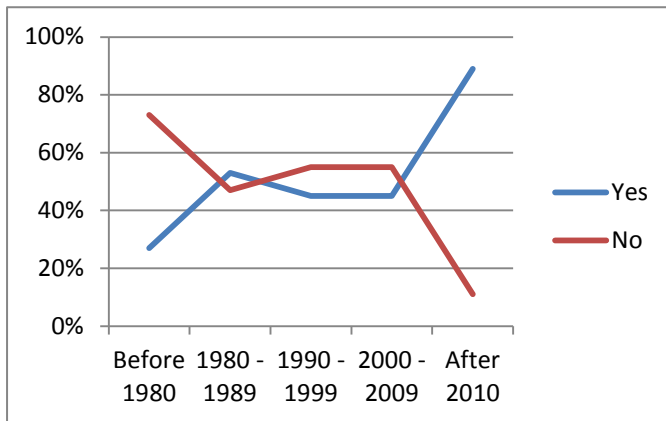
- Patients were concerned about further surgeries ‘**making things worse**’, especially those that had multiple surgeries as a child. They would prefer to know about non-surgical options which may help.
- The psychological impact of **being disappointed** by a cosmetic procedure was also a concern, as was the idea that they would **not be taken as seriously** as children or young adults when it came to cosmetic issues.
- Several respondents **worried about telling friends, family and colleagues** about seeking further treatment, as they felt this would be embarrassing.
- People often reported that their friends and family were accepting and positive, but this was not always the case in their professional lives or when meeting new people.
- **Bullying** could sometimes continue on into adult life, and it was felt that there is not enough focus on this as self-confidence is often an ongoing issue. While adults agreed that children should be the focus of these efforts, they still wanted to be able to **access psychological treatment** through the cleft team as an adult.
- **Discrimination at work** was reported – *“The agency that supports my employer refused help when I was being bullied, apparently on the basis that my problems were too deep seated.”*
- *“I am not comfortable with my ‘difference’, despite it being a lot less noticeable/ not as severe as others’ are. However, I do not wish to have any more surgery as I don’t feel like it’s warranted.”*
- *“I wish I had known years ago that I was entitled to treatment, I just found out 2 years ago aged 50 and had my palate repaired”*
- *“I hate the way I look but have come to terms with it”*
- *“I’ve spent a life accepting who I am...looking at making ‘improvements’ is hard to cope with now.*

Conclusions: Having a visible difference has different effects on adults with a cleft. Only 18.8% were firm in not wanting further surgery, so information on what is available should be accessible for

those that are considering it. Adults should be encouraged to visit the cleft team’s psychologist to talk about their reasons for wanting further treatment. They should also be given coping tactics for dealing with questions and comments about their condition, and/or signposting to organisations like Changing Faces and CLAPA for information on camouflage makeup and support groups.

THE BRIGHT SIDE

When asked if there were positives to being born with a cleft there was almost an even split, 48% said yes while 52% said no. Those born before 1965 were far more likely (73%) to say no, versus only 11% for those that turned 18 in the past few years, so attitudes are clearly changing.



When asked about what these positives might be, the most popular responses were that it ‘has made me stronger as a person’ (90% agreed), ‘has given me a different perspective on physical appearance (82%) and speech/hearing issues’ (51%). 41% agreed that it gave them a sense of identity, and 36% agreed that it helped to shape their ambitions and/or interests, as well as helping them to meet and/or help others.

Several adults mentioned that they would very much like to meet others with a cleft, as they’ve only ever met a handful.

A selection of quotes about the positives of being born with a cleft:

“We have the best smiles”

“It’s become a way for me to inform otherwise ignorant people about a condition so many people have. It has steered me into a profession in the healthcare realm.”

“Helped me become a Royal Navy surgeon and I was able to go on a medical mission to Ethiopia with Operation Smile and give back! 84 Surgeries in 3 ½ days!”

“Now I look back and see that the phrase ‘what doesn’t kill you makes you stronger’ is applicable. The bullying was not nice but I am a better person because of it.”

“I found I was so much happier when I finally accepted myself. I no longer look in the mirror and just see my cleft. I see me!”

“Has given me a different perspective on the way people treat other people.”

“Within my job as a makeup artist I try to encourage people to be happy and positive about their appearance. It’s what’s inside a person that matters.”

“I have gained a good judgement of character. As a child I put my energies into creative pursuits and gained skills in art, photography, computing and media.”