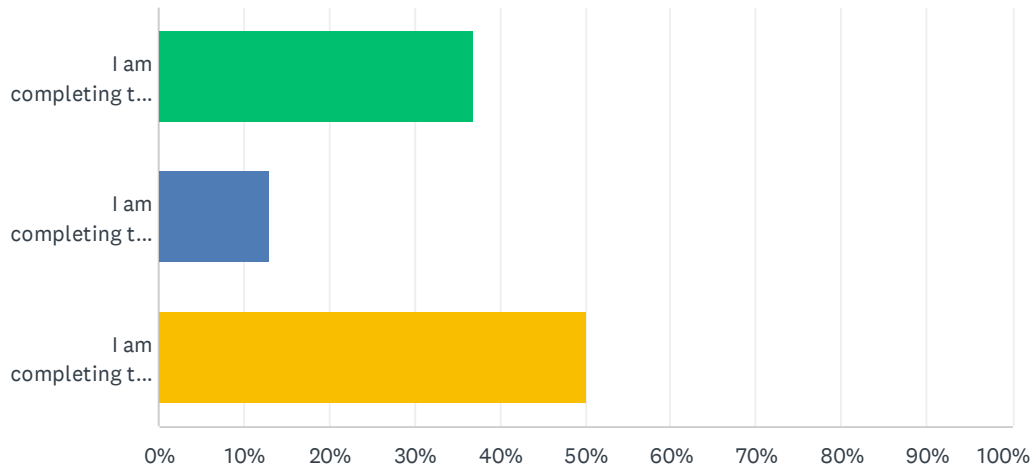


**Q1 Who is completing this form\*Please note, if you are a parent of 2 or more children with BBS you will need to complete a separate survey for each child.**

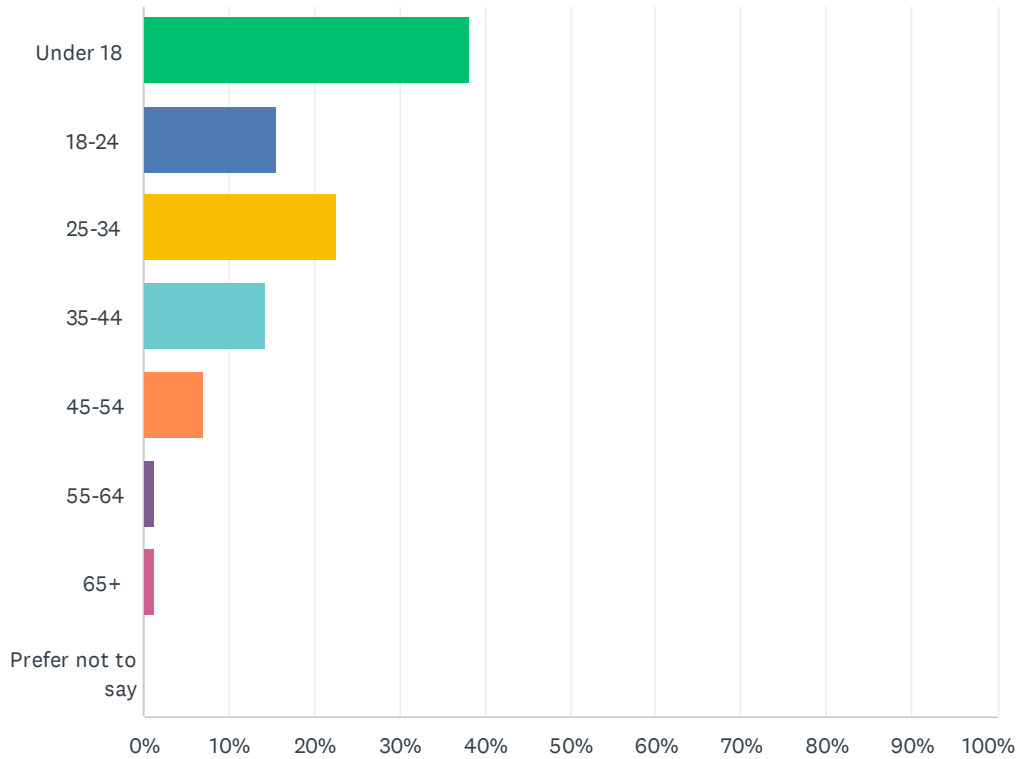
Answered: 84 Skipped: 0



ANSWER CHOICES	RESPONSES	
I am completing this as a person diagnosed with Bardet-Biedl Syndrome	36.90%	31
I am completing this on behalf of an adult diagnosed with Bardet-Biedl Syndrome. Views and perspectives provided are those of a diagnosed adult.	13.10%	11
I am completing this as a parent of someone diagnosed with Bardet-Biedl Syndrome. Views and perspectives provided are my own.	50.00%	42
<b>TOTAL</b>		<b>84</b>

