18 years and over survey: descriptive data and analysis of the survey findings

There were 77 responses to the adult 18 years and older survey. For some questions, responses were received from all 77 respondents. For other questions, responses from a smaller sample of the 77 respondents were received. The number of respondents completing each question is given in the description of the results. The design of the survey meant for some questions respondents were able to select more than one option, often selecting 2 or 3 responses. The descriptive results are described in detail for each question.

The questions and the results are grouped into five sections and the questions addressed in each section are given.

- Section 1 gives the demographic data about the respondents who completed the survey.
- 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.

The quantitative descriptive data is given along with the qualitative data. Qualitative data originates from the free text comments for some of the questions. These comments have been grouped into categories for ease of reference.
Section 1: Demographic data of the respondents

The demographic data is presented first. This data was obtained from the following questions:
Question 1: What is your postcode?
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?
77 people completed the survey.
- More than half were adults who were receiving or had received SLT at the time of the survey (n=41) (51%).
- Of the 36 remaining respondents:
  - 33 (43%) were family members or unpaid carers.
  - 3 (4%) were paid carers.
  - 2 (3%) were healthcare providers.
  - 1 (1%) was an adult trying to access SLT.

Country
- The majority of respondents lived in England (n=62) (81%).
- 7 (9%) lived in Scotland.
- 4 (5%) in Wales.
- 4 (5%) in Northern Ireland.

![Pie chart showing the distribution of respondents by country]
Postcode
Of the 77 responses, there were 48 with valid postcode entries. The other 29 postcode entries were either incorrect or from Scotland and Wales. The English indices of deprivation (Ministry of Housing, Communities and Local Government 2019) were used to obtain data about the level of deprivation of each postcode. The indices use categories of income, living environments, employment, education, skills and barriers to housing and services. The English Indices of Multiple Deprivation (IMD) were used to identify the IMD decile for the postcodes for these 48 respondents. The IMD decile range from 1 (10% most deprived) to 10 (10% least deprived). The following table shows the decile rankings of the postcodes of the 48 respondents.

<table>
<thead>
<tr>
<th>IMD Decile</th>
<th>Number of respondents (n=48)</th>
<th>Percentage of respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Most deprived</td>
<td>1</td>
<td>1.3</td>
</tr>
<tr>
<td>2</td>
<td>3</td>
<td>3.9</td>
</tr>
<tr>
<td>3</td>
<td>4</td>
<td>5.2</td>
</tr>
<tr>
<td>4</td>
<td>3</td>
<td>3.9</td>
</tr>
<tr>
<td>5</td>
<td>1</td>
<td>1.3</td>
</tr>
<tr>
<td>6</td>
<td>10</td>
<td>13.0</td>
</tr>
<tr>
<td>7</td>
<td>10</td>
<td>13.0</td>
</tr>
<tr>
<td>8</td>
<td>5</td>
<td>6.5</td>
</tr>
<tr>
<td>9</td>
<td>6</td>
<td>7.8</td>
</tr>
<tr>
<td>10 Least deprived</td>
<td>5</td>
<td>7.8</td>
</tr>
<tr>
<td>Total</td>
<td>48</td>
<td>100%</td>
</tr>
</tbody>
</table>
Gender
76 of the 77 respondents identified their gender.
- More than half of the respondents (n=48) (63%) identified as male.
- 27 respondents (36%) identified as female.

The remaining response was unclear citing his/her residence as a care home for both male and female residents.

Age
76 of the 77 respondents reported their age.
- Most respondents (n=22) (29%) were 65 years and over.
- 16 (21%) were aged 55-64 years.
- 13 (17%) were aged 18-25 years.
- 10 (13%) were aged 25-34 years.
- 7 (9%) were aged 35-44 years.

4 respondents (5%) reported not knowing their age and 4 (5%) preferred not to say.
Ethnicity
75 of the 77 respondents reported their ethnicity.
- The majority of respondents identified as White British/Irish (n=68) (91%).
- 2 (3%) identified as mixed or multiple ethnic group.
- 1 (1%) from another white background.
- 1 (1%) as Black/African/Caribbean/Black British.
- 1 (1%) as Asian/Asian British,
- 1 (1%) as another ethnic group.

