



## SWEDA CORONAVIRUS LOCKDOWN SURVEY

*“Threat of food shortages make the urge to hoard harder to ignore and the massive focus on weight gain during lockdown is hard to tolerate.”*

People suffering from eating disorders very often experience high levels of anxiety and other troubling feelings during normal life. With day-to-day life severely disrupted and a sense that our clients are struggling, we wanted to find out more about how they are coping during the COVID-19 crisis.

We designed our questionnaire to look at the emotional experience of clients as well as the particular areas that they were finding challenging. We also asked about the services they normally receive to help them (if any) and their experiences of seeking help and support at this time. Finally, we collected some basic demographics from our respondents. The survey was conducted in mid-May when full lockdown had been in place for about six weeks. At the time, there had been no clear guidance on lifting any restrictions. We hope to repeat the survey later in the year to provide some more data on how things have changed.

Our survey was distributed, by email, to 501 people on the SWEDA database – largely our service users but also some carers, supporter and healthcare professionals. We also shared the survey on social media and received a number of responses from people who are not clients of SWEDA but who are, or have been, affected by eating disorders. In total we received 48 responses – a return rate of approximately 10%.

### KEY FINDINGS

Some of the highlights of the report are shown here – further detail can be found in the body of the report.

- 50% of people said that they felt anxious all or much of the time
- Other words that were rated highly were ‘Fearful’, ‘Powerless’, ‘Stuck’ and ‘Grateful’.
- 65% of respondents said that lockdown had made their eating disorder harder to manage
- The biggest challenge for most people was ‘not feeling in control of my life’ with 65% saying they felt this way.
- 35% said that they had found it harder to access their usual forms of support such as their GP, CMHT or other similar services. The rest said that it had been about the same or that they did not usually use these services
- Of the people who usually accessed SWEDA support, 79% said that it was ‘the same’ or ‘easier’ to access SWEDA services.
- Several participants provided some feedback on SWEDA’s support during lockdown. Some of the comments are shown below

*“I have been incredibly grateful to have weekly counselling during the lockdown. In all honesty, it has been a lifeline and is the most important support I receive.”*

*“SWEDA and my counsellor have been really supportive during this time and gone above and beyond”*

*“Just so grateful for someone being on the end of a phone, message and someone willing to just be ‘real’ about the situation too x”*

*“I am currently in weekly contact with my counsellor via telephone, and she has been an incredible support. Not only does she provide me with this appointment but has been sending me useful links to online courses, skills and things I might find interesting in order to help during lock-down. I just want to say how helpful it has been and that I am so grateful for the service SWEDA provide.”*



## DEMOGRAPHICS

Overall, we had 48 responses. 32 of these were from clients within SWEDA's area of operation (Somerset and surrounds) whilst the rest came from across the UK including Scotland and Wales. Some of the demographics of the respondents are shown in the tables below

| GENDER | NO OF RESPONSES |
|--------|-----------------|
| Male   | 6.25%<br>3      |
| Female | 93.75%<br>45    |
| Other  | 0%<br>0         |

| AGE RANGE | RESPONSES    |
|-----------|--------------|
| 16-18     | 8.16%<br>4   |
| 19-24     | 14.29%<br>7  |
| 25-64     | 77.55%<br>37 |

Our respondents were largely female although one male in particular commented that: *"Older Men get ED's - I'm sure you realise this however it's not understood by the general public"*. The age range was mostly represented by adults although we got 11 responses from young people from 16-25.