## Q2 What is the age of the person affected by Bardet-Biedl Syndrome (BBS)?

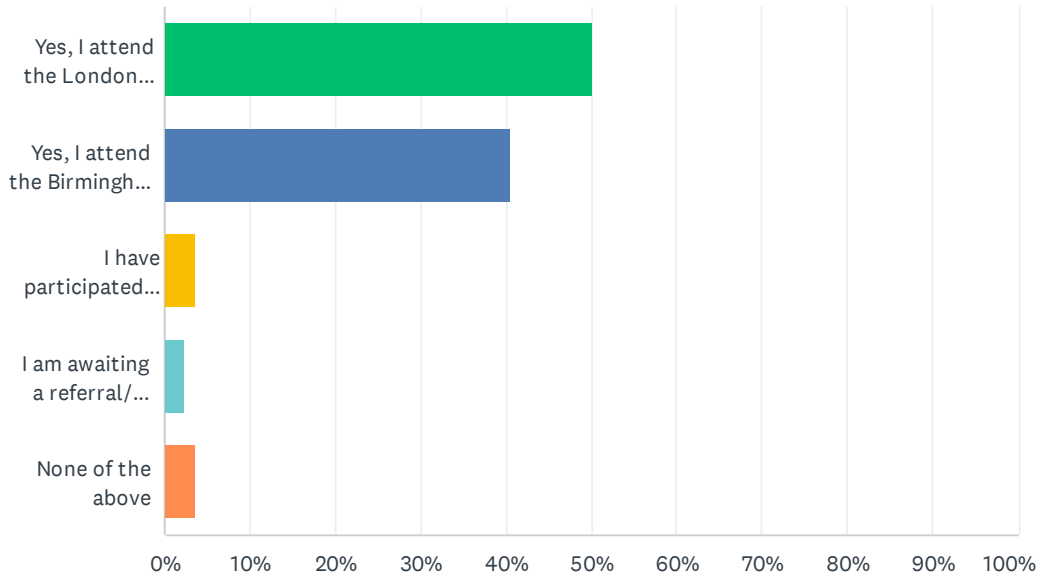
Answered: 84 Skipped: 0



ANSWER CHOICES	RESPONSES	
Under 18	38.10%	32
18-24	15.48%	13
25-34	22.62%	19
35-44	14.29%	12
45-54	7.14%	6
55-64	1.19%	1
65+	1.19%	1
Prefer not to say	0.00%	0
<b>TOTAL</b>		<b>84</b>

### Q3 Do you/your child attend the BBS multi-disciplinary clinics?

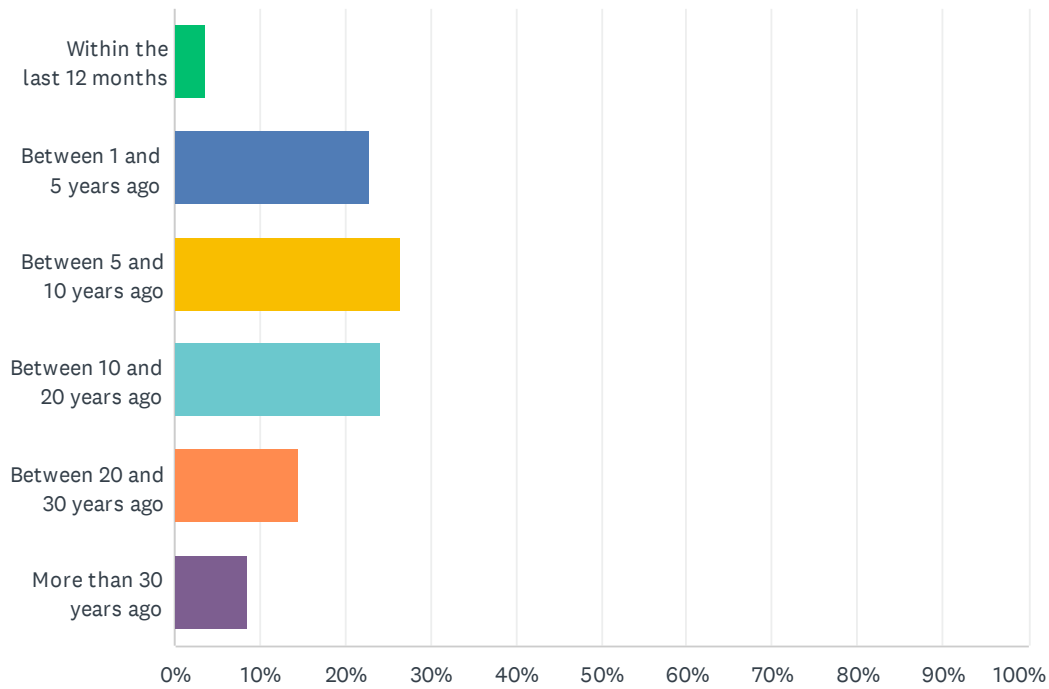
Answered: 84 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes, I attend the London Clinic	50.00%	42
Yes, I attend the Birmingham Clinic	40.48%	34
I have participated in the Telemedicine service only to date	3.57%	3
I am awaiting a referral/ appointment	2.38%	2
None of the above	3.57%	3
<b>TOTAL</b>		<b>84</b>

## Q4 How long ago were you/ the person affected by BBS diagnosed?

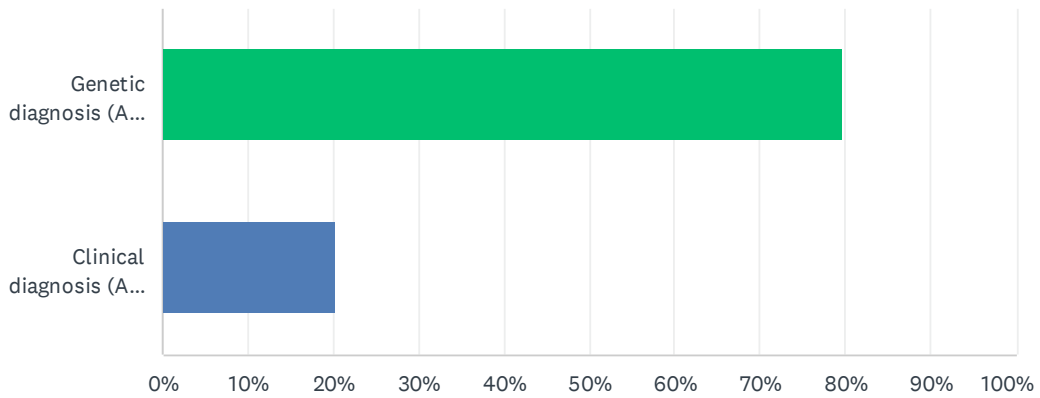
Answered: 83 Skipped: 1



ANSWER CHOICES	RESPONSES	
Within the last 12 months	3.61%	3
Between 1 and 5 years ago	22.89%	19
Between 5 and 10 years ago	26.51%	22
Between 10 and 20 years ago	24.10%	20
Between 20 and 30 years ago	14.46%	12
More than 30 years ago	8.43%	7
<b>TOTAL</b>		<b>83</b>