One respondent (1%) preferred not to say.
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 SLT?
Question 6: What does SLT help you with?
Question 5: When did you start having SLT?
Question 24: How does your SLT 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.

77 responses were received with many respondents selecting more than one condition indicating complex comorbidities. Conditions selected included:

- Parkinson’s Disease (n= 24) (31%) - the condition with the most responses.
- Learning disability (n=11) (14%).
- Stroke (n=11) (14%).
- Brain injury (n=10) (13%).
- Autism (n=9) (12%).
- Hearing loss and deafness (n= 6) (8%).
- Language disorder (n=6) (8%).
- Stammer (n=6) (8%).
- Developmental delay (n=4) (5%).
- Motor neurone disease (n=3) (4%).
- Dementia (n=3) (4%).
- Mental health diagnoses (n=2) (3%).
- Selective mutism (n=1) (1%).

The only condition not selected was head and neck cancer. Two respondents (3%) were waiting for a diagnosis.

13 respondents selected the other category and cited the following conditions:

- Suspected COVID-19 (n=2) (3%).
- Multiple system atrophy (n=2) (3%).
- Multiple sclerosis (n=1) (1%).
- Voice rehabilitation (n=1) (1%).
- Muscular dystrophy (n=1) (1%).
- Non-Hodgkin’s lymphoma (n=1) (1%).
- Angelman syndrome (n=1) (1%).
- Aphasia (n=1) (1%).
- Complications from laryngitis (n=1) (1%).

Reason for having speech and language therapy
All 77 respondents confirmed the reasons for having SLT.
- Almost all the respondents (n=69) (90%) received SLT for their speech, language and communication.
- 26 (34%) respondents reported receipt of SLT for their eating and drinking.

5 respondents selected other citing the following reasons:
- For all sorts (n=1) (1%).
- Tube feeding (n=1) (1%).
- Visual support (n=1) (1%).
- Staff training (n=1) (1%).
- Involvement in the initial diagnosis of MND (n=1) (1%).

When speech and language therapy started
Of the 77 respondents, more than two-thirds of the respondents (n=52) (68%) were in receipt of SLT before March 2020 and 25 (33%) after March 2020.
How speech and language therapy helps
76 of the 77 respondents described how SLT helps them.
- For the majority (n=58) (76%), SLT makes their life better.
- 22 respondents (29%) said it makes their carer’s life better.
- 4 (5%) respondents explained it makes their life worse.
- 7 respondents (9%) reported it makes no difference to their lives or the lives of their carers.
- 7 respondents (9%) did not know.

How speech and language was delivered before lockdown
73 of the 77 respondents reported how their SLT was delivered before lockdown in March 2020.
- 41% (n=30) received SLT outside of the home in health care settings.
- 29% (n=22) received it in person either at home.
- 14% (n=10) in school or college.
- 15% (n=11) respondents reported receiving SLT online and 1% (n=1) by phone.

7 respondents were not receiving SLT 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

75 of the 77 respondents reported changes in their receipt of SLT.

- Only 16 respondents (21%) reported they received the same amount of SLT before and during lockdown.
- More than half of the respondents (n=39) (52%) received less SLT.
- 8 (11%) received more.

12 respondents (16%) were unable to confirm.

Changes to speech and language therapy by postcode area

Responses were broken down using the English Indices of Multiple Deprivation (IMD). IMD decile 1 to 5 was collapsed into Group 1/Most deprived and IMD decile 6 to 10 was collapsed into Group 2/Least deprived. There were 12 respondents in Group 1 (most deprived) and 36 respondents in Group 2 (least deprived).
This has revealed that:

- Of those who saw an increase in their SLT during lockdown, a higher percentage lived in the most deprived areas than the least deprived areas.
- A higher percentage of people living in the least deprived areas had the same amount of SLT than people living in the most deprived areas.
- A higher percentage of people living in the most deprived areas received less SLT during lockdown than people living in the least deprived areas.