The government census records that the South West of England consists of 91.8% who report their ethnicity as 'White British'. This is reflected in our results as shown:

(NB: Ethnicities not selected by any respondent have been removed for space reasons)

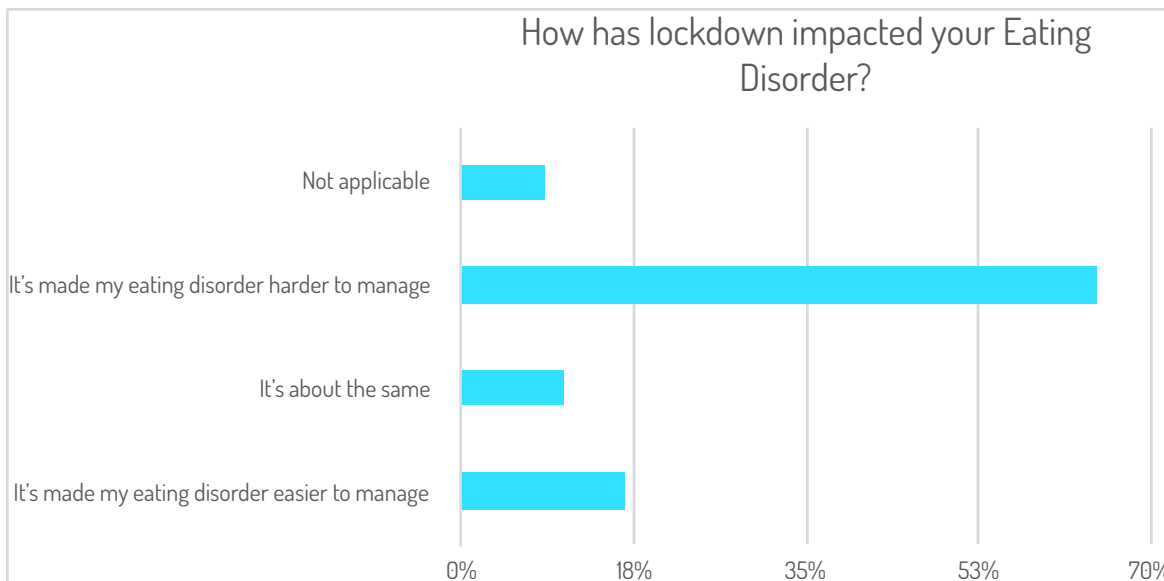
| ETHNICITY                       | RESPONSES    |
|---------------------------------|--------------|
| Bangladeshi                     | 2.08%<br>1   |
| Mixed White and Black Caribbean | 2.08%<br>1   |
| White British                   | 95.83%<br>46 |

We asked respondents to name the eating disorder they felt most closely resembled theirs. Only 47 answered this question – one respondent stated in the comments that she had Emetophobia and that this wasn't listed.

| TYPE OF EATING DISORDER                    | RESPONSES    |
|--|--------------|
| Anorexia                                   | 50.00%<br>23 |
| Bulimia                                    | 13.04%<br>6  |
| Binge Eating Disorder                      | 28.26%<br>13 |
| OSFED                                      | 10.87%<br>5  |
| ARFID                                      | 0.00%<br>0   |
| I care for someone with an eating disorder | 6.52%<br>3   |
| I am a health care professional            | 4.35%<br>2   |

## WHAT OUR RESPONDENTS TOLD US — MANAGING EATING DISORDERS IN LOCKDOWN

We asked respondents how lockdown had affected their ability to manage their eating disorder. 31 people or 65% said that the lockdown rules and the concerns around COVID-19 had made their eating disorder harder to manage while 13 people or 27% said it had made it easier or 'about the same'.



In terms of those who said that their eating disorder had been harder to manage, some participants included comments to give more detail. Some of these are shown here:

- *"Threat of food shortages make the urge to hoard harder to ignore and the massive focus on weight gain during lockdown is hard to tolerate."*
- *"I cannot shop for myself due to being in the vulnerable category and find it difficult not being able to get items I usually buy."*
- *"No gym, no work, all my thoughts are on my eating disorder and how much I weigh, restricting, and losing weight. I cannot go out with friends or my boyfriend or the gym with helped my mental wellbeing."*
- *"It's harder to get safe foods and I feel more guilty for eating when I'm not doing anything to earn it"*
- *"I have lost my routine and fallen back into my old habits. The stress of the pandemic and the issues associated with it has made me feel out of control with my ED."*
- *"I was prematurely discharged from ED inpatient due to COVID. I have a challenging home environment, isolating with family who struggle to support me. The outpatient teams not doing face to face, only 2 phone calls a week. Lack of safe foods. Reduces physical activity. Less distractions/activities to keep occupied. Missing friends."*
- *"I was seeing the ED clinic. That has stopped and I haven't had contact since start of lockdown. I know I am at a healthier weight and eating every day but I feel really out of control and conflicted in my head. It feels a battle between my ED and my recovery."*