## Q5 Is the diagnosis genetic or clinical?

Answered: 84 Skipped: 0



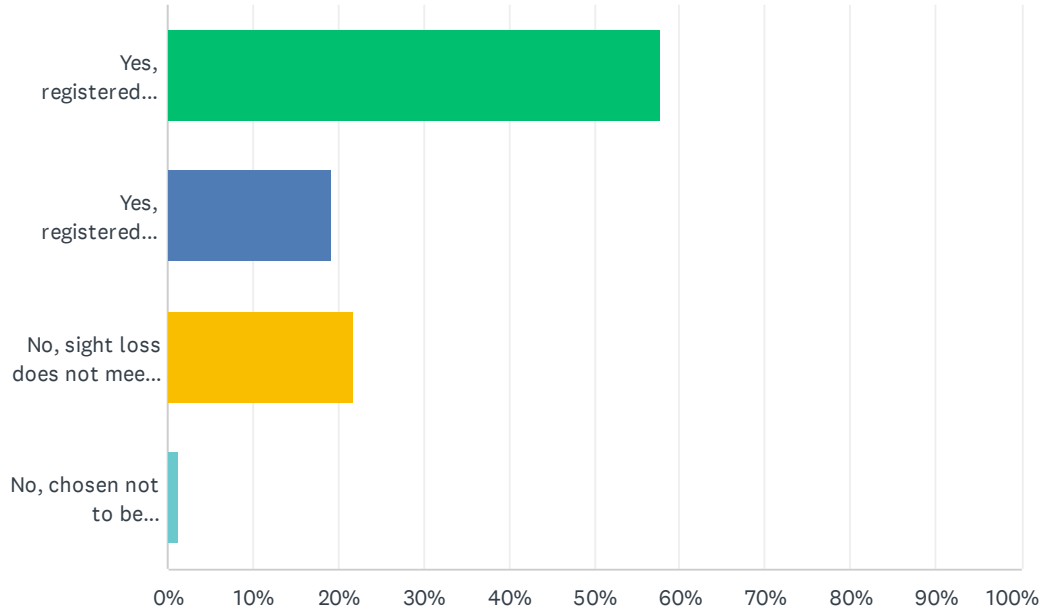
ANSWER CHOICES	RESPONSES	
Genetic diagnosis (A genetic diagnosis is established as a result of a genetic test)	79.76%	67
Clinical diagnosis (A clinical diagnosis is established on the basis of features and symptoms observed by a Clinician)	20.24%	17
<b>TOTAL</b>		<b>84</b>

Q6 If you have a genetic diagnosis, please tell us which BBS gene applies to you

Answered: 64 Skipped: 20

## Q7 Are you/ is your child registered as severely sight impaired or sight impaired?

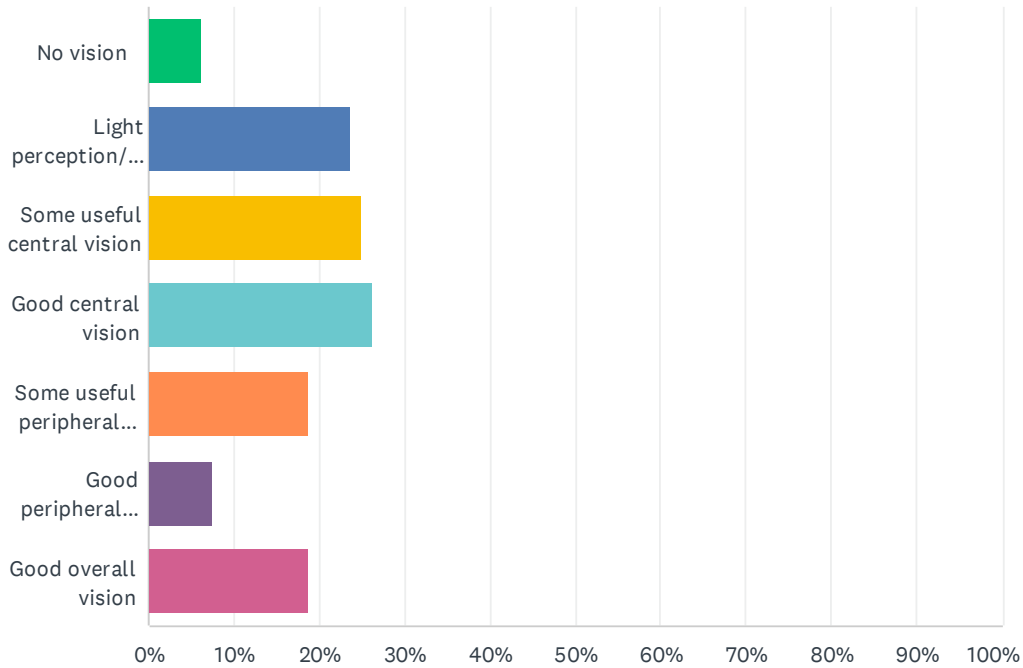
Answered: 83 Skipped: 1



ANSWER CHOICES	RESPONSES	
Yes, registered Severely Sight Impaired	57.83%	48
Yes, registered Sight Impaired	19.28%	16
No, sight loss does not meet the criteria	21.69%	18
No, chosen not to be registered	1.20%	1
<b>TOTAL</b>		<b>83</b>

