# Independent Living Survey Report

Report summarising the responses to the Brittle Bone Society's survey on assessing the independent living needs for those with Osteogenesis Imperfecta (OI)

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## Background

The Brittle Bone Society (BBS) recognised the lack of research available around the needs for adults with OI to live independently.

The core content of the survey, which was carried out in 2021, was to identify the main gaps in support services for adults living in the UK and Ireland and to also assess what resources the BBS could develop to assist individuals to live more independently.

## Osteogenesis Imperfecta

OI is a genetic condition present from birth. Its most striking feature is that fractures may occur easily. The prevalence of OI is thought to be 1 in 15,000 individuals.

OI is caused by a defect in the formation of collagen, a compound that occurs in almost every part of the body. The main impact of a lack of functioning collagen is fragile bones that break easily, often with no or minimum trauma. OI is a heterogenous condition, with varying degrees of severity. Over time, the cumulative defects in the skeleton result in severe physical implications beyond the trauma of repeated fractures. People with OI can have curved bones and skeletal deformities, chronic pain, hearing loss, brittle teeth, respiratory complications, gastrointestinal problems, and many other physical challenges caused by the disease. Many people with OI are fully dependent on wheelchairs and other physical aids. A person born with OI is affected throughout his or her lifetime. Depending on the severity, the combination of physical implications resulting from OI profoundly affects people's lives.

## Methods

The BBS conceived, developed and implemented an online survey in conjunction with a working group of 12 individuals with OI and with input from a multidisciplinary group of 4 healthcare professionals from both the BBS Medical Advisory Board and POINT (Paediatric Osteogenesis Imperfecta Team). In addition, the Office for Rare Conditions in Glasgow analysed and evaluated the results.

The survey was carried out using a Jotform and launched by the BBS using social media as well as email communication to all their members between March to May 2021.

The main ways respondents accessed the survey was through 'other' ways, Facebook, and the Newsletter (Other 38%, Facebook 28% and Newsletter 25%). A small percentage (12%) found out about the survey through either Twitter, Instagram, or the website.

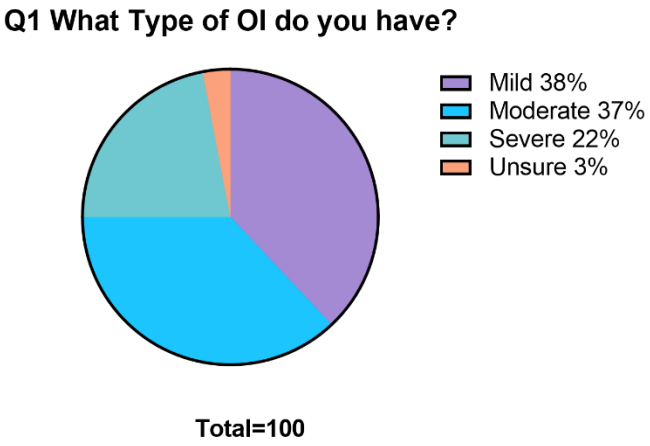
The initial survey subheadings were discussed by the BBS working group in Nov 2020 and covered 7 themes:

1. OI, Independence and Demographics;
2. Care and support individuals receive;
3. Housing needs and adaptations;
4. Wheelchair and Equipment requirements;
5. Travel and Transport;
6. Socialising;
7. Work and Careers.

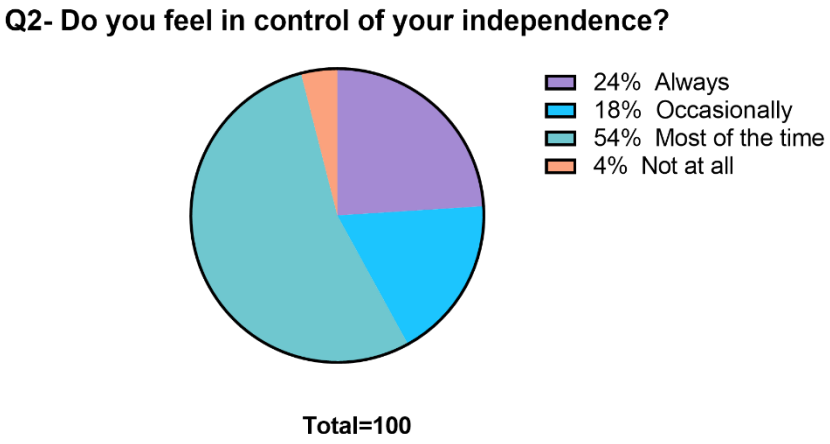
Following agreement of the subheadings the detailed content of each of the themes was developed by the BBS and tested by the working group of individuals with OI and with further input from a subgroup of 4 healthcare professionals which consisted of a Rheumatologist, Physiotherapist, Occupational Therapist and Nurse.

# Section 1:
# OI, Independence and Demographics

## OI, Independence and Demographics

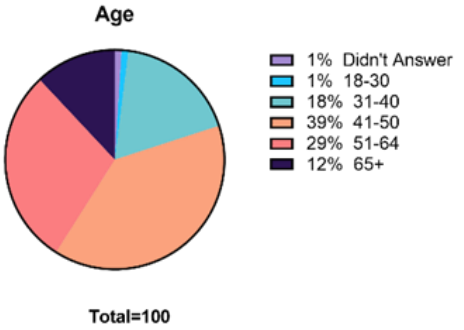



Out of the 100 participants, 38% said they had mild OI, 37% have moderate OI, 22% have severe OI and 3% of participants were unsure



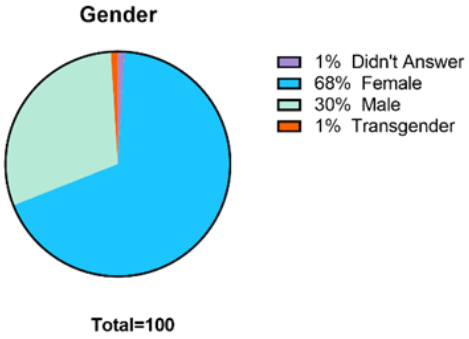

When asked how in control of their independence they felt, 24% felt in control always, 54% felt in control most of the time, 18% occasionally felt in control of their independence and 4% felt not at all in control.

