

Brittle Bone Society

Covid-19 Survey Analysis



This report analyses data from 107 respondents. The survey asked Brittle Bone Society members from around the UK and Ireland about their experiences of remote consultations during lockdown. How Covid-19 has affected their treatment, and interactions with healthcare professionals and The Brittle Bone Society.

75% of the respondents had OI, 23% were parents of those with OI, and 2% were carers of an individual with OI.

77% of respondents were based in England, 10% in Scotland, 5% in Northern Ireland, 4% in Wales, 2% in Ireland and 2% did not state their area.

Responses in relation to which hospitals individuals attended

Adult Hospital attended	Numbers attended	Childrens Hospital attended	Numbers attended
Addenbrookes	2	Birmingham	6
Belfast Trust	4	Bristol	1
Bristol Royal Infirmary	1	Great Ormond Street	6
Manchester Royal Infirmary	2	Newcastle	2
Newcastle	3	Manchester	1
Sheffield Northern	14	Sheffield	6
Oxford Nuffield	3	Dublin	1
Queen Elizabeth, Birmingham	1	Other Hospitals	2
RNOH	8	No answer given	3
Other Hospitals	18		
No answer given	23		

Responses in relation to postponed appointments:

When asked if they had any OI related appointments postponed due to Covid-19?

- 63% of respondents answered 'Yes.'
- 29% of respondents answered 'No.'
- 8% of respondents answered 'N/A'

Of the 63% postponed appointments:

- 55% were consultations.
- 25% were treatments.
- 8% were surgeries.
- The remaining 12% were hearing tests, OT, Physio, and other types of appointments.

When asked how this had impacted them:

Only 8 respondents indicated that this had not impacted them.

The most common areas mentioned were:

- Concerns around delays in investigation and starting treatments
- Pain management
- Bone density (not getting Dexa scans)
- Concerns and anxiety around not getting answers or condition possibly getting worse.

When asked if they had received Remote Consultations during lockdown:

- 52% of respondents answered 'Yes.'
- 44% of respondents answered 'No.'
- 5% of respondents answered 'N/A.'

Of those who did receive a remote consultation over lockdown, 89% did so for the first time.

Of those remote consultations which did occur:

- 77% occurred via telephone.
- 21% occurred via video call.
- 2% occurred via another method.

Of those remote consultations which did occur:

- 45% were with a consultant.
- 15% were with a GP.
- 15% were with Physio Therapists.
- 12% were with a Nurse.
- 5% were with an OT.
- 1% were with an OI Psychologist.
- 1% were with a Multi Disciplinary Team.

On a scale of 1-5 (where 5 is excellent and 1 is poor), these remote consultations were rated:

- 5 by 16 respondents.
- 4 by 13 respondents.
- 3 by 16 respondents.
- 2 by 8 respondents.
- 1 by 5 respondents.

Further breakdown in table shows the variance between responses received by Adults with OI to parents of children with OI.

Scale	Adults by %	Parents by %
5	26	31
4	23	21
3	31	21
2	15	10
1	5	16

When asked to rate whether this would be something they would like to see more of on a scale of 1-5 (where 5 is definitely and 1 is never):

- 5 by 21 respondents
- 4 by 18 respondents
- 3 by 26 respondents.
- 2 by 10 respondents.
- 1 by 11 respondents.

Further breakdown in table shows the variance between responses received by Adults with OI to parents of children with OI.

Scale	Adults by %	Parents by %
5	25	24
4	25	12
3	28	36
2	15	4
1	6	24

When asked if they prefer visiting the hospital in person:

- 44% of respondents answered 'Yes.'
- 8% of respondents answered 'No.'
- 47% did not give an answer

Adults by %	Parents by %
58 responded Yes	61 responded Yes
9 responded No	4 responded No
32 did not answer	35 did not answer

When asked if Covid-19 has impacted their rehab (i.e. post surgery/fracture):

- 49% of respondents answered 'N/A.'
- 26% of respondents answered 'Yes.'
- 25% of respondents answered 'No.'

When asked if Covid-19 had impacted their transition to adult services:

- 76% of respondents answered 'N/A.'
- 19% of respondents answered 'No.'
- 5% of respondents answered 'Yes.'

When asked if Covid-19 has impacted their ability to get a wheelchair assessment:

- 64% of respondents answered 'N/A.'
- 27% of respondents answered 'No.'
- 9% of respondents answered 'Yes.'

When asked if Covid-19 has impacted how they liaise with schools/further education:

- 64% of respondents answered 'N/A.'
- 21% of respondents answered 'Yes.'
- 15% of respondents answered 'No.'

When asked how Covid19 has impacted on mental health, the most common responses were

- Increased anxiety
- Feeling low and depressed
- Impact of isolation and loneliness more heightened
- Feeling vulnerable and fear of being in the shielding group.
- Effects of missing friends and family

Other ways Covid had an impact was:

- General Health and anxiety
- Heightened anxiety of fracturing and needing to go to A&E
- Diet and Exercise
- Increased Pain

Responses in relation the BBS Covid-19 information and BBS events:

When asked to rate how they found the BBS Covid-19 Information and Updates on a scale of 1-5 (where 5 is excellent and 1 is poor):

- 35 respondents answered 5.
- 34 respondents answered 4.
- 17 respondents answered 3.
- 7 respondents answered 2.
- 3 respondents answered 1.

When asked if they had watched the BBS Pilates Exercise Videos?

- 73% of respondents answered 'No.'
- 31% of respondents answered 'Yes.'

When asked to rate the helpfulness of the Pilates Exercise videos on a scale of 1-5 (where 5 is excellent and 1 is poor):

- 15 respondents answered 5.
- 12 respondents answered 4.
- 11 respondents answered 3.
- 1 respondent answered 1.

When asked if they had accessed any of the BBS Virtual events during lockdown (ie Pub Quiz, Chat Rooms, Film/Book Club, Singalong Session etc):

- 79% of respondents answered 'No.'
- 22% of respondents answered 'Yes.'

When asked if they would you like to see the BBS host more of these events in the future:

- 73% of respondents answered 'Yes.'
- 15% of respondents answered 'No.'

Suggested areas for future focus categorized into Themes are

- Ageing with OI and adult care
- Independent Living
- Psychological and Mental Health issues
- Fracture Management
- Pain Management
- How to get the best out of your Healthcare providers
- Continue with Social Events such as the Pub Quiz

Further comments

- Just keep doing what you do. Lockdown would have been a lot harder and miserable without you.
- You are doing great and going above and beyond
- I think you already cover a wide range of topics and I always read the information you send out.
- Continue with awareness raising