## Q8 Describe your vision/ your child's vision

Answered: 80 Skipped: 4

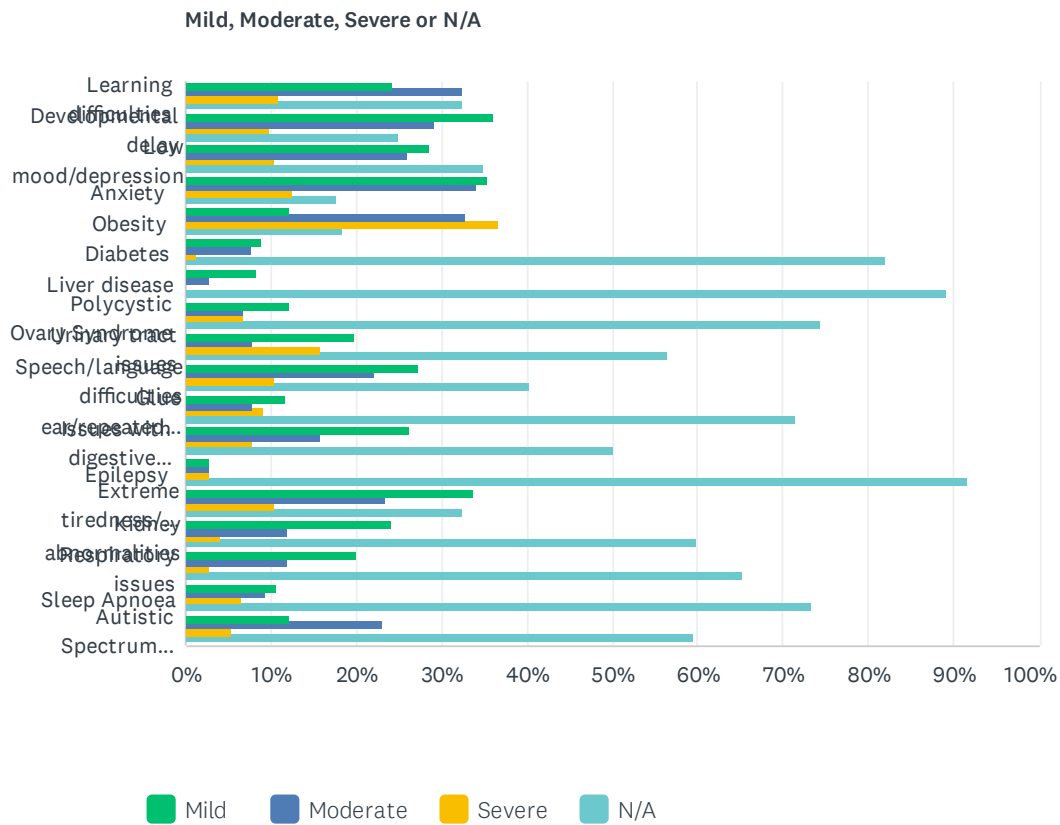


ANSWER CHOICES	RESPONSES	
No vision	6.25%	5
Light perception/ shadows only	23.75%	19
Some useful central vision	25.00%	20
Good central vision	26.25%	21
Some useful peripheral vision	18.75%	15
Good peripheral vision	7.50%	6
Good overall vision	18.75%	15
Total Respondents: 80		