## Demographics



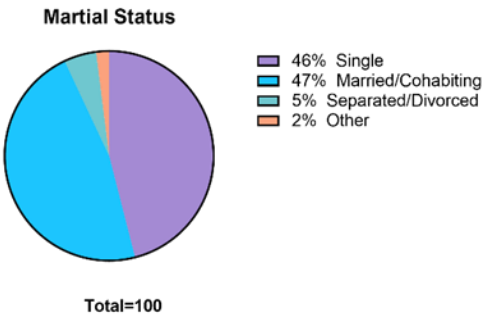

### Age

Of the 100 respondents, 39% were aged 40-50, 29% were 50-64, 18% fell into the 31-40 category, 12% were 65+, only 1 respondent was aged 18-30 and 1 respondent didn't answer the question.



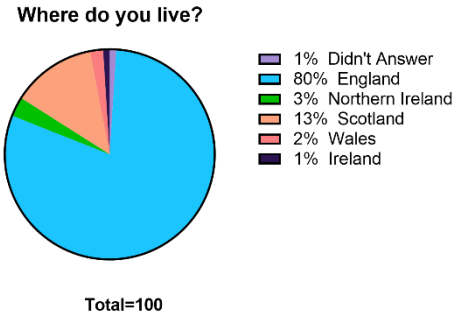

### Gender

Of the 99 respondents who answered this question, 68 identified as female, 30 identified as male and 1 identified as transgender.




### Marital Status

47% of respondents stated that they were married/cohabiting and 46% of the 100 respondents identified as being single. 5% were either separated or divorced and 2% selected 'Other'.

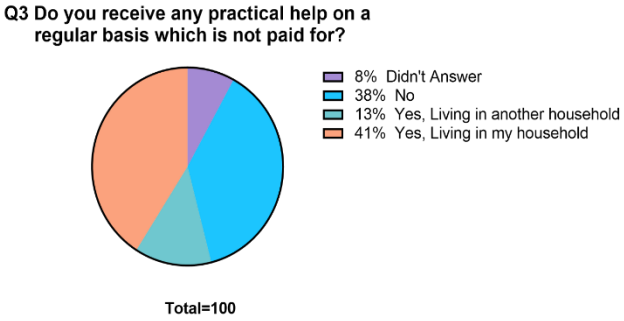



### Location

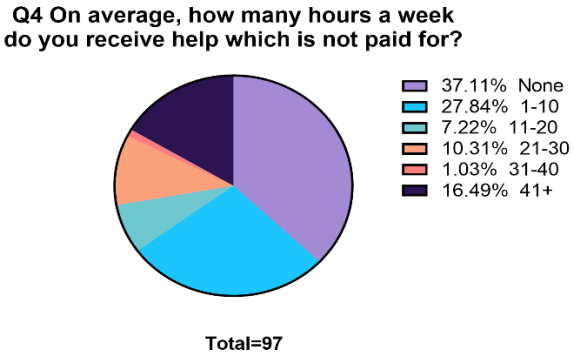
Of the 99 responses to this question, 80.81% are located in England, 13.3% in Scotland, 3.03% in Northern Ireland, 2.02% in Wales and 1.01% are located in Ireland.

# Section 2:
# Care and support individuals receive

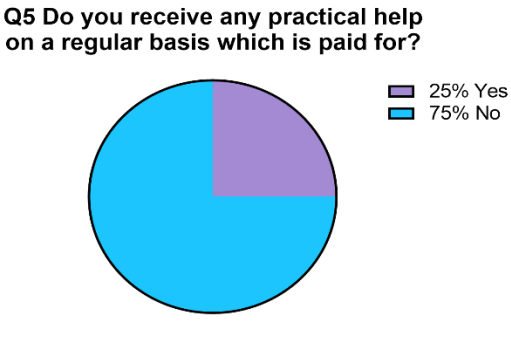
# Care and support individuals receive



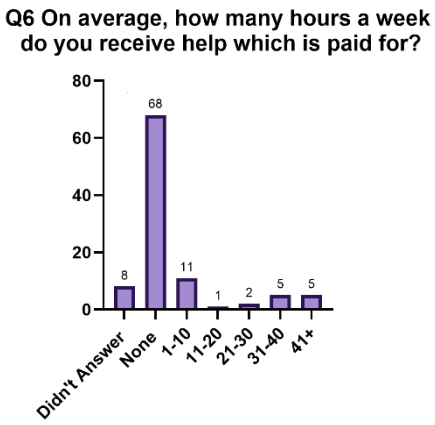

Of the 100 respondents, 41% receive practical help from someone living in their household, 13% receive support from someone living in another household, 38% do not receive any additional support and 8% didn't answer.



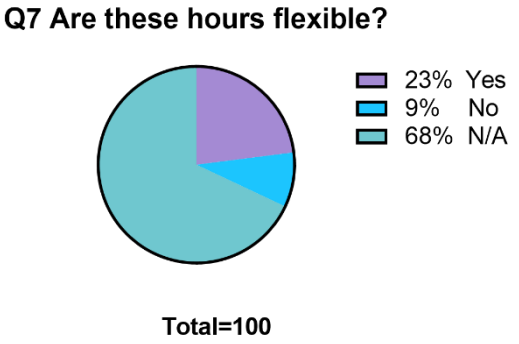

Of the 97 people who responded to question 4, 28% receive 1-10 hours of support a week, 7% receive 11-20 hours of support, 10% receive 21-30, 1% receive 31-40 and 16% receive over 41 hours of support.



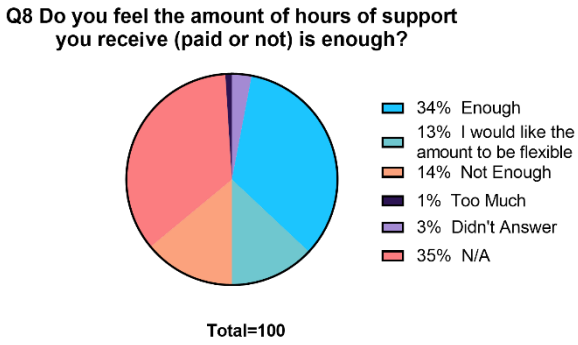

25% of respondents receive paid practical help on a regular basis.



