



## **BBS UK Membership Audit 2020**

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Dear BBS UK Member,

BBS UK are committed to providing the best service possible to all those affected by the condition. In order to achieve this, we are continually looking at ways we can improve primarily to ensure we remain focussed on the wishes and needs of our community. A vital part of this is ensuring that we listen to our members and use their feedback to direct our services effectively to reach the best possible outcome.

As part of our service review this year, we have created a questionnaire designed to assess how Bardet-Biedl Syndrome affects those diagnosed and their quality of life. It also aims to assess how well those affected have been supported by the charity where the gaps are and what they would like from BBS UK in the future. We are therefore making this questionnaire available to all of our members to complete and we really hope as many of you as possible do so. We are so grateful for the support you continue to provide and cannot emphasise enough how valuable your suggestions and comments are for the development of the services we provide.

This questionnaire does not ask for or record specific identifiable data, i.e. names and addresses, however we understand that some answers may inadvertently enable identification. Individual questionnaires will not be shared with any other party or used for any other purpose. The collated, anonymised results from this membership audit will be used to improve our services and will be shared with our membership. The completed questionnaires will be treated with the utmost care, all data will be stored securely and according to the requirements of the Data Protection Act 2018 and General Data Protection Regulation (GDPR).

We understand that some of these questions may be difficult to answer and may trigger uncomfortable or upsetting feelings or emotions and if that case, please feel free to leave the question blank. If you would like to talk to someone about this, please contact your Liaison Officer, Angela Scudder or Amy Clapp. If you would like help completing the form, please contact Liz Loughery; all contact details can be found at the end.

Thank you in advance for your help,

Kindest regards  
Tonia Hymers  
Service Manager, BBS UK

**1. Who is completing this form:**

- I am completing this as a person diagnosed with Bardet-Biedl Syndrome
- I am completing this on behalf of an adult diagnosed with Bardet-Biedl Syndrome. Views and perspectives provided are those of the diagnosed adult.
- I am completing this as a parent or carer of someone diagnosed with Bardet-Biedl Syndrome. Views and perspectives provided are my own.

*\*Please note, if you are a Parent of 2 or more children with BBS you will need to complete a separate survey for each child.*

**2. The age of the person affected by BBS:**

- 0-17
- 18-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65+
- Prefer not to say

**3. Do you/your child attend the BBS multi-disciplinary clinics?**

- Yes, I attend the London Clinic
- Yes, I attend the Birmingham Clinic
- I have participated in the Telemedicine Service only to date
- I am awaiting a referral / appointment

None of the above

### Questions relating to the impact of BBS and Sight Loss

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#### 4. How long ago were you / the person affected by BBS diagnosed?

- Within the past 12 months
- Between 1 and 5 years ago
- Between 5 and 10 years ago
- Between 10 and 20 years ago
- More than 20 years ago

#### 5. Is the diagnosis genetic or clinical?

- Genetic diagnosis (A genetic diagnosis is established as a result of a genetic test)
- Clinical diagnosis (A clinical diagnosis is established on the basis of features and symptoms observed by a Clinician)

#### 6. If you have a genetic diagnosis, please tell us which BBS gene applies to you

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#### 7. Are you / is your child registered as severely sight impaired or sight impaired?

- Yes, registered as severely sight impaired
- Yes, registered as sight impaired
- No, sight loss does not meet the criteria
- No, chosen not to be registered

#### 8. Describe your vision / your child's vision:

- No vision

- Light perception/shadows only
- Some useful central vision
- Good central vision
- Some useful peripheral vision
- Good peripheral vision
- Good overall vision

**9. Tick the box to indicate which of the following BBS symptoms you / your child has. Please also indicate whether it is mild, moderate or severe by underlining the response that is applicable to you.**