### Q9 Which of the following symptoms do you have? Indicate in the dropdown box whether it is mild, moderate or severe.

Answered: 83 Skipped: 1

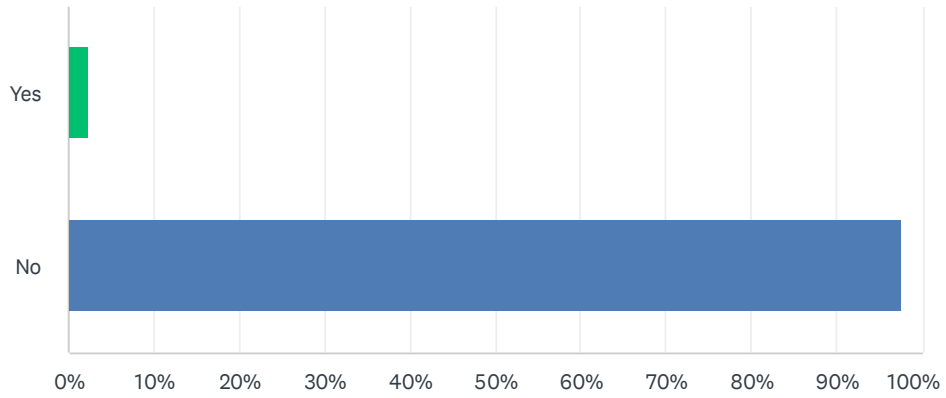


## BBS UK Membership Audit

Mild, Moderate, Severe or N/A					
	MILD	MODERATE	SEVERE	N/A	TOTAL
Learning difficulties	24.32% 18	32.43% 24	10.81% 8	32.43% 24	74
Developmental delay	36.11% 26	29.17% 21	9.72% 7	25.00% 18	72
Low mood/depression	28.57% 22	25.97% 20	10.39% 8	35.06% 27	77
Anxiety	35.44% 28	34.18% 27	12.66% 10	17.72% 14	79
Obesity	12.20% 10	32.93% 27	36.59% 30	18.29% 15	82
Diabetes	8.97% 7	7.69% 6	1.28% 1	82.05% 64	78
Liver disease	8.22% 6	2.74% 2	0.00% 0	89.04% 65	73
Polycystic Ovary Syndrome	12.16% 9	6.76% 5	6.76% 5	74.32% 55	74
Urinary tract issues	19.74% 15	7.89% 6	15.79% 12	56.58% 43	76
Speech/language difficulties	27.27% 21	22.08% 17	10.39% 8	40.26% 31	77
Glue ear/repeated ear infections	11.69% 9	7.79% 6	9.09% 7	71.43% 55	77
Issues with digestive system	26.32% 20	15.79% 12	7.89% 6	50.00% 38	76
Epilepsy	2.74% 2	2.74% 2	2.74% 2	91.78% 67	73
Extreme tiredness/ fatigue	33.77% 26	23.38% 18	10.39% 8	32.47% 25	77
Kidney abnormalities	24.00% 18	12.00% 9	4.00% 3	60.00% 45	75
Respiratory issues	20.00% 15	12.00% 9	2.67% 2	65.33% 49	75
Sleep Apnoea	10.67% 8	9.33% 7	6.67% 5	73.33% 55	75
Autistic Spectrum Disorder (ASD)	12.16% 9	22.97% 17	5.41% 4	59.46% 44	74