- “I was starting to increase the amount of food and variety of foods that I eat-have not been able to get hold of the foods that I had planned.”
- “Uncontrolled eating-usually as a result of feeling upset, frustrated. I Can't get space for myself.”

Of those who had found that lockdown made their eating disorder easier to manage, comments included:

- “It has simplified life - removed stress of work and chances to buy binge food”
- “It has allowed me time to focus on recovery in order to improve my health and lessen my risk.”
- “It's not been as easy to buy so much food for binges, with shops limiting how much people can buy and feeling as though others are looking at what you're buying more.”
- “I've had more time to prepare food”
- “I've enjoyed having my food delivered; it removes the stress of shopping”

Having asked people which eating disorder they identified as having, we were able to break down the responses by eating disorder type. As there are fewer respondents for Bulimia, Binge Eating Disorder and OSFED, it is not possible to draw any real conclusions from this. It largely reflects the overall results in that most people found their eating disorder harder to manage in lockdown conditions with a few findings that the controlled atmosphere and increased time available helped them to manage.

|          | Number of respondents | UNDER LOCKDOWN, MY EATING DISORDER IS: |     |                |     |                  |     |     |     |
|----------|-----------------------|--|-----|----------------|-----|------------------|-----|-----|-----|
|          |                       | Easier to manage                       |     | About the same |     | Harder to manage |     | N/A |     |
| Anorexia | 23                    | 2                                      | 9%  | 3              | 13% | 18               | 78% | 0   | 0%  |
| Bulimia  | 5                     | 1                                      | 20% | 0              | 0%  | 4                | 80% | 0   | 0%  |
| BED      | 10                    | 3                                      | 30% | 2              | 20% | 5                | 50% | 0   | 0%  |
| OSFED    | 5                     | 1                                      | 20% | 0              | 0%  | 3                | 60% | 1   | 20% |

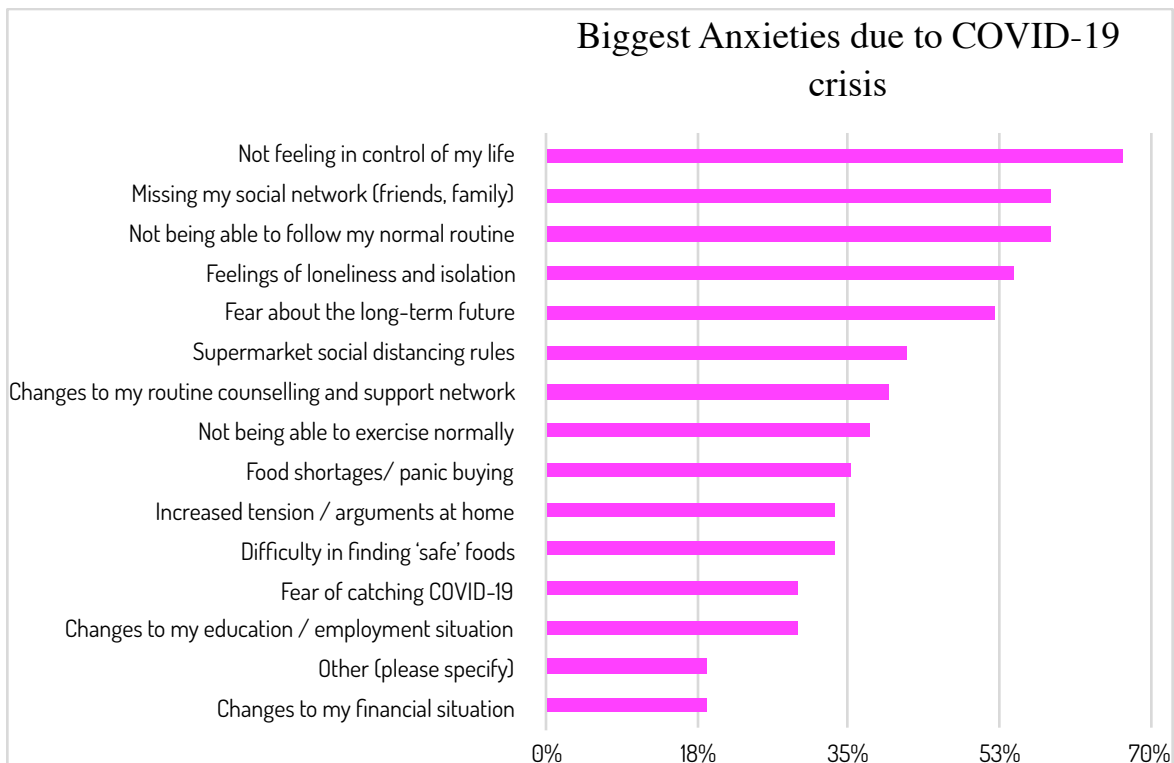
## WHAT OUR RESPONDENTS TOLD US — WHAT HAS BEEN MOST DIFFICULT FOR YOU?