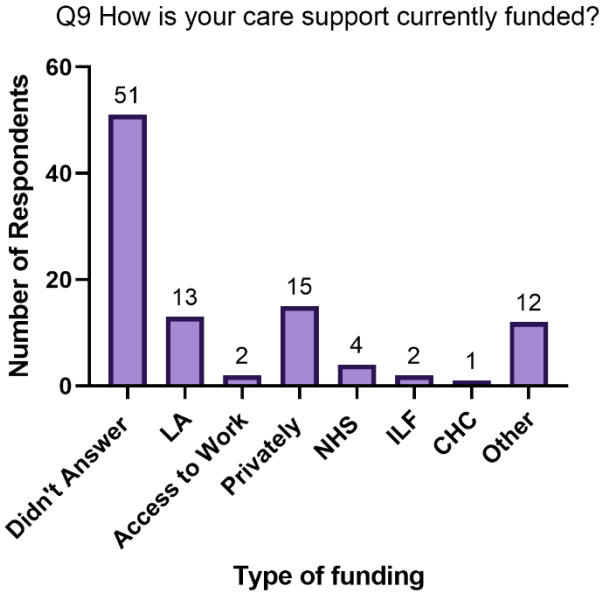

The majority of respondents do not receive any paid help. Of those who do, 5 receive over 41 hours a week, 5 receive between 31-40 hours a week, 2 respondents receive 21-30 hours of paid support, 1 between 11-20hrs and 11 receive 1-10 hours of paid practical support




Following question 6, 23% stated the number of hours they get support for are flexible. 9% said they were not flexible and 68% answered N/A.

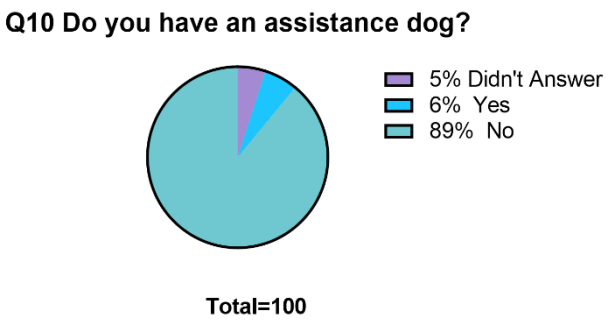



Of the 100 respondents, 34% felt the hours of support they received were enough. 13% would have preferred the hours to be more flexible, 14% think that the hours they receive aren't enough and 1% feel the support they receive is too much. 35% responded N/A and 3% didn't provide an answer.



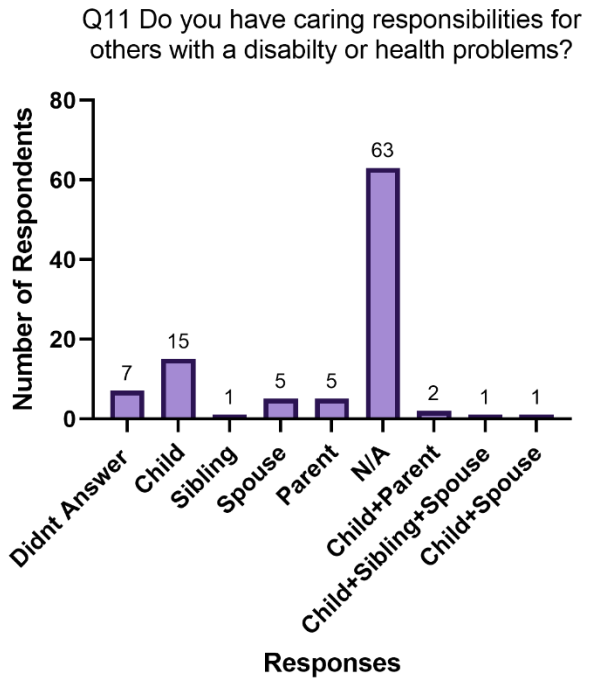

The majority of paid support is funded privately or through LA. A small number of paid help is funded through access to work, NHS, ILF and CHC. Other sources of funding included: Carers Allowance, PIP and Family help.

See Appendix A for further comments on support care funding.




6% of respondents report they have an assistance dog, 89% do not have one. 5% did not answer this question.

Some of the comments regarding assistance dogs included how they are trained to locate keys, fetch morphine, alert when alarms are activated on ventilators and oxygen generators.



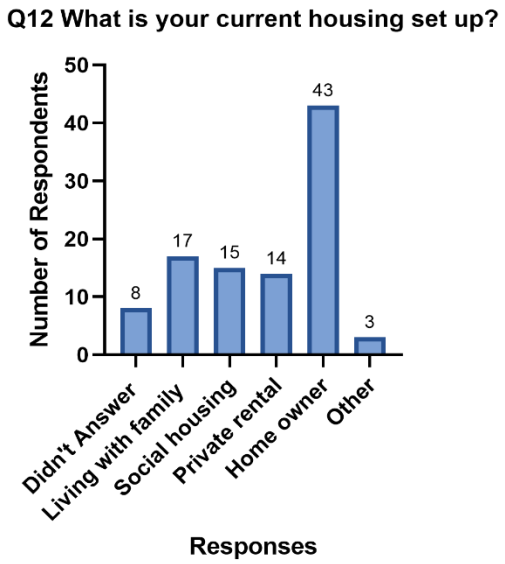

When asked about caring responsibilities for others, one person reported having responsibility for 3 people; a child, a sibling, and a spouse, one had responsibility for two; a child and a spouse and two people had responsibility for both a child and a parent.

Several comments reported the detrimental affect applying for funding for social care has had on their mental wellbeing. Another common worry reported was a fear that the person that gives them support (usually a family member or spouse) dies or is suddenly unable to provide regular support and therefore their independence will be adversely affected. There was a lack of confidence in relying on local councils or government in providing enough support.