## Q10 Have you had a kidney transplant?

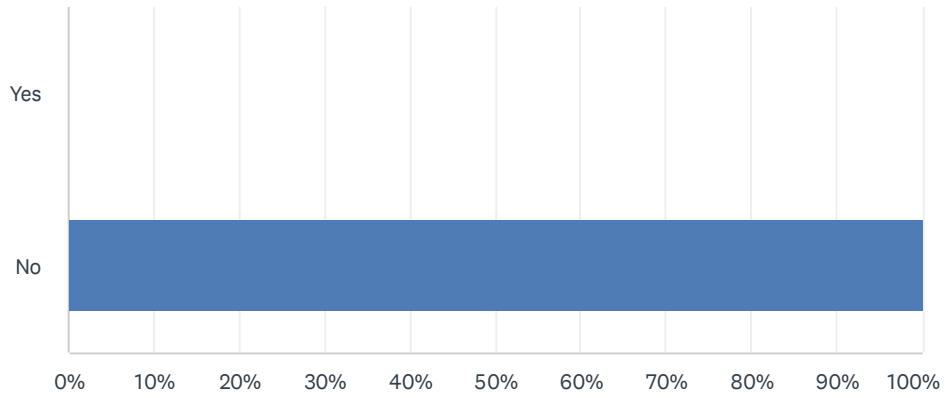
Answered: 83 Skipped: 1



ANSWER CHOICES	RESPONSES	
Yes	2.41%	2
No	97.59%	81
TOTAL		83

## Q11 Are you undergoing kidney dialysis?

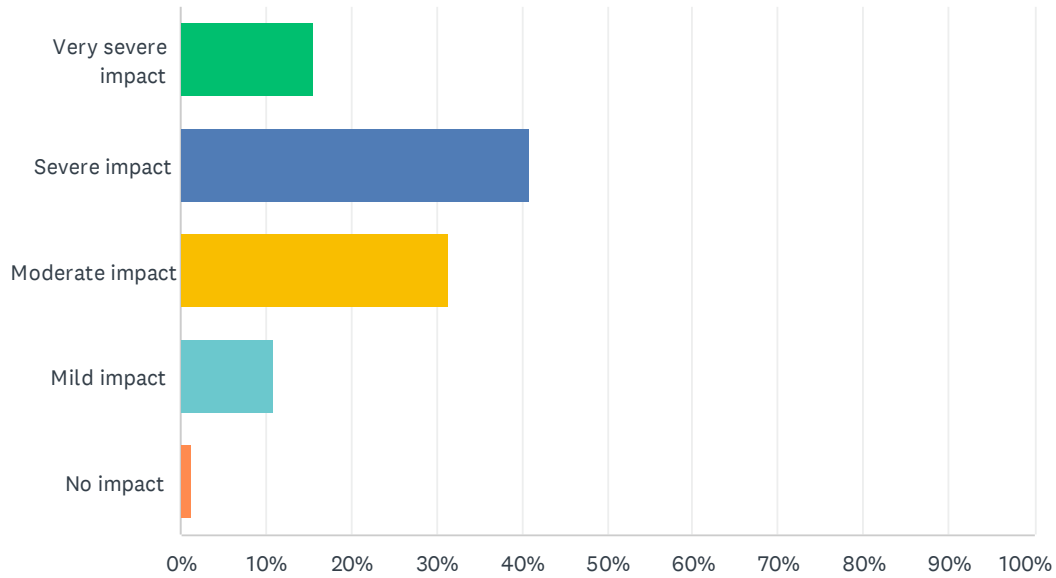
Answered: 81 Skipped: 3



ANSWER CHOICES	RESPONSES	
Yes	0.00%	0
No	100.00%	81
<b>TOTAL</b>		<b>81</b>

## Q12 Describe how BBS affects your life/ child's life

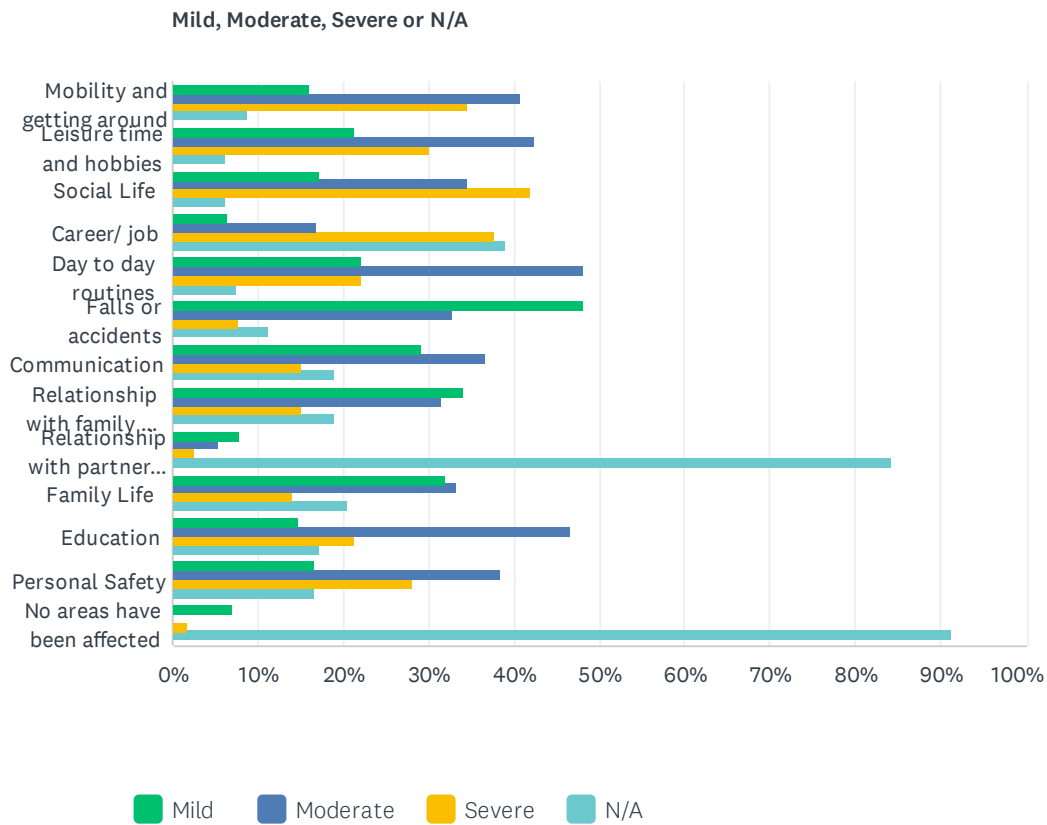
Answered: 83 Skipped: 1



ANSWER CHOICES	RESPONSES	
Very severe impact	15.66%	13
Severe impact	40.96%	34
Moderate impact	31.33%	26
Mild impact	10.84%	9
No impact	1.20%	1
<b>TOTAL</b>		<b>83</b>

Q13 Which areas of your life have been affected by BBS? Indicate in the dropdown box whether the impact has been mild, moderate or severe.