We asked the participants to choose some statements that described various difficulties that they might experience during lockdown based on what we already know and on what clients have told us.

The top concern was the feeling of not being in control whilst concerns around food, and other more eating-disorder-specific concerns such as panic buying, and shopping under social distancing conditions were also felt by a significant proportion of clients. The top three concerns were:

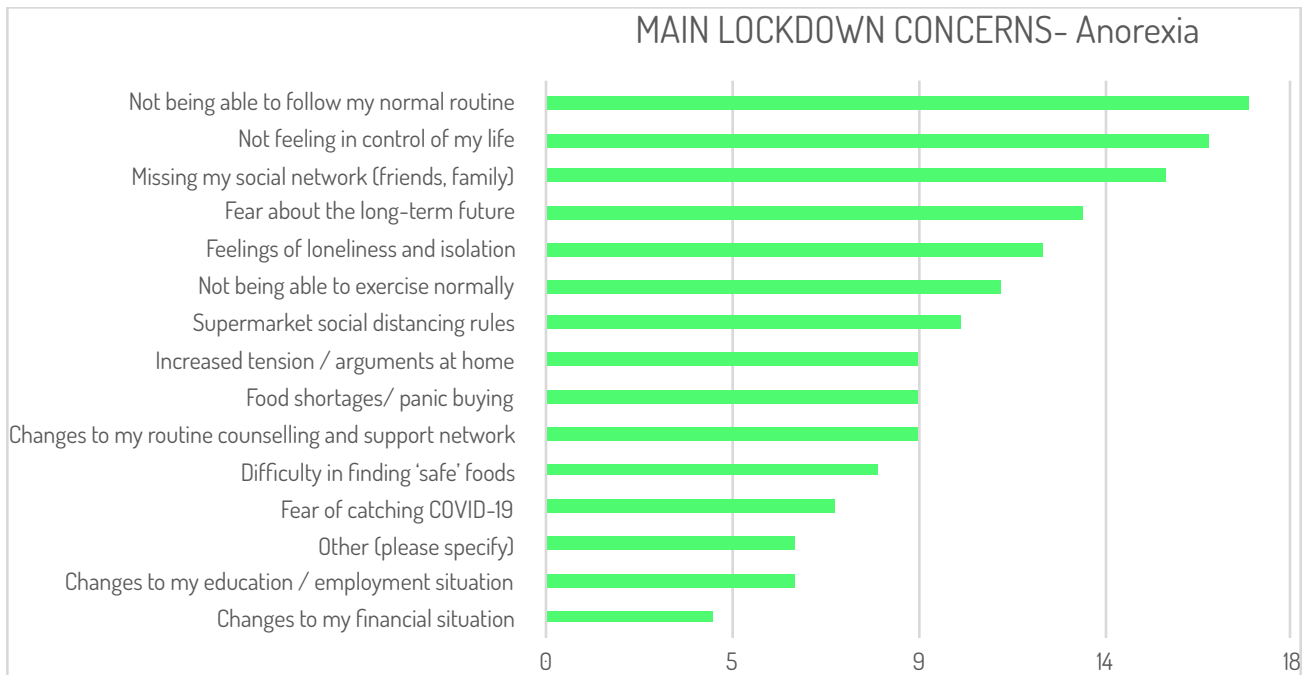
- 'Not feeling in control of my life'
- 'Missing my social network - friends, family'
- 'Not being able to follow my normal routine'

