

Patient feedback for the Cleft Service, Health Board and Commissioners.

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The Welsh Centre for Cleft Lip and Palate



- Microsoft form questionnaire sent to all 39 patients on the adult waiting list - July 2021
- 4 questionnaires were sent by post as we did not have an e-mail address, these have not yet been returned but will be added to the data set, should they be returned.
- 32 patients responded, showing excellent engagement with the cleft service and a response rate of 82%

Summary headlines

2. How old are you?

18-25 years	17
26- 30 years	5
31-40 years	2
41-50 years	4
Over 50 years	4



53% were between 18-25years, with
13% in the over 50 age bracket

3. Are you?

Male	13
Female	19
Would rather not say	0



41% male
59% female

4. How long have you been waiting for your operation?

● Under 1 year	12
● Between 1-3 years	15
● 3-5 years	3
● 5-7 years	1
● 7 years plus	1



38% had been waiting under 1 year
47% had been waiting between 1-3 years
1 (3%) patient had been waiting over 7 years

5. What type of operation are you waiting for? Please highlight all that apply.

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● Speech surgery	5
● Rhinoplasty (nose)	22
● Lip revision	9
● Implant/dental work	5

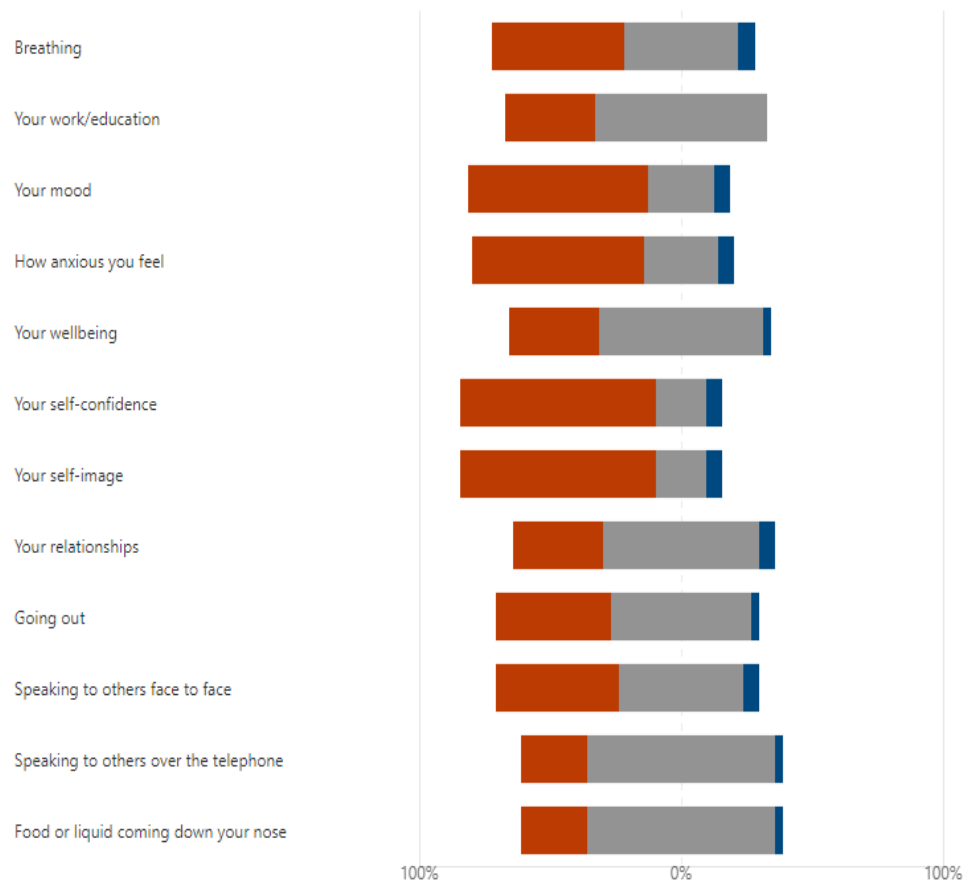


54% were waiting for
rhinoplasty surgery
12% for speech surgery

6. Have any of the following areas of your life been impacted due to waiting for surgery for your condition with the cleft service? Please highlight each factor below

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■ Negative impact ■ No impact ■ Positive impact