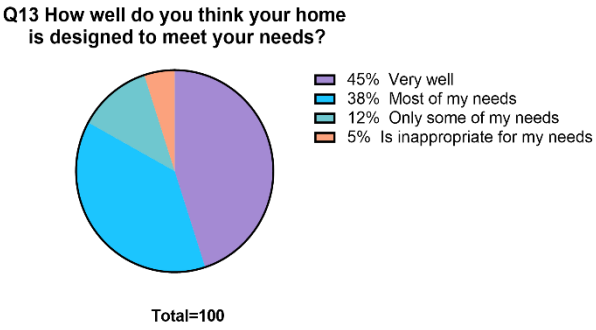
See Appendix A for further comments on social care and caring responsibilities for others.

# Section 3:
# Housing Needs and Adaptations

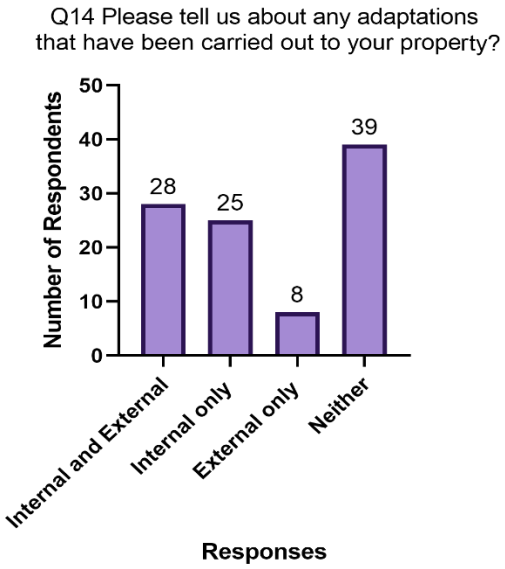
# Housing Needs and Adaptations




43% of respondents reported that they are a homeowner, 17% are living with family, 15% are living in social housing, 14% are living in private rental accommodation, 3% selected 'other' and 8% didn't answer.



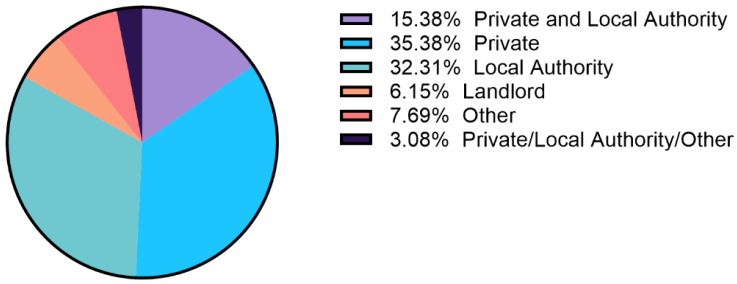

45% of respondents thought their home meets their needs very well, 38% reported it met most of their needs, 12% said their house only met some of their needs and 5% reported their accommodation is inappropriate for their needs




When asked about adaptations to their property, 28 have had adaptions internally and externally, 25 have only had internal adaptions, 8 have only had external adaptions and 39 have had no adaptions made to their property.

A few examples of adaptations listed, both internal and external included: Altered bathrooms or wet rooms/ ramps internally and externally/ lower worktops/overhead hoists and profiling-beds.

**Q15 If yes, how were your adaptations funded?**




**Total=65**

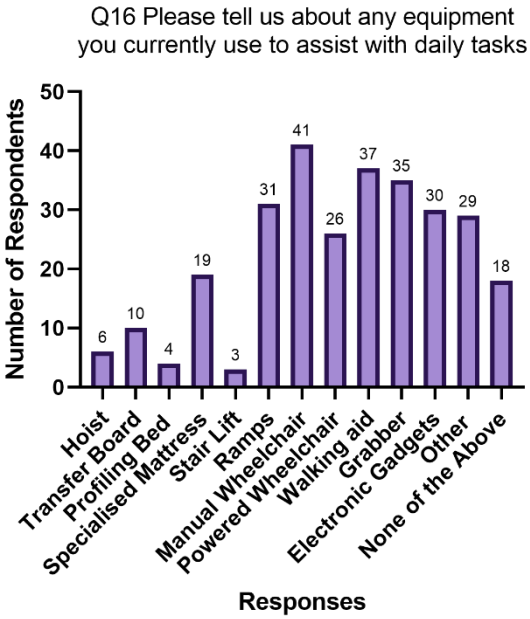
Of the 65 respondents who have had adaptions to their house, 35% funded these adaptations privately, 32% received funding from local authority, 15% had a combination of private and council funding and 6% of adaptations were funded by a landlord.

Respondent's experiences of funding were varied, with some unsure of what funding might be available and others put off by the length of time taken for the application to be progressed. Some respondents found the means testing aspect of assessment to be demeaning with the outcomes often disappointing. There were also some who responded positively and reported their experiences with local council 'helpful' and 'cooperative'.

See Appendix B for further comments on funding for adaptations.

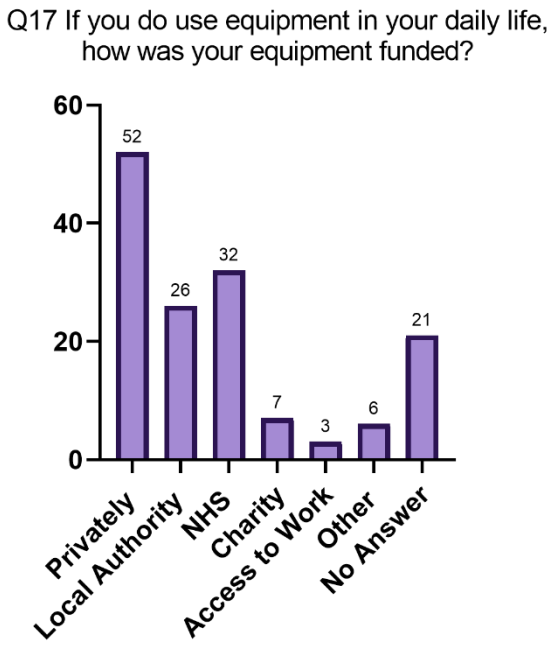
# Section 4:
# Wheelchair and Equipment requirements