Answered: 82 Skipped: 2

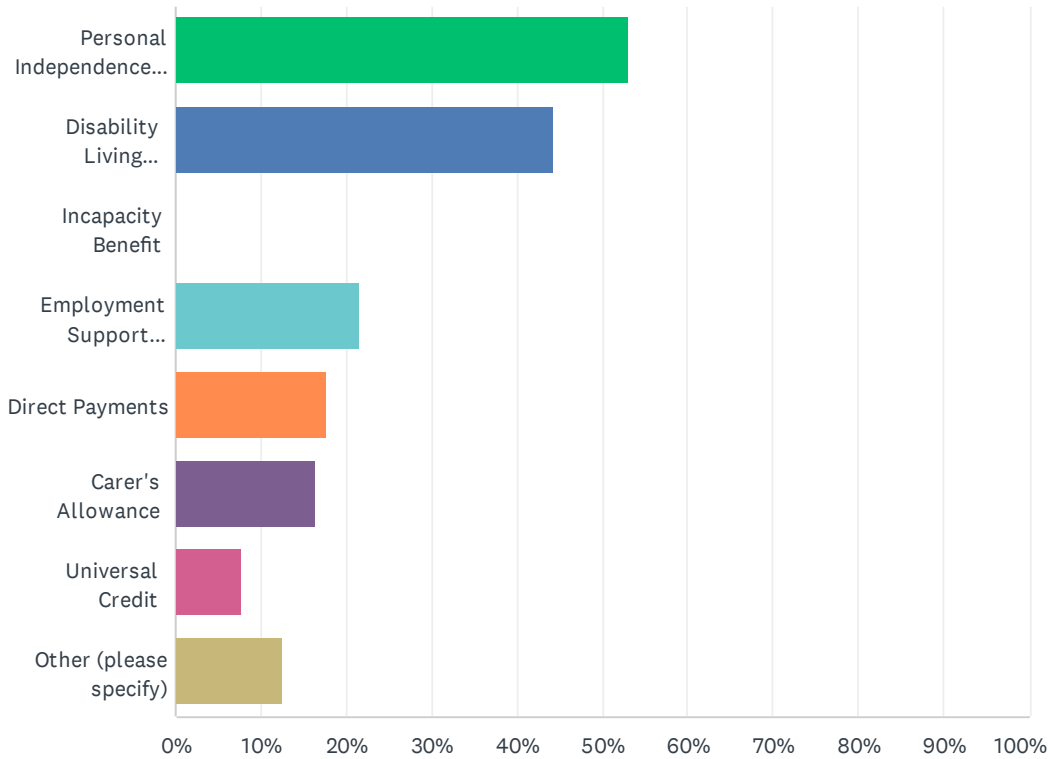


## BBS UK Membership Audit

Mild, Moderate, Severe or N/A					
	MILD	MODERATE	SEVERE	N/A	TOTAL
Mobility and getting around	16.05% 13	40.74% 33	34.57% 28	8.64% 7	81
Leisure time and hobbies	21.25% 17	42.50% 34	30.00% 24	6.25% 5	80
Social Life	17.28% 14	34.57% 28	41.98% 34	6.17% 5	81
Career/ job	6.49% 5	16.88% 13	37.66% 29	38.96% 30	77
Day to day routines	22.22% 18	48.15% 39	22.22% 18	7.41% 6	81
Falls or accidents	48.10% 38	32.91% 26	7.59% 6	11.39% 9	79
Communication	29.11% 23	36.71% 29	15.19% 12	18.99% 15	79
Relationship with family and friends	34.18% 27	31.65% 25	15.19% 12	18.99% 15	79
Relationship with partner/ spouse	7.89% 6	5.26% 4	2.63% 2	84.21% 64	76
Family Life	32.05% 25	33.33% 26	14.10% 11	20.51% 16	78
Education	14.67% 11	46.67% 35	21.33% 16	17.33% 13	75
Personal Safety	16.67% 13	38.46% 30	28.21% 22	16.67% 13	78
No areas have been affected	7.02% 4	0.00% 0	1.75% 1	91.23% 52	57

## Q14 Tick the boxes to indicate which disability benefits you are in receipt of

Answered: 79 Skipped: 5

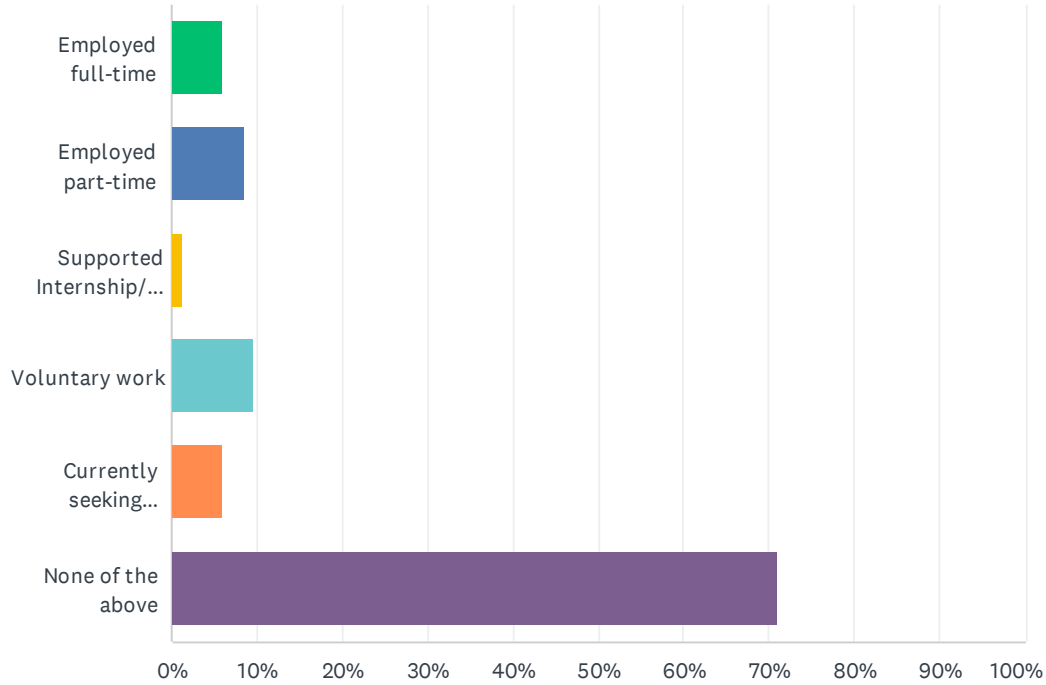


ANSWER CHOICES	RESPONSES	
Personal Independence Payment (PIP)	53.16%	42
Disability Living Allowance (DLA)	44.30%	35
Incapacity Benefit	0.00%	0
Employment Support Allowance (ESA)	21.52%	17
Direct Payments	17.72%	14
Carer's Allowance	16.46%	13
Universal Credit	7.59%	6
Other (please specify)	12.66%	10
Total Respondents: 79		