- |   |                          |
|---|--------------------------|
| <input type="checkbox"/> Learning difficulties            | Mild / Moderate / Severe |
| <input type="checkbox"/> Developmental delay              | Mild / Moderate / Severe |
| <input type="checkbox"/> Low mood/depression              | Mild / Moderate / Severe |
| <input type="checkbox"/> Anxiety                          | Mild / Moderate / Severe |
| <input type="checkbox"/> Obesity                          | Mild / Moderate / Severe |
| <input type="checkbox"/> Diabetes                         | Mild / Moderate / Severe |
| <input type="checkbox"/> Liver disease                    | Mild / Moderate / Severe |
| <input type="checkbox"/> Polycystic Ovary Syndrome        | Mild / Moderate / Severe |
| <input type="checkbox"/> Urinary tract issues             | Mild / Moderate / Severe |
| <input type="checkbox"/> Speech/language difficulties     | Mild / Moderate / Severe |
| <input type="checkbox"/> Glue ear/repeated ear infections | Mild / Moderate / Severe |
| <input type="checkbox"/> Issues with digestive system     | Mild / Moderate / Severe |
| <input type="checkbox"/> Epilepsy                         | Mild / Moderate / Severe |

- |   |                          |
|---|--------------------------|
| <input type="checkbox"/> Extreme tiredness/fatigue                | Mild / Moderate / Severe |
| <input type="checkbox"/> Kidney abnormalities                     | Mild / Moderate / Severe |
| <input type="checkbox"/> Respiratory issues                       | Mild / Moderate / Severe |
| <input type="checkbox"/> Sleep Apnoea                             | Mild / Moderate / Severe |
| <input type="checkbox"/> Autistic Spectrum Disorder (ASD)         | Mild / Moderate / Severe |
| <input type="checkbox"/> Additional symptoms not mentioned above: |                          |
| .....   |                          |
| .....   |                          |
| .....   |                          |
| .....   |                          |

**10. Have you had a kidney transplant?**

- Yes
- No

**11. Are you undergoing kidney dialysis?**

- Yes
- No

**12. Describe how BBS affects your life / your child's life:**

- Very severe impact
- Severe impact
- Moderate impact
- Mild impact
- No impact

**13. Which areas of your life have been affected by BBS? Please also indicate whether the impact is mild, moderate or severe by underlining the response that is applicable to you.**

- |   |                          |
|---|--------------------------|
| <input type="checkbox"/> Mobility and getting around        | Mild / Moderate / Severe |
| <input type="checkbox"/> Leisure time and hobbies           | Mild / Moderate / Severe |
| <input type="checkbox"/> Social Life                        | Mild / Moderate / Severe |
| <input type="checkbox"/> Career /job                        | Mild / Moderate / Severe |
| <input type="checkbox"/> Day to day routines                | Mild / Moderate / Severe |
| <input type="checkbox"/> Personal Safety                    | Mild / Moderate / Severe |
| <input type="checkbox"/> Communication                      | Mild / Moderate / Severe |
| <input type="checkbox"/> Relationship with family & friends | Mild / Moderate / Severe |
| <input type="checkbox"/> Relationship with partner          | Mild / Moderate / Severe |
| <input type="checkbox"/> Family Life                        | Mild / Moderate / Severe |
| <input type="checkbox"/> Education                          | Mild / Moderate / Severe |
| <input type="checkbox"/> No areas have been affected        |                          |

**14. Disability Benefits: Tick the boxes to indicate which disability benefits you are in receipt of**

- Personal Independence Payment
- Disability Living Allowance
- Incapacity Benefit
- Employment Support Allowance
- Direct Payments
- Carer's Allowance

Universal Credit

Other.....

**15. Employment: tick the boxes to indicate the employment status of the person this survey is about:**

Employed, Full-time

Employed, part-time

Supported Internship/Traineeship

Voluntary Work

Currently seeking employment

None of the above

**16. Education – tick the box to indicate your (your child’s) education status. Please also tell us if the education received is specialist, mainstream or select 'N/A' if these categories do not apply.**

Pre-School Specialist /Mainstream/N/A

Primary School Specialist /Mainstream/N/A

Secondary School Specialist /Mainstream/N/A

College/Sixth-Form Specialist /Mainstream/N/A

Vocational College Specialist /Mainstream/N/A

University Specialist /Mainstream/N/A

**17. If you, or your child is no longer in education, please indicate the education level attained:**

Secondary School

College/Sixth Form

Vocational College

University

**18. Do you (or does your child) have an Individual Education Plan (IEP)?**

Yes

No

**Services and Support: General**

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**19. Do you (or does your child) have an Education, Health and Care Plan (EHCP)**

Yes

No

The following questions can be answered from your perspective as a person living with BBS or as a parent of someone with BBS.