<table>
<thead>
<tr>
<th></th>
<th>Group 1 Most deprived</th>
<th>Group 2 Least deprived</th>
</tr>
</thead>
<tbody>
<tr>
<td>It was more</td>
<td>2 (16.7%)</td>
<td>5 (13.8%)</td>
</tr>
<tr>
<td>It was the same</td>
<td>2 (16.7%)</td>
<td>11 (30.5%)</td>
</tr>
<tr>
<td>It was less</td>
<td>6 (50%)</td>
<td>15 (41.6%)</td>
</tr>
<tr>
<td>I don’t know</td>
<td>2 (16.7%)</td>
<td>5 (13.8%)</td>
</tr>
<tr>
<td>Total</td>
<td>12 (100%)</td>
<td>36 (100%)</td>
</tr>
</tbody>
</table>

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

44 of the 77 respondents were able to report what happened to the SLT appointments.

- For 16 of the 44 respondents (35%), the speech and language therapist cancelled the appointment.
- 13 respondents (30%) received their SLT appointment online.
- 2 respondents (5%) received a phone appointment.
- For 11 of the 44 respondents (25%), the speech and language therapist cancelled the home visit appointment.
- 2 respondents (5%) cancelled their own SLT appointments.

31 respondents reported reasons for the cancellations. These ranged across:

- Shielding (n=5) (16%).
- Closure of health centres (n=3) (10%).
- Feeling unsafe to attend appointment (n=2) (7%).
- Closure of community/work centre (n=2) (7%).
19 respondents reported other reasons including:

- SLTs being redeployed.
- Cancellation of group SLT sessions.
- SLTs unable to make visits to care homes.
- SLTs having COVID-19,
- Closure of colleges.
- No contact received from SLT services.

What people told us about why their appointments were cancelled during lockdown

Some respondents were not contacted at all, while others were contacted only to say that appointments were cancelled due to lockdown. In a few cases, face-to-face appointments were not able to happen, particularly in care homes.
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
73 of the 77 respondents reported on the delivery of SLT.

- Nearly half of the respondents (n=32) (44%) did not receive any SLT during lockdown.
- 24 respondents (33%) did not receive SLT in person.

Of the remaining 17 respondents who did receive SLT in person:

- 16 (22%) received SLT at home.
- 1 (1%) received SLT outside of the home.
Speech and language therapy in person by postcode area during lockdown

In relation to whether people had in person SLT during lockdown:

- A lower percentage of respondents from the most deprived areas received in person SLT during lockdown than people from the least deprived areas - 17% and 27% respectively.
- A higher percentage of people living in the most deprived areas received no in-person SLT than people living in the least deprived areas.
- A higher percentage of people living in the least deprived areas reported not having any SLT at all than people living in the most deprived areas.

<table>
<thead>
<tr>
<th></th>
<th>Group 1 Most deprived</th>
<th>Group 2 Least deprived</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>2 (16.7%)</td>
<td>10 (27%)</td>
</tr>
<tr>
<td>I did not receive SLT in person during the virus lockdown</td>
<td>7 (58.3%)</td>
<td>12 (32.4%)</td>
</tr>
<tr>
<td>I did not get any SLT during the virus lockdown</td>
<td>3 (25%)</td>
<td>13 (35.1%)</td>
</tr>
<tr>
<td>Missing</td>
<td>0</td>
<td>2 (6.4%)</td>
</tr>
<tr>
<td>Total</td>
<td>12 (100%)</td>
<td>37 (100%)</td>
</tr>
</tbody>
</table>
Speech and language therapy over the phone
43 of the 77 respondents reported on the delivery of SLT over the phone.
- 11 of the 43 respondents (26%) received SLT via the phone.
- 28 of the 43 respondents (65%) did not.
- 4 respondents (9%) attempted to receive SLT via the phone but this proved unsuccessful.

Experiences of speech and language therapy over the phone
15 respondents reported on their experiences of receipt of SLT over the phone.
- 9 of the 15 respondents (60%) found the phone delivery ‘OK’.
- 3 (20%) liked the phone delivery.
- 2 (13%) did not like the phone delivery.