The chart shows more detail:



These top three concerns were replicated in those participants who identified as having **ANOREXIA** as shown in the chart below although, as these people made up the largest part of those who took part, this is not especially surprising.

- 'Not feeling in control of my life'
- 'Not being able to follow my normal routine'
- 'Missing my social network – friends, family'

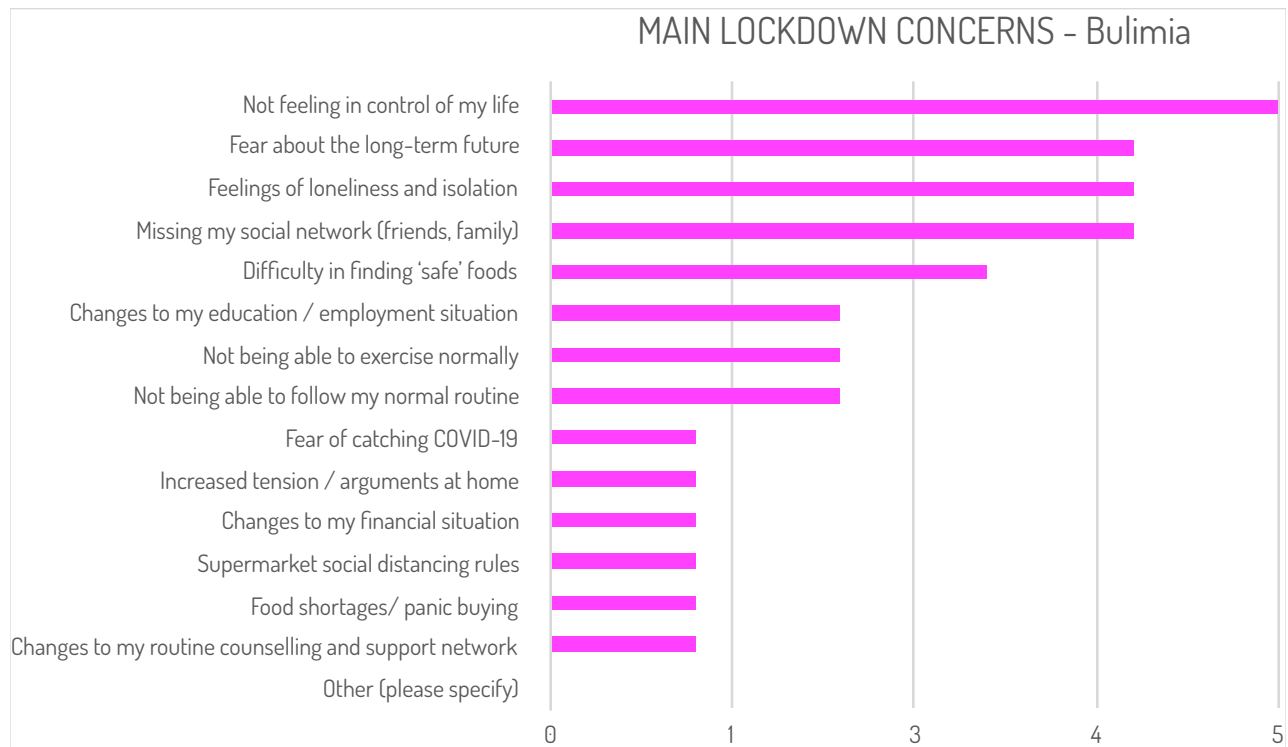


Amongst the respondents identifying as having **BULIMIA**, there was some difference with the top three concerns being:



