Adult Services Survey Analysis

In 2015 the Brittle Bone Society conducted a short survey to gather views on Adult OI Services. The results of the 100 responses from this survey will help the Brittle Bone Society prepare a proposal for an Adult OI Service to the NHS.

The age demographics of participants are as follows

- 10 respondents are aged 18-25
- 13 respondents are aged 26-35
- 32 respondents are aged 36-50
- 43 respondents are aged 51+

Please note this is based on 98 responses as 2 responses did not provide an answer to this question.

People with OI currently under an OI Specialist

- 45% of the respondents are currently under the care of an OI specialist
- 55% of the respondents are not currently under the care of an OI specialist

How many years has it been since last seeing an OI specialist, if ever

- 29% of respondents have seen an OI specialist in the last 12 months
- 6% of respondents in the last 1-2 years
- 12% of respondents in the last 3-5 years
- 9% of respondents in the last 6-10 years
- 17% of respondents in the last 11+ years
- 27% of respondents have never seen an OI specialist

Please note this is based off 96 responses as 4 respondents did not answer this question.

The main benefits perceived of a regular check-up with a healthcare specialist who understands OI are:

Out of the 100 respondents, there were 89 responses to this question.

The most common benefit mentioned was having access to an expert with knowledge of OI and having continuing care.

- 60% of respondents said the main benefit was seeing someone who had knowledge of OI and who could provide continuing care.
- 12% of respondents said the main benefit was access to bone density scans
- 8% of respondents mentioned the importance of other associated health concerns (i.e., hearing, pain, dental referrals)

Examples of some comments

- Peace of mind, my GP makes me feel like I’m wasting their time
- Someone who understands the problems associated with OI and doesn’t dismiss it as only fragile bones
- To have a central person who is aware of all my medical info and fractures
Range of Specialists currently seen by people with OI and who they would like to see.

<table>
<thead>
<tr>
<th>SPECIALITY</th>
<th>People who Currently see</th>
<th>Who people would like to see</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ortho</td>
<td>34</td>
<td>34</td>
</tr>
<tr>
<td>Rheumatology</td>
<td>19</td>
<td>24</td>
</tr>
<tr>
<td>Nursing</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>Cardio</td>
<td>3</td>
<td>19</td>
</tr>
<tr>
<td>Psychology</td>
<td>1</td>
<td>24</td>
</tr>
<tr>
<td>Genetics</td>
<td>8</td>
<td>24</td>
</tr>
<tr>
<td>ENT</td>
<td>15</td>
<td>15</td>
</tr>
<tr>
<td>Dentistry</td>
<td>15</td>
<td>23</td>
</tr>
<tr>
<td>Physio</td>
<td>11</td>
<td>48</td>
</tr>
<tr>
<td>Occupational Therapy</td>
<td>6</td>
<td>33</td>
</tr>
<tr>
<td>Endocrine</td>
<td>16</td>
<td>20</td>
</tr>
<tr>
<td>Neurologist</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>None of Above</td>
<td>12</td>
<td>4</td>
</tr>
</tbody>
</table>

Access to Wheelchair Services

- 44 respondents do have access to wheelchair services
- 22 respondents do not have access to wheelchair services
- This question was not applicable to 33 of the respondents

These results are based off 99 responses as one respondent did not answer this question.

What things work well within the current Health System for adults with OI

Out of the 100 responses, 68 respondents answered this question.

The answers all had a similar theme that when people have access to an OI specialist they receive good care and have a solid source of information from these specialists. Access to treatments and specialists who had knowledge and understanding of OI were the most common themes

- 19% of respondents said access to treatments worked well
- 19% of respondents said having access to experts with knowledge in OI worked well
- 7% of respondents said having access to scans worked well
20% of respondents simply stated that in their region there wasn't any help available to them so they were unable to comment on anything positive.

What are the main failings with the current Health System for adults with OI

89 of the 100 respondents answered this question

The overall main failing that is mentioned is the lack of knowledge of the condition. This includes overall knowledge from GP’s and the A&E department when treating fractures. It is also noted multiple times the lack of communication and “links” between the different departments. This causes an inconsistent plan for future treatment regarding their OI. Some examples of answers are:

- 36% of respondents said lack of knowledge about OI was a failing
- 11% of respondents said having access to services was an issue (for example GP not knowing where to refer to)
- 10% of respondents said lack of communication between different departments was an issue (ie no multi-disciplinary care)
- 7% of respondents stated the lack of knowledge in A&E was issue and that fractures are not always detected on x-ray, so they are sent away with no care.

Other Comments

In this section there were 45 responses. This ranged from positive comments on the idea of an Adult Services and how much of a positive impact this would have on their lives. Examples of some comments:

- “It would be great if there was a clinic where you could see OI specialists in all areas in one place”
- “I would like to be able to see an OI specialist every now and then. My local A/E have no idea how to treat me.”
- “My only information re OI has come from BBS. My 3 children have had about 80 fractures between them. I have had 25-30 fractures.”
- “Where would a person born with OI in the 1970’s even start?!?”
- “My doctor has ever once suggested any information with regards to OI, and I have never been offered any help”
- “All people with OI need support, people with mild OI are often left isolated and not taken seriously as their disability is less visible”