75% felt self esteem and self image had been impacted

69% mood affected

66% impacted how anxious they felt

50% impact on breathing

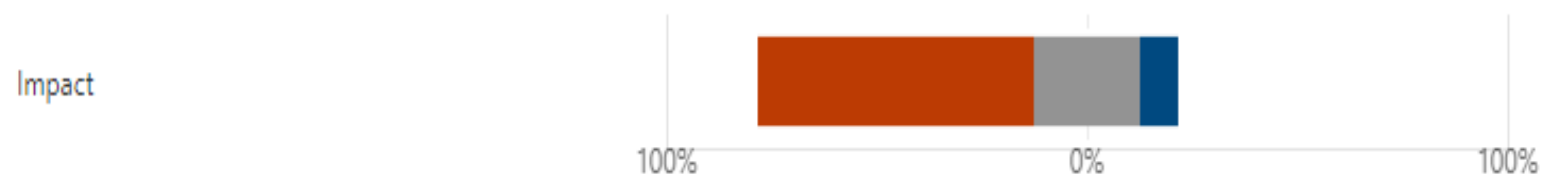
47% speaking to others face to face

44% going out

7. Overall, which option below would best describe how waiting for surgery has impacted your life?

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■ Negative Impact ■ No impact ■ Positive impact



67% describe a negative impact

8. Please provide any further detail that will help us understand how waiting for surgery has had an effect upon your life:

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 Insights

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Responses

- Has brought my anxiety to the highest level. Also stopping me from doing normal day to day things
- I'm doing a-levels so I've been quite anxious that the operation won't happen before I go University next year
- I have problems breathing through my nose due to scar tissue, therefore I breathe primarily from my mouth, I am very self-aware of this and embarrassed, it has caused me to snore terribly and therefore affecting my sleep, I have had reoccurring sinus infections which I believe this contributes to. The scar tissue has affected the shape of my nose which has made me extremely self-conscious and I have a negative opinion on my appearance therefore affects my confidence and I tend to cover my nose when I talk to people. I hate seeing photos of myself and this makes me depressed

- I feel that my speech has declined rapidly since losing full breathing abilities from my nose
- My life is on hold
- I'm keen to have the surgeries done, before I get much older, I believe it would enhance myself esteem self confidence
- My appearance is really effecting my confidence to the point I won't leave the house
- to be able to breath thought my nose
- Following surgery in 2019 which was successful this operation is an enhancement on the tip of the nose

- I currently can't have regular filler treatment as we don't know when surgery is. If they were to give me filler it would mean surgery can't go ahead. The left side of my lip is not symmetrical and affects my confidence massively. Not knowing how long I have to be unhappy with the way I look is frustrating but I understand it's out of everyone's hands. I'm also waiting for rhinoplasty, I cannot breathe through the left side of nose, I'm also asthmatic so when I get a general cold I tend to feel very poorly and struggle with my breathing causing me to have time off work

- Waiting itself hasn't caused that much of an impact, I lived with the disfigurement for 21 years before seeking help so another couple has been ok I suppose. Would really like to get it sorted and get on with my life mind
- Feels like my life has been either recovering from operations or waiting for operations. I had a great appointment where there was so much that can be done however over a years waiting is very disheartening

- Due to my breathing difficulties it's been ever harder wearing mask coverings. My breathing issue has always been ongoing but I had to wait because of age. My sleep has also had a big negative impact with actually getting to sleep and when I'm eating and drinking. This is because I regularly have to take breaks whilst eating and drinking to allow myself to breath through my mouth because I can't breath at all through my nose




- I do not go out much due to my anxiety as I don't feel comfortable with going out by myself so I have someone else there with me
- The wait has mostly been impacting me with my breathing and food/liquids coming down the nose as I need the nose surgery, but also my self confidence and how I worry about how others view me due to the lip
- It is mainly insecurities and being self conscious when talking to people
- As I'm getting older I just feel I'm becoming more self conscious of my appearance in particular, my nose

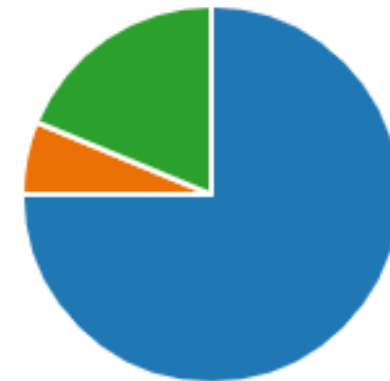
- Delay in surgery is endless
- it has exacerbated my suffering from anxiety and depression
- My self confidence is low and I am very conscious about how my nose and lips look
- Just feeling confused of when I'll get it or if I still will get it

9. Do you know that the cleft team offers a psychology service?

[More Details](#)

 Insights

 Yes	24
 No	2
 Was not sure	6



75% knew the team offered a psychology service

10. The psychology service is available to support you during this time, would you like to access this service?

[More Details](#)



16% would like to
access psychology and
31% maybe

11. On occasions, we ask patients to tell us more about their story. Would you be happy for us to contact you about this in the future?

[More Details](#)



75% would be happy to be contacted to share their story further

- The questionnaire clearly demonstrates that waiting for adult cleft surgery impacts negatively on patients physical and emotional health and on their daily life
- Patients who have requested support from psychology will be offered an appointment
- Patients who have indicated that they may want to access this support will be contacted by the psychology team to discuss further