- Not feeling in control of my life
- Fear about the long-term future
- Feelings of isolation

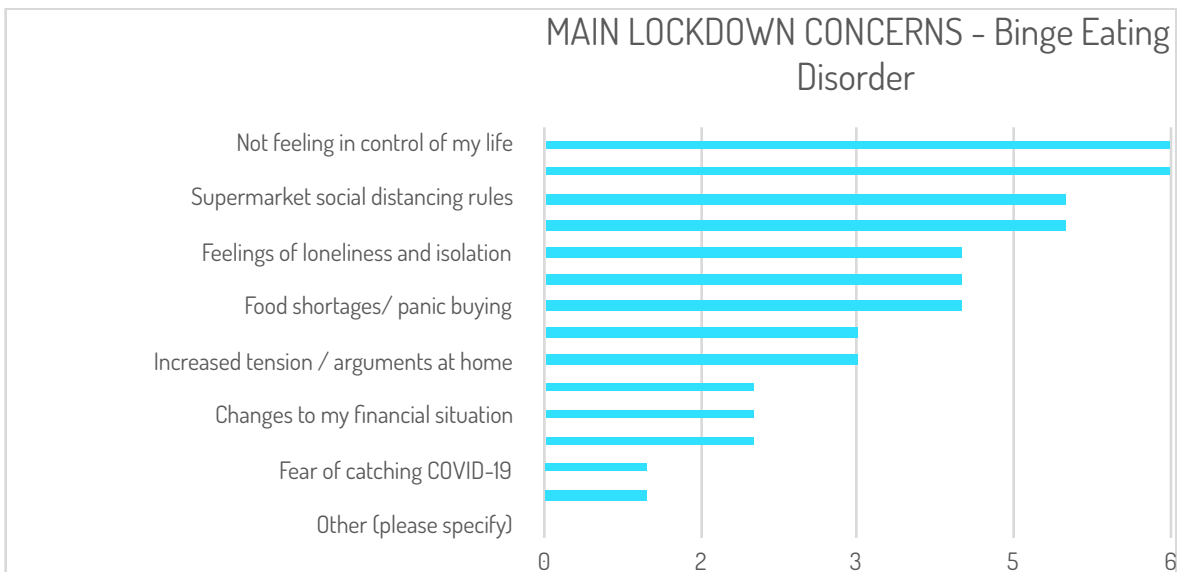
However, with there being such a small number of respondents with Bulimia as their main concern, it is not possible to know if this would be replicated in a larger sample.



In **BINGE EATING DISORDER**, the top three concerns were:

- Not feeling in control of my life
- Not being able to follow my normal routine
- Supermarket social distancing rules/ Changes to my routine counselling and support network

The main difference in BED is the reference to food shopping and the difficulties caused by having rules within supermarkets, despite two respondents with BED saying that supermarket limitations had helped them avoid buying binge foods perhaps reflecting how this may be both 'helpful' and 'a concern' at the same time.



Finally, we gave a space for respondents to write their own 'biggest concern' – here are some of the comments we collected:

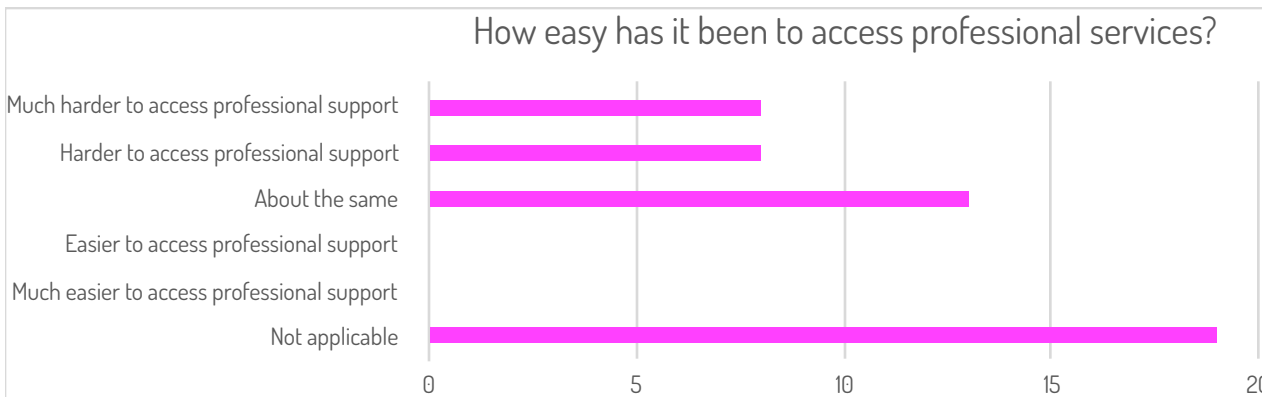
- “Not being able to go volunteering, adult community learning course and see peers with EDs, as these are all protective factors that help me manage my ED and give me purpose and meaning in life outside my ED”
- “As a carer trying to normalise a difficult situation so as prevent possible triggers for relapse”
- “Feeling like I am putting my family at risk if I ask them to go to particular shops (I am too ill to go to shops myself, parents who care for me are over 70)”
- “Fear of loved ones being ill”

## WHAT OUR RESPONDENTS TOLD US — ACCESS TO HELP IN LOCKDOWN

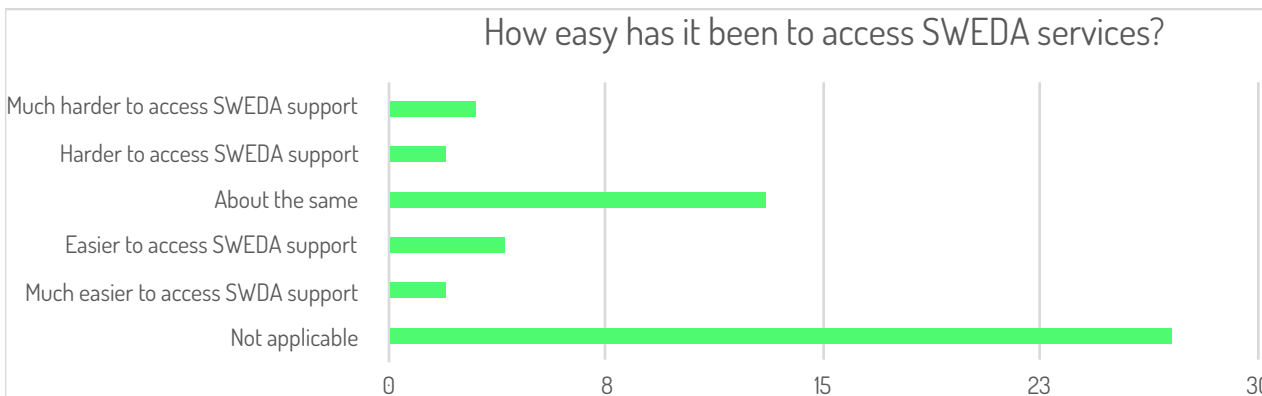
We asked our participants about the help they normally received from SWEDA and other organisations and how easy it had been for them to access it.

Initially we asked how easy it had been for people to access services such as their GP, Community Mental Health Teams or specialist Eating Disorder services since lockdown began. The largest group of our participants (40%) did not usually have access to these services for their eating issues whilst, of those who did, about half (45%) had had about the same ease of access whilst the rest (55%) said they had found it harder or much harder.

The overall results are shown below.