# Wheelchair and Equipment requirements




Responses given in category 'Other':

| Other | Equipment listed |
|---|---|
| Hearing | Hearing aids, hearing implants, vibrating fire alarms and clocks, TV loop system, light up alarms. |
| Access | Car, mobility scooter, Tri ride, banisters/rails. |
| Posture | Chairs: rise/recline; height adjustable, ergonomic office/student chairs, cushions for driving, wheelchairs, shoe inserts. |
| Toileting | Toilet seats with arms, bidet, toilet step. |
| Bathing | Shower chairs, trolley, bath boards, |
| Kitchen/Eating | Low level units, adapted cutlery, bottle opener, low level sockets, kitchen step, perching stool. |
| Miscellaneous | Key turning tool, "smart drive", "snoozle" "housemate system" |




Of those who use equipment in their daily life, the majority have privately funded the equipment they use in their home. 32 respondents have received funding through the NHS, 26 receive funding for equipment through the local authority, 7 through charity and 3 from Access to Work.

Other sources of funding included health insurance, Disabled Student's Allowance, Brittle Bone Society, private suppliers of hearing aids/equipment and donations from friends.

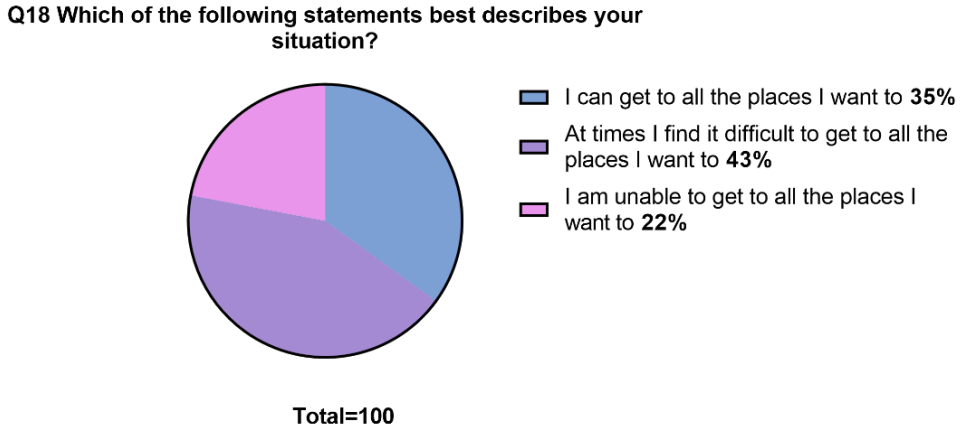
Respondents reported their frustration and disappointment at assessments which resulted in the provision of inappropriate equipment, the lack of awareness by assessors on the physical implications of OI, the variability of the condition and changing needs, the provision of standard items that do not meet need and the lack of flexibility for individual situation/need. Difficulties around funding were again due to lack of awareness of what is available and frustration about the time taken to process the application and supply the equipment. There were also some positive experiences of receiving funding for equipment, reporting that the process for receiving funding through local councils, charities and NHS was straight forward.

Some suggestions for equipment that can provide greater support included: hot water tap instead of a kettle, specialist desk chair, colour changing light bulbs which can be controlled via remote, hearing aids and a Ring doorbell camera.

Please see Appendix C for further comments on funding equipment and useful tips.

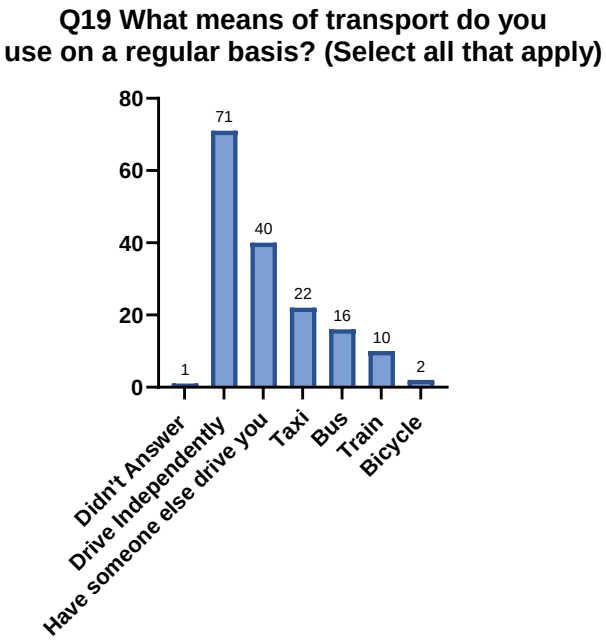
# Section 5:
# Travel and Transport

# Travel and Transport



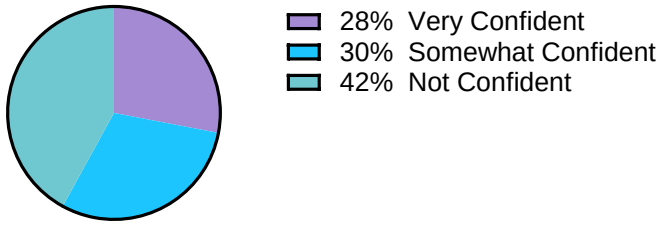

When asked to think about getting out and about outside the home, 43% of participants found it difficult to get to all the places they want at times, 35% can get to all the places they want and 22% said they are unable to get to all the places they want to. None of the participants stated that they do not leave the house.

Of those that stated they either 'at times they find it difficult to get to all the places they want', or they 'are unable to get to the places they want to go' (65%), the majority either drive independently or have someone else drive them. 17% of this group use a taxi service on a regular basis whereas none who stated they can get to all the places they want use a taxi service on a regular basis.




Several reports were provided in the comments explaining why some found it difficult to leave their homes. Many respondents rely on their car for transport. Reports of canted roads and pavements have proven a hazard to some and inhibited their ability to get to places. Others reported they felt unsafe using taxis and public transport is too unreliable in terms of providing sufficient support.

