



# **#BuildBackBetterSLT – neurological conditions: what people with neurological conditions told us**

## **Summary**

- There were 45 responses from people with neurological conditions to the survey for people aged 18 and over.
- This represented 45% of the total responses to the 18 years and over surveys.
- The neurological conditions included in this analysis are brain injury, dementia, multiple sclerosis, motor neurone disease, Parkinson's disease, and stroke.

## **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](https://bit.ly/BuildBackBetterSLT)
- Contact: [peter.just@rcslt.org](mailto:peter.just@rcslt.org) and [padraigin.oflynn@rcslt.org](mailto: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

45 people completed the survey.

- Most were people having speech and language therapy (n=26) (58%).
- Of the 20 remaining respondents, 16 (44%) were family members or unpaid carers and others were healthcare professionals or paid carers.

### Country

Of the 45 respondents, 33 (73%) lived in England, 6 (13%) lived in Scotland, 3 (7%) lived in Wales, and 3 (7%) lived in Northern Ireland.

### Gender

With respect to gender, 44 of 45 respondents identified their gender.

- Most of the respondents (n=27) (61%) identified as male.
- 17 respondents (39%) identified as female.

### Age

43 of 45 respondents reported their age.

- 2 respondents (0.9%) were aged 18-34.
- 5 (12%) was aged 35-54 years.
- 13 (30%) were aged 55-64 years.
- 23 (53%) were aged over 65 years.

Two respondents preferred not to say.

### Ethnicity

All 45 respondents reported their ethnicity.

- The majority of respondents identified as White British/Irish (n=43) (96%).
- 2 (4%) identified from mixed or other ethnic groups.

## 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 neurological conditions, respondents also selected comorbid conditions, including stammer, mental health, hearing loss / deafness and learning disability.

### Reason for having speech and language therapy

All 45 respondents confirmed the reasons for having SLT.

- Almost all the respondents (n=41) (91%) received SLT for their speech, language and communication.
- 22 (49%) respondents reported receipt of SLT for their eating and drinking.

### When speech and language therapy started

Of the 45 respondents, most of the respondents (n=29) (64%) were in receipt of SLT before March 2020 and 16 (36%) after March 2020.

### How speech and language therapy helps

All 45 respondents described how SLT helps them.

- For the majority (n=35) (78%), SLT makes their life better.
- 15 respondents (33%) reported it makes no difference to their lives.
- 10 respondents (22%) said it makes their carer's life better.
- 4 respondents (9%) did not know.
- 6 respondents (13%) said it made their life worse or made no difference.

## **How speech and language was delivered before lockdown**

43 of the 45 respondents reported how their SLT was delivered before lockdown in March 2020.

- 40% (n=17) received it in person but not at home.
- 33% (n=14) received SLT in person at home.
- 23% (n=10) reported receiving SLT by video/online.
- 9% (n=4) were still on a waiting list before lockdown.

## **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**

44 of 45 respondents reported changes in their receipt of SLT.

- 21 respondents (48%) received less SLT.
- 10 respondents (23%) reported they received the same amount of SLT before and during lockdown.
- 4 respondents (9%) received more.
- 2 respondents (5%) did not receive any SLT during lockdown.

Six respondents (14%) did not know.

### **What happened to speech and language therapy appointments**

28 of the 45 respondents were able to report what happened to the SLT appointments.

- For 10 respondents (36%), the speech and language therapist cancelled the appointment.
- 9 respondents (32%) received their SLT appointment online or on the phone.
- For 6 respondents (21%), the speech and language therapist cancelled the home visit appointment.
- 3 respondents (11%) cancelled their own appointments.

Sixteen respondents reported reasons for the cancellations. These included not feeling safe enough to go to appointments, shielding, closure of schools/colleges, and redeployment of SLTs.

## **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**

44 of 45 respondents reported on the delivery of SLT.

- 18 respondents (41%) did not receive any SLT during lockdown.
- 14 respondents (32%) did not receive SLT in person.