**20. Which of these statements best describes your / your child's current situation?**

I understand BBS and how to manage it, and support is in place to help me live my life / take care of my child's needs.

I understand BBS and how to manage it, and I know I can access help and support if I need it.

I want to understand and manage BBS better, but I am unsure how to access the support I need.

I want to understand and manage BBS better, but I have been unable to access the support I need.

I am / my child is recently diagnosed, and still adjusting to life with BBS.



**21. What are the emotional and psychological impacts of having BBS? Tick any / all that apply:**

- Loss of confidence
- Anxiety
- Stress
- Fear
- Anger
- No emotional or psychological impact
- Other (Please specify)

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**22. Please indicate who provided the diagnosis of BBS (if you can't remember leave blank):**

- GP
- Consultant: Indicate their specialism, i.e. Geneticist (Genetics),  
Ophthalmologist (Eyes), Neurologist (Brain), Nephrologist (Kidneys)
- A Regional Genetics Team
- BBS Multi-disciplinary Clinic
- Other (Specify)

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**23. With reference to when you received your diagnosis please indicate by selecting either 'Yes' or 'no' which statements apply to you:**

There was an opportunity to ask questions during the diagnosis

Yes

No

The person giving the diagnosis had a good knowledge of the condition

Yes

No

The person giving the diagnosis had a good understanding of how I / my child might be feeling

Yes

No

Information about the ongoing support was made available

Yes

No

Information about the support available from BBS UK was provided

Yes

No

Emotional / psychological support was offered

Yes

No

Genetic counselling was offered

Yes

No

Additional comments:

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**24. Do you understand your genetic diagnosis? Tick the box to indicate which statement applies to you**

I understand why I have BBS and I am clear about the risks of it being passed on if I have children

I understand a little bit about why I have BBS, but I am not clear about the risks of it being passed on if I have children

I have very little understanding about why I have BBS

**25. How happy are you with the ongoing care you receive from the BBS Clinics service?**

Very happy

Happy

Neither happy nor unhappy

Unhappy (please provide an explanation using the additional comments section below)

Very unhappy (please provide an explanation using the additional comments section below))

Additional comments:

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**26. Tick all the following services you have accessed in your local area or via the BBS Clinics service. If you haven't accessed them, leave the box blank. Please also indicate whether the service is not good, good or excellent by underlining your response.**

- |  |                             |
|--|-----------------------------|
| <input type="checkbox"/> Advice on claiming benefits                 | Not Good / Good / Excellent |
| <input type="checkbox"/> Mobility training                           | Not Good / Good / Excellent |
| <input type="checkbox"/> Access to work scheme                       | Not Good / Good / Excellent |
| <input type="checkbox"/> Counselling                                 | Not Good / Good / Excellent |
| <input type="checkbox"/> Occupational health support                 | Not Good / Good / Excellent |
| <input type="checkbox"/> Physiotherapy                               | Not Good / Good / Excellent |
| <input type="checkbox"/> Social services support                     | Not Good / Good / Excellent |
| <input type="checkbox"/> Eye clinic support and signposting (ECLO)   | Not Good / Good / Excellent |
| <input type="checkbox"/> Genetic counselling                         | Not Good / Good / Excellent |
| <input type="checkbox"/> Genetic testing                             | Not Good / Good / Excellent |
| <input type="checkbox"/> Support with obtaining employment           | Not Good / Good / Excellent |
| <input type="checkbox"/> Support with securing a volunteer placement | Not Good / Good / Excellent |