**Q21 How confident are you to travel overseas?**




**Total=100**

When asked how confident they feel travelling overseas. 42% said they did not feel confident at all. 30 % were somewhat confident and 28% were very confident.

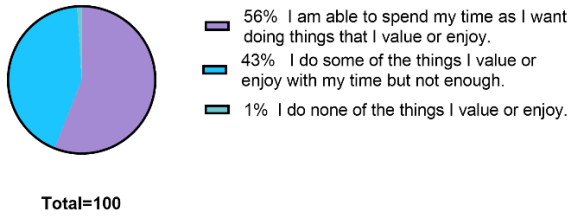
Several respondents reported worries about travelling overseas in regard to having fractures abroad and needing to go to hospital. The cost of travel insurance was reported to be very high, and some feel their holiday destinations are dependent on the quality of healthcare in the country. There were further concerns over taking equipment, such as wheelchairs, oxygen tanks and liquid painkillers, on planes. Some respondents praised the BBS passport and suggested this could be reviewed and refreshed to include more languages and contact details for the BBS.

For further comments on transport and travelling abroad, please see Appendix D.

# Section 6: Socialising and Relationships

# Socialising and Relationships

**Q23 Which of the following statements best describes how you spend your time? (please think pre-covid)**

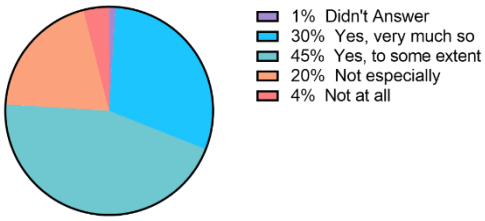



Total=100

56% of respondents stated that they can spend their time as they want, doing things they value or enjoy. 43% said that they would like to be able to do more of the things they enjoy but do somethings and 1 respondent said that they do none of the things they enjoy.

Respondents commented on how they often rely on friends/family to do the things they enjoy which limits their independence. Social confidence was reported as a barrier to some activities along with physical difficulty accessing some venues.

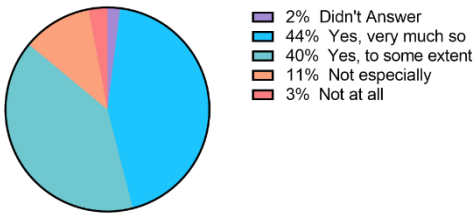
**Q24 Do you find it easy to form relationships with others?**




Total=100

30% of respondents found it very easy to form relationships with others. 45% find it easy but to an extent. 20% do not find it especially easy to form relationships with others and 4% experience lots of difficulty. 1 respondent did not answer the question.

**Q25 Are you satisfied with the relationships you have in your life?**




Total=100

Of the 100 participants, 84% are either very satisfied with their relationships or satisfied to an extent. Of the respondents who answered 'not at all' or 'not especially' to how satisfied they are in relationships, the majority (64%) also experienced difficulties in forming relationships with others.

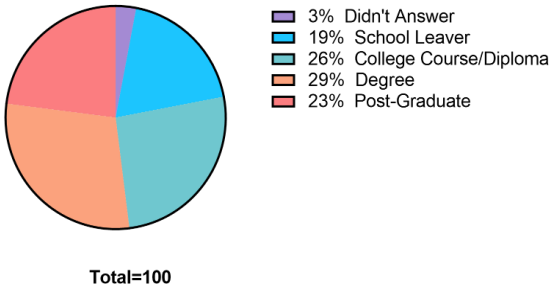
Respondents voiced that having OI has hindered their ability to form relationships and sometimes contributes to their anxiety regarding social interactions. Respondents often find it difficult and frustrating when searching for suitable venues for social activities and feel the need to take on the 'burden of research and organisation' of events.

For further comments on social interactions, please see Appendix E

# Section 7:
# Work and Careers

# Work and Careers

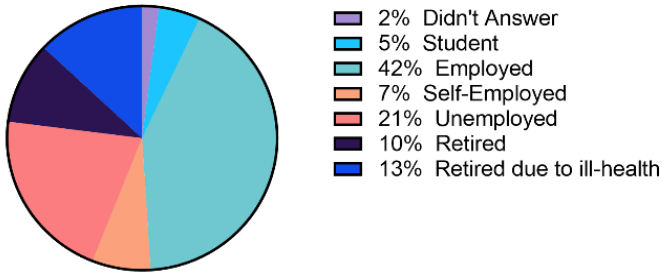
**Q26 Please state your highest level of education?**




Total=100

Of the 100 respondents, 29% have a degree, 23% have post-graduate education, 26% have completed a college course or Diploma, 19% are school leavers and 3% didn't answer.

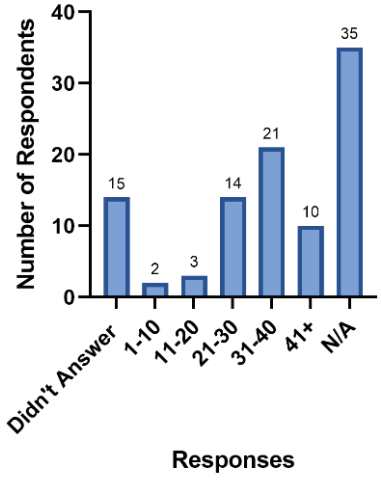
**Q27 Employment Status**




Total=100

Regarding employment status, 42% said they were employed, 21% are unemployed, 13% are retired due to ill-health, 10% are retired, 7% are self-employed, 5% are students and 2% didn't answer.