1 respondent (7%) reported not being able to engage in SLT over the phone.
What people liked about speech and language therapy over the phone
Those who accessed SLT over the phone were grateful to have some form of contact with a speech and language therapist, because it helped them feel supported. Additionally, phone-based check-ins helped them consistently engage with resources.

What people did not like about speech and language therapy over the phone
The primary difficulty that respondents noted was that phone appointments were no replacement for face-to-face appointments and it was more difficult to assess via phone. Additionally, some found it difficult to access therapy over the phone. They also mentioned that it was hard to lose the peer support that they had found via in-person appointments or group sessions.

Speech and language therapy by video
43 of the 77 respondents reported on the delivery of SLT by video (online).
- 25 (58%) of the 43 respondents reported receipt of SLT delivery by video (online).
- 15 (35%) did not receive SLT in this mode of delivery.
- 3 respondents (7%) attempted to secure SLT by video but this proved unsuccessful.

Experiences of online speech and language therapy
28 respondents reported on their experiences of video (online) delivery.
- 16 of the 28 (57%) respondents liked this delivery.
- 9 (32%) found this delivery ‘OK’.
• 3 (11%) were not able to engage in this delivery.

**Ease of using technology**

In terms of the ease of use of the technology:

- 13 of the 28 (46%) respondents found it easy to use computers and phones for SLT.
- 11 (39%) found it OK.
- 3 (11%) found it hard
- 1 (4%) reported not being able to use this technology.

**Difficulties using technology**

8 respondents explained why it was hard to engage with this technology.

- 3 respondents (38%) reported unreliable internet connections.
- 3 (38%) cited a lack of experience with the technology.
- 2 (25%) reported general difficulties.
- 1 (12%) cited security issues as a barrier.

**Other speech and language therapy support**
28 of the 77 respondents responded to the question about receiving SLT for other support, such as printed materials or social media.
- 14 respondents (50%) did receive this support.
- 14 (50%) did not.

**Communication tools**
75 of the 77 respondents responded to the question asking if they had received help in updating their communication support tools. 40 (53%) reported not having any communication support tools.

Of the 47% who did have communication support tools:
- 21 (28%) did not receive any help.
- 14 (19%) 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. 18 responses were received.

- 10 of the 18 (56%) respondents reported not wearing a mask.
- 8 (44%) did.

Of the 8 who did wear a mask:
- 4 (22%) reported this was ‘OK’.
- 3 (17%) found it hard.
- 1 (6%) found it easy.
13 of the same 18 respondents reported their speech and language therapist wore a mask. Of these 13 respondents, 6 (33%) found it hard.
- 5 (28%) found it OK.
- 2 (11%) found it easy.

What people told us about their communication support during lockdown
Many people lost support completely and found it difficult to access online resources. However, online resources were helpful for some and they were grateful to still have that link to their speech and language therapist. Those who received phone check-ins from their speech and language therapist found them helpful and motivating. Those who accessed SLT via video found it useful, but most did not see it as a replacement for face-to-face appointments. For some, a majority of their communication support came from family members and carers, a few of whom benefitted from liaising with a speech and language therapist.

What people told us about their speech and language therapy
Many accessed SLT to support their speech, language and communication. Some received support on their eating and drinking, and were grateful for the speech and language therapist's input in this area. SLT allowed them to feel more confident in expressing themselves. A few accessed SLT in a group setting. Family members and carers brought up that they were the primary contact for the speech and language therapist and were grateful to have this contact and guidance. A few had not yet received SLT due to waiting lists or difficulty accessing support.
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 15: 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

76 of the 77 respondents reported if their communication or swallowing became worse during lockdown.

- Only 8 respondents (11%) felt their communication or swallowing was better.
- 28 (37%) reported it was worse.
- 33 respondents (43%) reported their communication or swallowing stayed the same.
- 7 (9%) did not know.

![Chart showing the distribution of responses regarding communication and swallowing during lockdown.](chart.png)
**Impact on people's lives of having less speech and language therapy**

43 of the 77 respondents confirmed they had less SLT during lockdown. These 43 respondents identified things that were now worse for them because of having less SLT. Respondents selected more than one option.

