



#BuildBackBetterSLT - Parkinson's disease: what people living with Parkinson's told us

Summary

- There were 26 responses from people living with Parkinson's to the survey for people aged 18 and over.
- This represented 26% of the total responses we received to the 18 years and over surveys.
- Parkinson's was the single biggest condition on which we received 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 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

26 people completed the survey.

- Most were people having speech and language therapy (SLT) (n=17) (65%).
- Of the 9 remaining respondents, 8 (31%) were family members or unpaid carers.

Country

Of the 26 respondents, 21 (81%) lived in England. The remainder lived either in Scotland or Northern Ireland.

Gender

With respect to gender, all 26 respondents identified their gender.

- Most of the respondents (n=22) (85%) identified as male.
- 4 respondents (15%) identified as female.

Age

25 of 26 respondents aged 18+ reported their age.

- 2 respondents (8%) were aged 35-54.
- 5 (20%) were aged 55-64 years.
- 18 (72%) were aged over 65 years.

One respondent preferred not to say.

Ethnicity

All 26 respondents reported their ethnicity.

The majority of respondents identified as White British/Irish (n=25) (96%).

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 Parkinson's disease, respondents also selected comorbid conditions. These included mental health, brain injury, dementia, multiple sclerosis, motor neurone disease, and stroke.

Reason for having speech and language therapy

All 26 respondents confirmed the reasons for having SLT.

- Almost all the respondents (n=25) (96%) received SLT for their speech, language and communication.
- Nine (35%) respondents reported receipt of SLT for their eating and drinking.

When speech and language therapy started

Of the 26 respondents, most of the respondents (n=16) (62%) were in receipt of SLT before March 2020 and 10 (38%) after March 2020.

How speech and language therapy helps

All 26 respondents described how SLT helps them.

- For the majority (n=20) (77%), SLT makes their life better.
- 10 respondents (38%) said it makes their carer's life better.
- 2 respondents (8%) reported it makes no difference to their lives.
- 3 respondents (12%) did not know or said it made their life worse.

How speech and language was delivered before lockdown

24 of the 26 respondents reported how their SLT was delivered before lockdown in March 2020.

- 50% (n=12) received it in person but not at home.
- 21% (n=5) received SLT in person at home.
- 21% (n=5) respondents reported receiving SLT by video/online.

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

25 of 26 respondents reported changes in their receipt of SLT.

- 11 respondents (44%) received less SLT.
- 7 respondents (28%) reported they received the same amount of SLT before and during lockdown.
- 2 respondents (8%) received more.

Five respondents (20%) did not know.

What happened to speech and language therapy appointments

13 of the 26 respondents were able to report what happened to the SLT appointments.

- For 4 respondents (31%), the speech and language therapist cancelled the appointment.
- 4 respondents (31%) received their SLT appointment online.
- For 3 respondents (23%), the speech and language therapist cancelled the home visit appointment.
- 2 respondents (15%) cancelled their own appointments.

Eight respondents reported reasons for the cancellations. These included not feeling safe enough to go to appointments, shielding, closure of community and work centres 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

25 of 26 respondents reported on the delivery of SLT.

- 10 respondents (40%) did not receive any SLT during lockdown.
- 8 respondents (32%) did not receive SLT in person.

The remaining 7 respondents (28%) who did receive SLT in person received SLT at home.

Speech and language therapy over the phone

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

- 5 respondents (33%) received SLT via the phone.
- 10 respondents (67%) did not.

Experiences of SLT over the phone

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

- 3 respondents (60%) liked delivery over the phone)
- 2 respondents (40%) found the phone delivery 'OK'.

Speech and language therapy by video

14 of 26 respondents reported on the delivery of SLT by video (online).

- 7 (50%) respondents reported receipt of SLT delivery by video (online).
- 7 (50%) did not receive SLT in this mode of delivery.

Experiences of online SLT

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

- 6 (75%) respondents liked this delivery.
- 2 (26%) found this delivery OK or did not like it.

Ease of using technology

In terms of the ease of use of the technology:

- 6 of the 8 respondents (75%) found it easy.
- 2 (26%) found it OK or did not like it.

Other speech and language therapy support

Eight of the 26 respondents responded to the question about receiving SLT for other support such as printed materials or social media.

- 4 respondents (50%) did not receive this support.
- 4 (50%) did.

Communication tools

25 of 26 respondents reported if they had received help in updating their communication support tools. 14 (56%) reported not having any communication support tools.

Of the 44% who did have communication support tools:

- 7 (28%) did not receive any help.
- 4 (16%) 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. 5 respondents (83%) reported wearing a mask. Of those:

- 3 (60%) reported this was OK.
- 2 (40%) found it hard.

Five of the same 6 respondents reported their speech and language therapist wore a mask. Of these 5 respondents, 2 (40%) found it hard, 3 (60%) found it OK or easy.

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

- 3 respondents (12%) felt their communication or swallowing was better.
- 9 (35%) reported it stayed the same.
- 11 respondents (42%) reported it was worse.

Three respondents (12%) 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:

- Social life and friendships 75% (n=9)
- Home and domestic life 58% (n=7).
- Mental health 50% (n=6).
- Physical health 33% (n=4).
- Hobbies and leisure 17% (n=2).

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 26 respondents told us what got worse for their families and carers because of having less SLT. They identified:

- Mental health (n=7) (70%)
- Home and domestic life (n=7) (70%).
- Social life and friendships (n=6) (60%).
- Physical health (n=2) (20%).
- Hobbies and leisure (n=2) (20%).

Face to face speech and language therapy after lockdown ended

24 of the 26 respondents confirmed if they had received SLT face to face since the end of lockdown (June 2020).

- 20 (83%) had not received any face to face SLT since June 2020.
- 4 (17%) had.

Access to speech and language therapy in the future

25 of the 26 respondents described if they were concerned about receiving SLT in the future.

- 8 (32%) respondents were concerned.
- 15 (60%) were not concerned.
- 2 (8%) did not know.

13 of these 25 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:

- Home and domestic life (n=11) (85%).
- Social life and friendships (n=10) (77%).
- Mental health (n=8) (62%).
- Physical health (n=5) (38%).
- Hobbies and leisure (n=3) (23%).