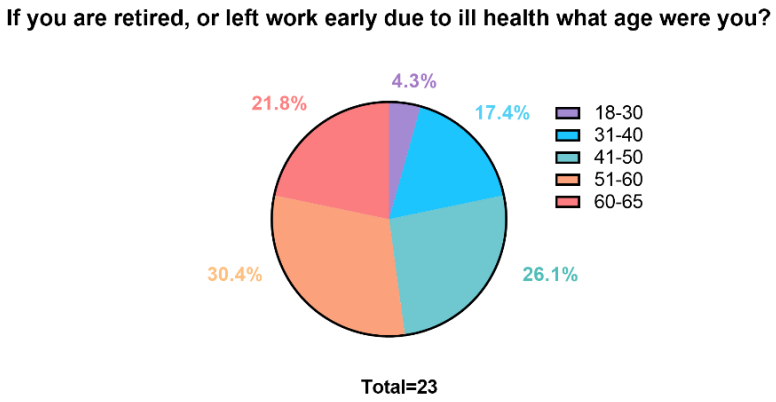
**If employed how many hours a week do you do?**



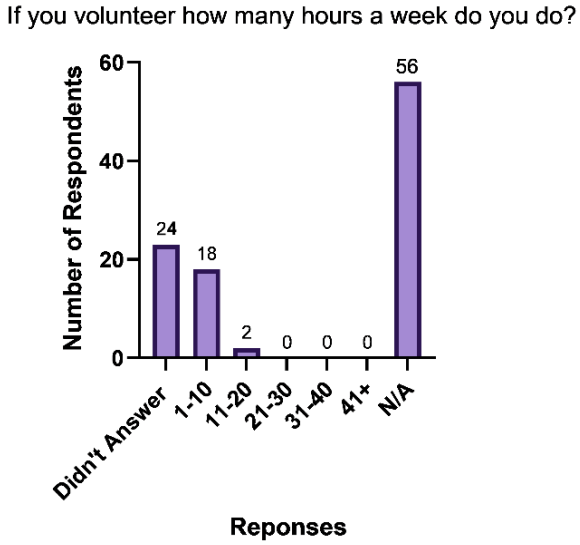

When asked how many hours they work each week, 2 respondents answered between 1-10 hours per week(hpw), 3 between 11-20 hpw, 14 work 21-30 hpw, 21 work between 31-40 and 10 work over 41 hours per week.

7 respondents also receive Access to Work support.

Respondents commented on the helpfulness and the efficient service that Access to Work can provide whereas some had never heard of the service.




23 participants have either retired or retired due to ill health. Of these 23, 30.4% retired between the ages of 51-60, 26.1% retired between 41-50, 21.8% retired between 60-65, 17.4% between 31-40 with only 1 respondent retiring between the ages of 18-30.




Of 100 participants, 20 said that they volunteer. Of these 20, 18 volunteer 1-10 hours a week and 2 said between 11-20 hours a week.

*How OI has impacted your career choices?*

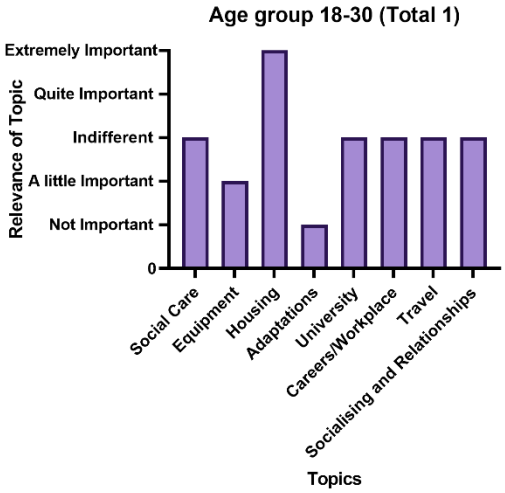
Many respondents commented that their OI has limited their career choices to certain jobs where the risk of fatigue is low. Careers within the NHS are popular due to their experiences within hospitals and having the benefit of an established occupational health team.

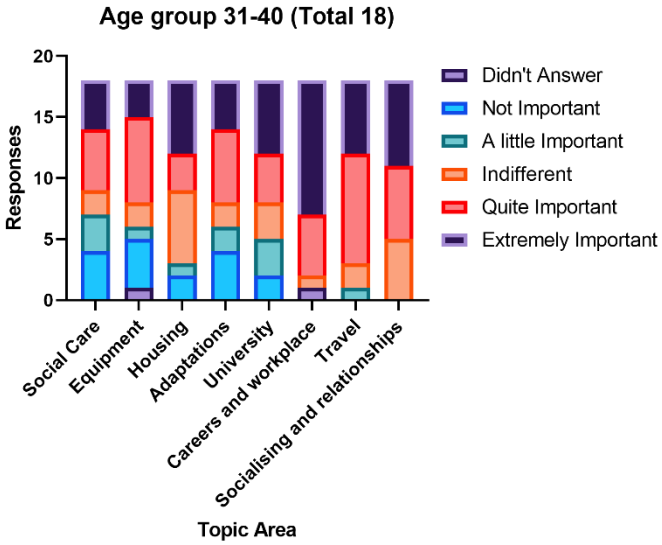
See Appendix F for further comments on Careers and Workplace.

