



#BuildBackBetterSLT – cleft lip and palate: what people with cleft lip and palate told us

Summary

- There were 15 responses to the aged 0-18 survey from people with cleft lip and palate.
- This represents 4% of the total 0-18 survey responses.

Survey responses

Survey responses are grouped into five sections*:

- Section 1 gives the demographic data about the survey respondents.
- Section 2 describes the respondents' background history of receiving speech and language therapy (SLT).
- Section 3 describes the respondents' experiences of SLT during lockdown (March to June 2021).
- Section 4 describes the delivery of SLT during lockdown (March to June 2020) and the respondents' experiences of this.
- Section 5 details the respondents' experiences of SLT during and after the end of lockdown.

* Percentages may not always add up to 100% as we have removed some responses with very small percentages.

More information

- Visit the dedicated #BuildBackBetterSLT webpage: bit.ly/BuildBackBetterSLT
- Contact: peter.just@rcslt.org and padraigin.oflynn@rcslt.org

Section 1: Demographic data of the respondents

The demographic data is presented first. This data was obtained from the following questions:

Question 2: Which country do you live in?

Question 3: Please tell us who you are.

Question 30: How old are you?

Question 31: How would you describe your gender?

Question 32: What is your ethnicity?

Who were the respondents

15 people completed the survey.

- Most were family members and unpaid carers (n=10) (67%).
- Of the 5 remaining respondents:
 - 3 (20%) were people having speech and language therapy.
 - 2 (13%) were paid professionals.

Country

Of the 15 respondents, nearly all lived in England.

Gender

With respect to gender, 14 of 15 respondents identified their gender.

- Most of the respondents (n=9) (64%) identified as male.
- 5 respondents (36%) identified as female.

Age

14 of 15 respondents reported their age.

- 5 respondents (36%) were aged 0-4.
- 7 (50%) were aged 5-11.
- 2 (14%) were aged 12-16.

Ethnicity

All 15 respondents reported their ethnicity.

- The majority of respondents identified as White British/Irish (n=12) (80%).
- 3 (20%) identified from another ethnic group.

Section 2: Background history of receiving SLT

In this section, the reasons why people were having SLT and when SLT started are presented. This covers the following survey questions:

Question 7: Why are you having speech and language therapy?

Question 6: What does speech and language therapy help you with?

Question 5: When did you start having speech and language therapy?

Question 24: How does your speech and language therapy help you?

Question 11: How did you have your SLT before the virus lockdown (March to June 2020)?

Condition

The survey asked respondents to identify the condition for which they were receiving SLT.

In addition to cleft lip and palate, respondents also selected comorbid conditions, including autism, hearing loss / deafness, developmental delay, developmental language disorder or language disorder, stammer, learning disability, selective mutism, ADHD, and speech sound disorder.

Reason for having speech and language therapy

All the respondents (n=15) (100%) received SLT for their speech, language and communication.

When speech and language therapy started

Of the 15 respondents, most (n=13) (87%) were in receipt of SLT before March 2020 and 2 (13%) after March 2020.

How speech and language therapy helps

All 15 respondents described how SLT helps them.

- For the majority (n=12) (80%), SLT makes their life better.
- 3 respondents (20%) said it makes their carer's life better.
- 2 respondents (13%) did not know.

How speech and language was delivered before lockdown

All 15 respondents reported how their SLT was delivered before lockdown in March 2020.

- 67% (n=10) received it in person but not at home.
- 53% (n=8) respondents reported receiving SLT in person at school or college.
- 13% (n=2) received SLT in person at home.

Section 3: Experiences of SLT during lockdown (March to June 2020)

In this section, the experiences of receiving SLT during lockdown are presented. This covers the survey questions of:

Question 8: Did your SLT change during lockdown (March to June 2020)?

Question 9: What happened to your SLT appointments?

Question 10: Why were your SLT appointments cancelled?

Changes to speech and language therapy

All 15 respondents reported changes in their receipt of SLT, with all 15 respondents (100%) receiving less SLT.

What happened to speech and language therapy appointments

14 of the 15 respondents were able to report what happened to the SLT appointments.

- For 7 respondents (50%), the speech and language therapist cancelled the appointment.
- 7 respondents (50%) received their SLT appointment online or over the phone.

Eight respondents reported reasons for the cancellations. These included closure of schools/colleges, redeployment of SLTs, closure of community/work/health centres, and shielding.

Section 4: Delivery of SLT and experiences of SLT delivery during lockdown (March to June 2020)

In this section, how SLT was delivered during lockdown is presented. This covers the survey questions of:

Question 12: Did you get SLT in person during the virus lockdown (March to June 2020)?