The thing that people said had most got worse as a result of having less SLT was their mental health. 56% (n=24) said their mental health had deteriorated.

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

- Social life and friendships identified by 54% (n=23) of respondents.
- Home and domestic life reported by 51% (n=22).
- Physical health 23% (n=10).
- Education 16% (n=7).
- Hobbies and leisure 14% (n=6).
- Employment 7% (n=3).

Other aspects reported were speech deterioration, lack of access to physical and social activities, and loss of skills. One respondent reported an improvement in their self-reliance.

**Impact on families and carers of having less speech and language therapy**

Family members and carers were also asked to describe the impact of less SLT on their own lives. 37 of the 77 respondents described this impact on their own lives with respect to the things that were now worse for them because of having less SLT.

Again, the thing that people said had most deteriorated by their loved ones or the people they care for having less SLT was their mental health (n=23) (62%) and their home and domestic life (n=23) (62%).
Families and carers lives said their lives got worse in other ways too because of having less SLT:

- Social life and friendships (n=19) (51%).
- Physical health (n=7) (18%).
- Hobbies and leisure (n=5) (14%).
- Education (n=3) (8%).
- Employment (n=2) (5%).

Other aspects reported were an increased need for support, lack of respite care and therefore increased caring responsibilities, social isolation and increased concerns about the future.

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

76 of the 77 respondents confirmed if they had received SLT face to face since the end of lockdown (June 2020).

- 58 (76%) had not received any face-to-face SLT since June 2020.
- 18 (24%) had.
Face-to-face speech and language therapy since the end of the first UK wide lockdown (June 2020) by postcode area

In relation to whether people had in person SLT after lockdown ended:

- Of the people who did have face-to-face SLT after lockdown, a considerably higher percentage did so in the least deprived areas rather than the most deprived areas.
- A considerably higher percentage of people living in the most deprived areas also had less in-person SLT after lockdown ended than people living in the least deprived areas.

<table>
<thead>
<tr>
<th></th>
<th>Group 1 Most deprived</th>
<th>Group 2 Least deprived</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>2 (16.7%)</td>
<td>11 (29.7%)</td>
</tr>
<tr>
<td>No</td>
<td>10 (83.3%)</td>
<td>26 (70.3%)</td>
</tr>
<tr>
<td>Total</td>
<td>12 (100%)</td>
<td>37 (100%)</td>
</tr>
</tbody>
</table>

Access to speech and language therapy in the future

73 of the 77 respondents described if they were concerned about receiving SLT in the future. There was a fairly even split:

- 36 (49%) respondents were concerned.
- 29 (40%) were not concerned.
- 8 (11%) did not know.
54 of these 73 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=35) (65%).
- Mental health (n=33) (61%).
- Home and domestic life (n=29) (37%).
- Physical health (n=20) (37%).
- Hobbies and leisure (n=13) (24%).
- Education (n=10) (19%).
- Employment (n=10) (19%).

Other aspects of concern were decreased self-esteem, trouble holding a conversation, going out in public, basic communication skills, implications on future care due to diminishing communication, lack of support for the service, monitoring, access to services if SLT remains scaled down, and the long-term impact of access to resources.

**Other things people told us about their speech and language therapy**

Some respondents discussed how grateful they were for SLT, both in person and online, particularly noting how supportive their speech and language therapist had been throughout lockdown. Many found access to SLT particularly difficult during lockdown. For some, this was because online and video resources were not accessible due to service users’ conditions, while for others it was because the service lacked resources or transitions led to complications in access at the new location. Even where online alternatives were provided, a few recognised a substantial difference without face-to-face appointments, which they preferred. When printed resources were provided respondents found them useful. Some needed SLT to improve their communication, but struggled to access it in the first instance due to these communication difficulties.
Considerations for the descriptive analysis
Response rates varied across the 29 questions in the survey with some questions receiving a complete response rate of 77 responses and others a minimum of 28 responses. This variation in responses did limit the extent of the descriptive analysis completed. Some of the questions in the survey overlapped in content, which meant there was not always a consistent response rate across these questions. This means there were some differences in the responses received to questions asking the same content.