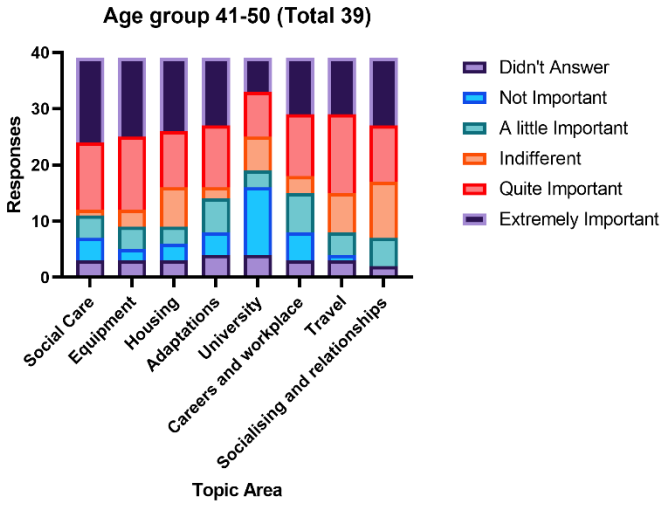
# Section 8: Summary

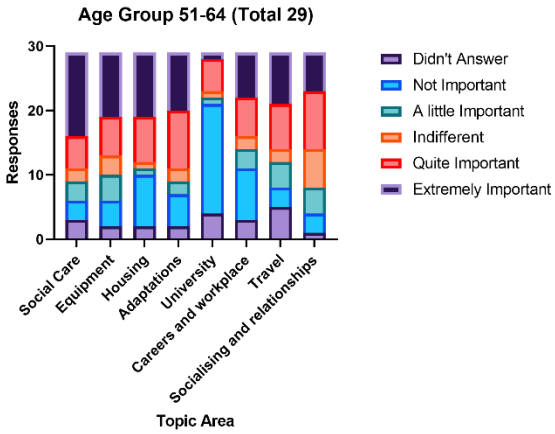
# Summary

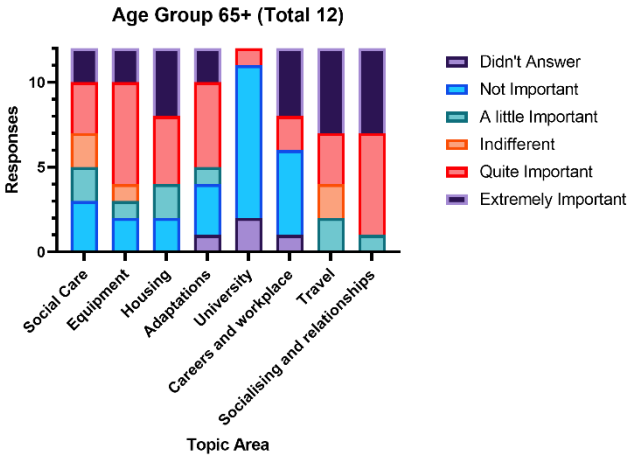
Respondents were asked to rate how important different topic areas (social care, equipment, housing, adaptations, university, travel, socialising and relationships) were to them. The responses have been separated by age group. Among the younger age groups (18-40), careers, university and housing were the most important topics. Whereas the older age groups (41-64) prioritised social care and equipment. Respondents aged 65+ felt that travel and socialising/relationships were the most important topics to them.

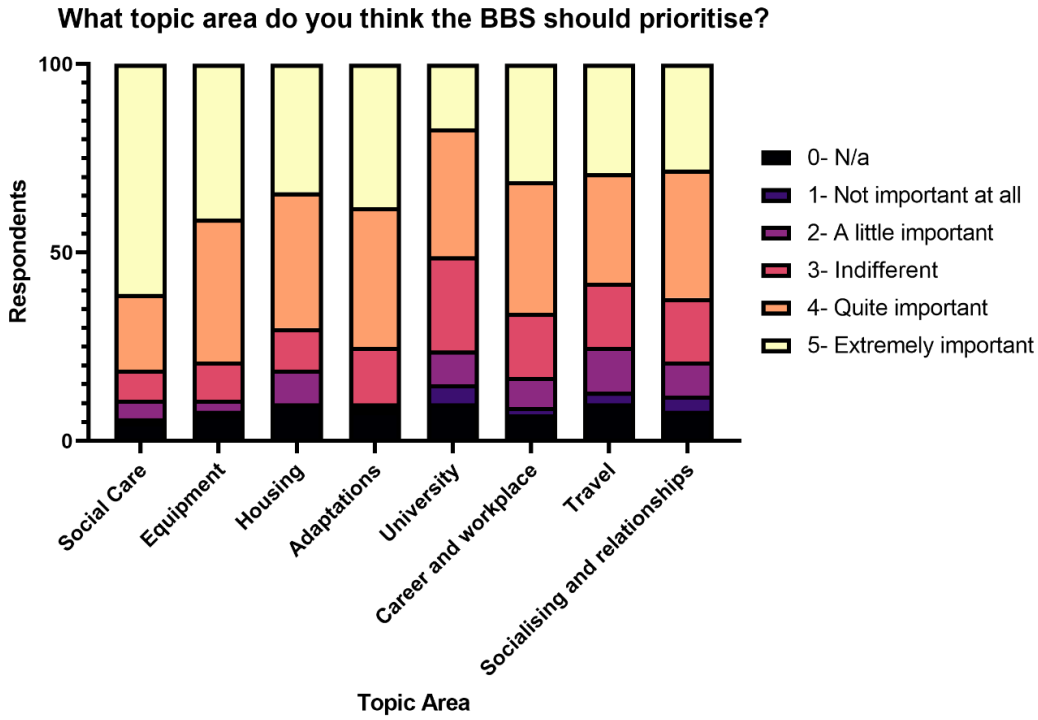





61% of respondents thought that social care is an 'extremely important' issue that the BBS should prioritise. More than 60% of respondents also thought that Equipment, Housing, Adaptations and Career and workplace were either 'extremely important' or 'quite important' topics that should be a priority for the BBS.

Respondents highlighted other topics that they would want the BBS to provide information about. Some examples included: applying for funding for carers, wellbeing tips, women's health, family life (genetic counselling), financial management and activities for younger members.

See Appendix G for further comments on topics the BBS should be looking at and other useful tips and resources.

# Summary

**Quantitative findings**
Adults with OI rated variable levels of support needs, requirements, and experiences of receiving support and funding. Of note 54% of adults felt in control of their independence most of the time, 24% all of the time and only 4% saying not at all.

**Discussion**
The voice of the individual living with OI is a critical component and driver for improving outcomes and provides valuable insights into current delivery of services that may challenge current thinking from policymakers and clinicians. This survey has demonstrated a general positive response to living independently but has highlighted areas in the lack of knowledge and funding when being provided with right the equipment and care packages.

The survey had a modest response rate with representation across the major OI types. The survey was conducted during the COVID19 pandemic; however, the questions did ask people to think about experiences pre Covid. The responses were all anonymous.

**In conclusion**
Varied and honest responses from participants across the UK and Ireland. The helpful and detailed answers from participants can aid the BBS in identifying topic areas in which to prioritise resources and support. This data report can be used to identify specific areas that the BBS could focus on and explore in greater depth.

**Acknowledgements**
We would like to thank everyone who gave up their time freely to participate in the working group meetings and to all the adults who took part in the survey. The Brittle Bone Society would also like to thank Alexion Pharmaceutical for sponsoring the Survey.

***The survey was conducted by the Brittle Bone Society and the report compiled by the Office for Rare Conditions Glasgow***.

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