Question 13: Did you get your SLT over the phone during the first virus lockdown (March to June 2020)?

Question 14: How was your SLT over the phone?

Question 15: Did you get your SLT by video during the virus lockdown (March to June 2020)?

Question 16: How was your SLT help on video (online)?

Question 17: How easy was it to use the computer/laptop/tablet/smartphone?

Question 18: Did you get your SLT through other support, for example social media or printed materials during the virus lockdown (March to June 2020)?

Question 19: Did you get help updating things on your communication support tools (for example communication pictures, communication books, electronic aids)?

Question 21: What has it been like if you have to wear a mask during your SLT?

Question 22: What has it been like if your SLT has to wear a mask during your SLT?

The delivery of speech and language therapy

All 15 respondents reported on the delivery of SLT.

- 8 respondents (53%) did not receive any SLT during lockdown.
- 5 respondents (33%) did not receive SLT in person
- 2 respondents (13%) did receive SLT in person.

Speech and language therapy over the phone

7 of the 15 respondents reported on the delivery of SLT over the phone.

- 3 respondents (43%) either received SLT via the phone or tried but it did not work.
- 4 respondents (57%) did not receive SLT via the phone.

Speech and language therapy by video

7 of 15 respondents reported on the delivery of SLT by video (online).

- 4 (57%) respondents reported receipt of SLT delivery by video (online).
- 3 (43%) either did not receive SLT in this mode of delivery or tried but it did not work.

Experiences of online SLT

Six respondents reported on their experiences of video (online) delivery.

- 4 (66%) found this delivery OK.
- 2 (33%) did not like it.

Ease of using technology

In terms of the ease of use of the technology:

- 4 of the 6 respondents (75%) found it either easy or okay.
- 2 (13%) found it hard.

Communication tools

All 15 respondents reported if they had received help in updating their communication support tools. 3 (20%) reported not having any communication support tools.

Of the 80% who did have communication support tools, nearly all did not receive any help.

Section 5: Experiences of SLT during and after the end of lockdown

In this section, data on people's experiences of SLT during and after lockdown is presented. This covers the survey questions of:

Question 23: Has your communication or swallowing become worse during COVID-19?

Question 25: If you had less SLT help during lockdown (March to June 2020), tick the things it made worse.

Question 26: If you are a family member or carer of someone who had less SLT during lockdown (March to June 2020) tick the things it made worse for you.

Question 20: Have you received SLT face to face since the end lockdown (June 2020)?

Question 27: Are you worried about getting your SLT help in the future?

Question 28: What are you worried about (if you don't have SLT help?)

Impact on communication and swallowing

All 15 respondents reported if their communication or swallowing became worse during lockdown.

- 2 respondents (13%) felt their communication or swallowing was better.
- 8 (53%) reported it stayed the same.
- 3 (20%) reported it was worse.

Two respondents (13%) did not know.

Impact on people's lives of having less SLT

12 respondents identified things that were now worse for them because of having less SLT. Respondents selected more than one option.

People identified areas of their lives that had got worse because of having less SLT:

- Mental health 50% (n=6).
- Social life and friendships 42% (n=5).
- Education 42% (n=5).
- Home and domestic life 33% (n=4).
- Physical health 25% (n=3).
- Hobbies and leisure 25% (n=3).

Impact on families and carers of having less SLT

Family members and carers were also asked to describe the impact of less SLT on their own lives. Ten of the 15 respondents described this impact on their own lives with respect to the things that were now worse for them because of having less SLT.

Families and carers said their lives got worse in the following ways because of their loved ones or the people they care for having less SLT:

- Mental health (n=6) (60%).
- Home and domestic life (n=6) (60%).
- Social life and friendships (n=6) (60%).
- Education (n=3) (30%).
- Physical health (n=2) (20%).
- Hobbies and leisure (n=2) (20%).

Face to face speech and language therapy after lockdown ended

All 15 respondents confirmed if they had received SLT face to face since the end of lockdown (June 2020).

- 12 (80%) had not received any face to face SLT since June 2020.
- 3 (20%) had.

Access to speech and language therapy in the future

All 15 respondents described if they were concerned about receiving SLT in the future.

- 12 (80%) respondents were concerned.
- 3 (20%) were either not concerned or did not know.

14 of these 15 respondents went on to describe their concerns. Respondents selected more than one response. Concerns people identified if they had less SLT in the future were:

- Education (n=12) (86%).
- Social life and friendships (n=9) (64%).
- Home and domestic life (n=7) (50%).
- Mental health (n=6) (43%).
- Hobbies and leisure (n=6) (43%).
- Physical health (n=2) (14%).