The remaining 12 respondents (27%) who did receive SLT in person received SLT at home.

### **Speech and language therapy over the phone**

26 of the 44 respondents reported on the delivery of SLT over the phone.

- 8 respondents (31%) received SLT via the phone.
- 16 respondents (62%) did not.
- 2 respondents (8%) tried but it did not work.

### **Experiences of SLT over the phone**

Ten respondents reported on their experiences of receipt of SLT over the phone.

- 3 respondents (30%) liked delivery over the phone.

- 7 respondents (70%) found the phone delivery either 'OK' or bad.

### **Speech and language therapy by video**

25 of 45 respondents reported on the delivery of SLT by video (online).

- 14 (56%) respondents reported receipt of SLT delivery by video (online).
- 11 (44%) did not receive SLT in this mode of delivery or tried but it did not work.

### **Experiences of online SLT**

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

- 10 (63%) respondents liked this delivery.
- 4 (25%) found this delivery OK.
- 2 (13%) did not like it or could not do it at all.

### **Ease of using technology**

In terms of the ease of use of the technology:

- 7 of the 16 respondents (44%) found it easy.
- 6 (38%) found it okay.
- 3 (19%) found it hard.

### **Other speech and language therapy support**

16 of the 45 respondents responded to the question about receiving SLT for other support such as printed materials or social media.

- 9 respondents (56%) did not receive this support.
- 7 (44%) did.

### **Communication tools**

44 of 45 respondents reported if they had received help in updating their communication support tools. 21 (48%) reported not having any communication support tools.

Of the 52% who did have communication support tools:

- 13 (30%) did not receive any help.
- 10 (23%) did receive help.

### **Face masks**

Respondents were asked if they or their speech and language therapist had worn a mask during their appointments and their experiences of this. Six responses were received.

- 6 of the 12 (50%) respondents reported not wearing a mask.
- 6 (50%) did.

Of the 6 who did wear a mask:

- 4 (67%) reported this was OK.
- 2 (33%) found it hard.

8 of the same 12 respondents reported their speech and language therapist wore a mask. Of these 8 respondents, 4 (50%) found it hard, and 4 (50%) found it easy or okay.



## 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 45 respondents reported if their communication or swallowing became worse during lockdown.

- 5 respondents (11%) felt their communication or swallowing was better.
- 17 (38%) reported it stayed the same.
- 18 respondents (40%) reported it was worse.

Five respondents (11%) did not know.

### Impact on people's lives of having less SLT

27 of 45 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:

- Social life and friendships 59% (n=16)
- Home and domestic life 52% (n=14).
- Mental health 52% (n=14).
- Physical health 37% (n=10).
- Hobbies and leisure 19% (n=5).

Other areas included education, employment, and speech deterioration.

## **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. 23 of the 45 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 lives said their lives got worse in the following ways because their loved ones or the people they care had less SLT:

- Mental health (n=13) (57%).
- Home and domestic life (n=13) (57%).
- Social life and friendships (n=12) (52%).
- Physical health (n=3) (13%).
- Hobbies and leisure (n=3) (13%).

## **Face to face speech and language therapy after lockdown ended**

41 of the 45 respondents confirmed if they had received SLT face to face since the end of lockdown (June 2020).

- 33 (80%) had not received any face to face SLT since June 2020.
- 8 (20%) had.

## **Access to speech and language therapy in the future**

43 of the 45 respondents described if they were concerned about receiving SLT in the future.

- 22 (51%) respondents were concerned.
- 16 (37%) were not concerned.
- 5 (12%) did not know.

28 of these 43 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:

- Social life and friendships (n=20) (71%).
- Home and domestic life (n=17) (61%).
- Mental health (n=15) (54%).
- Physical health (n=11) (39%).
- Hobbies and leisure (n=7) (25%).
- Education (n=2) (7%).
- Employment (n=2) (7%).