**27. If you haven't accessed any of the services listed in Question 26 please tell us why**

- Unable to access the services
- Chosen not to access the services
- The services have not been offered to me

**28. Of the services listed below which have you NOT accessed but would like to?**

- Advice on claiming benefits
  - Mobility training
  - Access to work scheme
  - Counselling
  - Occupational health support
  - Physiotherapy
  - Social services support
  - Eye clinic support and signposting (ECLO)
  - Genetic counselling
  - Genetic testing
  - Support with obtaining employment
  - Support securing a volunteer placement
  - Other
- .....

**Services and Support: BBS UK**

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**29. How did you hear about BBS UK?**

- From a healthcare professional
- Word of mouth
- Internet search
- From another charity or support group
- In the media

Other .....

**30. In what ways have you engaged with BBS UK? (Tick any / all that apply)**

- I access information and/or support
- I engage via social media
- I attend events
- I am a member
- I donate or raise funds
- I am a volunteer
- I am a paid member of staff
- None of above

**31. Which of these statements do you agree with? (Tick any / all that apply)**

- I know how to contact BBS UK
- I would feel comfortable getting in touch with BBS UK
- I trust BBS UK to do what it says it will do
- BBS UK is ambitious on behalf of people affected by the syndrome
- BBS UK works hard to improve the lives of those with BBS
- BBS UK is focussed on the wishes of its members and their everyday needs
- People with BBS have a say in what BBS UK does

Additional comments:

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Bardet-Biedl Syndrome UK

**32. Which of these statements reflect the difference BBS UK has made to you?**

- I understand the condition more fully
- I am better informed about research into the condition
- I have greater awareness of the support available
- I am more confident in managing the challenges of my/ my child's condition including my/ my child's sight loss.
- I am more able to lead a fulfilling life.
- Other (Specify)

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**33. Overall, of those services you have accessed, how would you rate the information, support and services provided by BBS UK? If you haven't accessed them, leave the box blank.**

- |  |                             |
|--|-----------------------------|
| <input type="checkbox"/> Newsletters                             | Not Good / Good / Excellent |
| <input type="checkbox"/> Website                                 | Not Good / Good / Excellent |
| <input type="checkbox"/> Annual conference                       | Not Good / Good / Excellent |
| <input type="checkbox"/> Information booklets                    | Not Good / Good / Excellent |
| <input type="checkbox"/> Support with fundraising                | Not Good / Good / Excellent |
| <input type="checkbox"/> Information for children & young people | Not Good / Good / Excellent |
| <input type="checkbox"/> General contact and support             | Not Good / Good / Excellent |

**34. Which of the following would be of interest (Tick all that apply):**

- Social opportunities and activities
- Local/Regional groups
- Updates on treatments
- Updates on research
- Opportunities to participate in research
- Information on assistive technologies
- Managing everyday life with BBS
- Managing everyday life with sight loss
- Support with maintaining a healthy diet and lifestyle
- Support with exercise
- Information on independent living and getting around independently



- Stories about other people living with BBS
- Information on how to continue to work or study
- Ways to fundraise for, or donate to BBS UK
- Opportunities to volunteer
- Anything else (Specify):

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**35. Any other comments:**

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If you would like help completing this form, telephone BBS UK Officer Manager:

**Liz Loughery      07421 312731      [liz.loughery@bbsuk.org.uk](mailto:liz.loughery@bbsuk.org.uk)**

If you are feeling unsettled or upset by any of the questions in this form, you can talk to your Patient Liaison Officer:

**Angela Scudder    07591 206788      [angela.scudder@bbsuk.org.uk](mailto:angela.scudder@bbsuk.org.uk)  
Amy Clapp        07591 206787      [amy.clapp@bbsuk.org.uk](mailto:amy.clapp@bbsuk.org.uk)**



This form can be completed and returned online to [liz.loughery@bbsuk.org.uk](mailto:liz.loughery@bbsuk.org.uk) or printed and returned by post to:

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