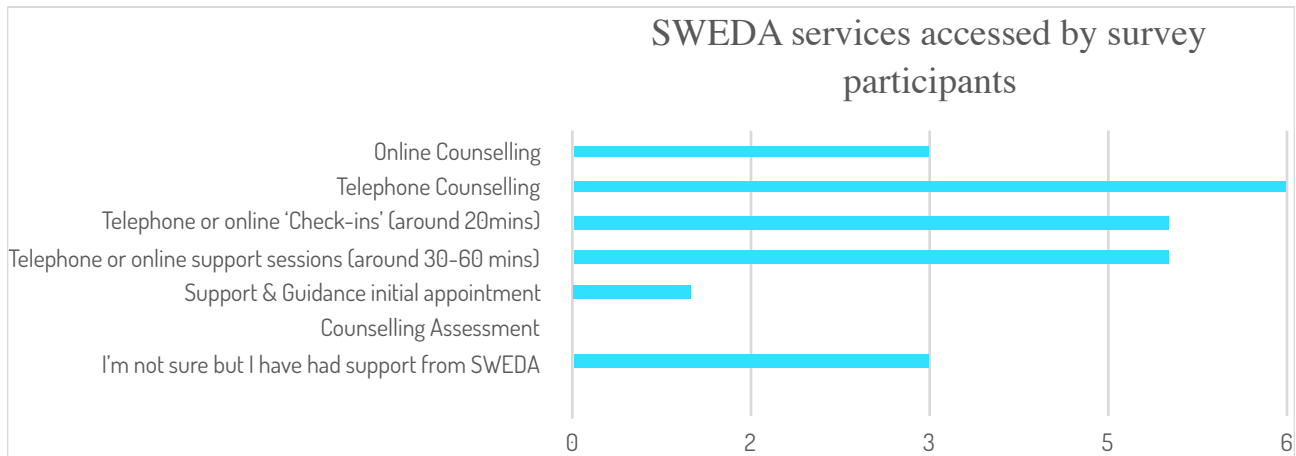
We asked our participants the same questions about SWEDA services. Again, the largest group was those who were not currently receiving any service from SWEDA (56%). Of the remaining respondents, 62% found ease of access about the same, 29% found it easier or much easier to access services whilst a small number 24%, had found it harder.



Before lockdown began, all SWEDA clients were contacted to ask them how they would like to be supported given the restrictions in place. There were some clients who did not have access to any private space or time to receive a service and this is likely to be, at least in part, the reason why some people answered that they had found access harder.

In the case of both SWEDA and other services, access is necessarily limited by a person's ability to find private space, free time and the necessary psychological space to engage. Other factors might be availability of practitioners, appointment time limitations or reservations about receiving a non-face-to-face service.

Finally, for information, the chart below shows which types of service our participants who were accessing SWEDA services were receiving.



## CONCLUSION

Lockdown has presented significant challenges for everyone's mental wellbeing but for those who have difficulties maintaining good mental health, it is especially challenging with a high risk of relapse or worsening of symptoms. We think our survey shows some of the ways in which this has manifested within eating disorders specifically and the difficulties that this brings.

Coronavirus, COVID-19, and the restrictions it has forced upon society, have presented huge logistical problems in terms of supporting our clients at SWEDA and, according to colleagues in other organisations, elsewhere as well.

At the beginning of the pandemic, we created a series of ways in which our existing clients could carry on accessing the support that they were receiving by adjusting our working practices and working flexibly with what our clients and counsellors could manage. Many of our clients, some needing more encouragement and support than others, were able to carry on working with us. We have successfully made the transition as an organisation to remote working with everyone in the organisation being able to work from home. We are immensely proud of what we have achieved for our clients during the pandemic and have used the opportunity to innovate and find new ways of working. The survey also has begun to tell us how well these are working and what we might do to improve our services.

As we carry on working in a COVID-19 environment over the next few weeks and months, we hope to repeat this survey later in the year to find out how things have changed and what the next steps might be. This will enable us to plan what we might need to do to keep on offering support to people with eating disorders in Somerset and beyond.