## Q15 Tick the boxes to indicate the employment status of the person this survey is about:

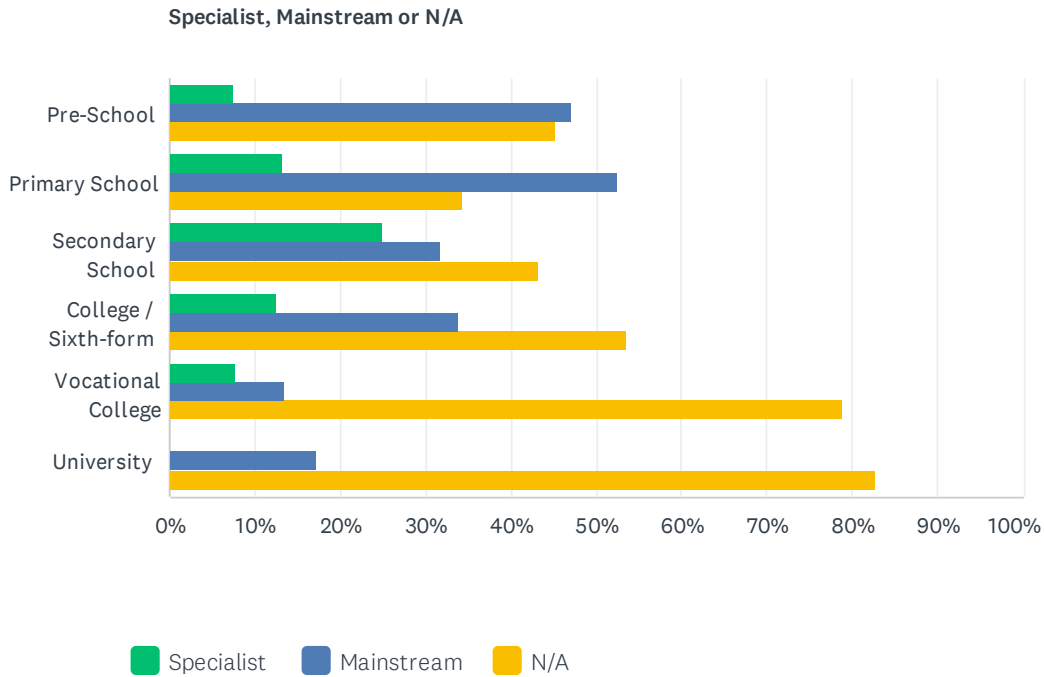
Answered: 83 Skipped: 1



ANSWER CHOICES	RESPONSES	
Employed full-time	6.02%	5
Employed part-time	8.43%	7
Supported Internship/ Traineeship	1.20%	1
Voluntary work	9.64%	8
Currently seeking employment	6.02%	5
None of the above	71.08%	59
Total Respondents: 83		

Q16 Tick the boxes to indicate your / your child's education status. Please also tell us if the education received is mainstream, specialist or select 'N/A' if these categories do not apply.

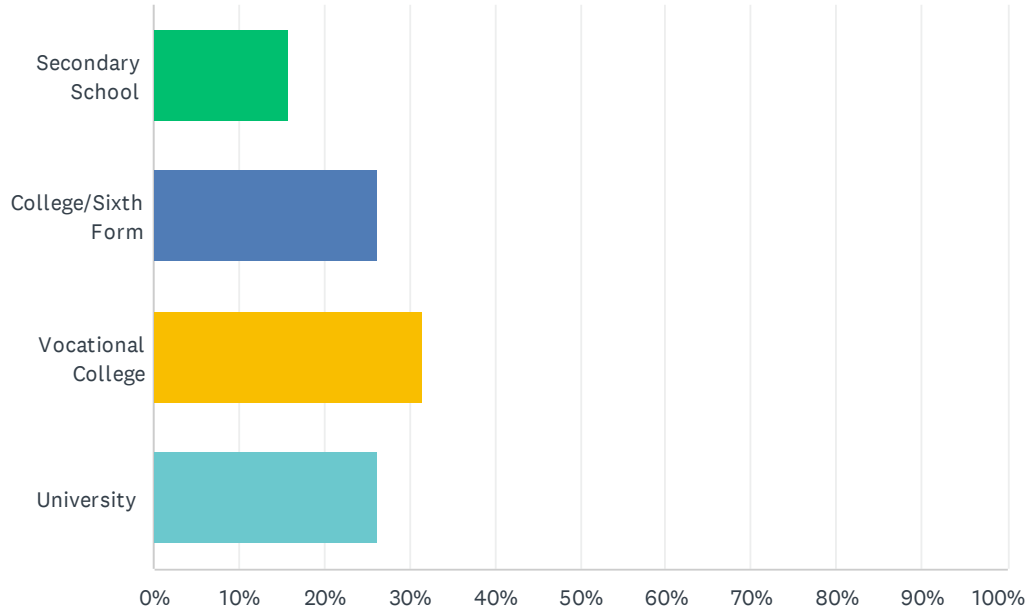
Answered: 76 Skipped: 8



Specialist, Mainstream or N/A				
	SPECIALIST	MAINSTREAM	N/A	TOTAL
Pre-School	7.55% 4	47.17% 25	45.28% 24	53
Primary School	13.11% 8	52.46% 32	34.43% 21	61
Secondary School	25.00% 15	31.67% 19	43.33% 26	60
College / Sixth-form	12.50% 7	33.93% 19	53.57% 30	56
Vocational College	7.69% 4	13.46% 7	78.85% 41	52
University	0.00% 0	17.31% 9	82.69% 43	52

### Q17 If you, or your child is no longer in education, please indicate the education level attained:

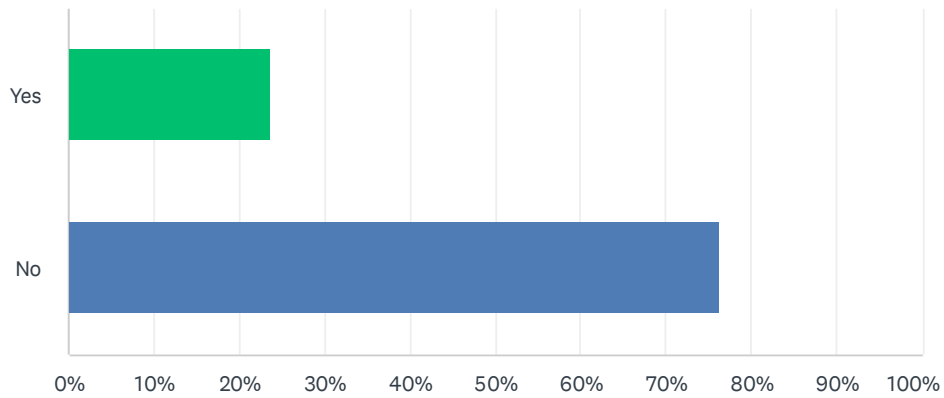
Answered: 38 Skipped: 46



ANSWER CHOICES	RESPONSES	
Secondary School	15.79%	6
College/Sixth Form	26.32%	10
Vocational College	31.58%	12
University	26.32%	10
<b>TOTAL</b>		<b>38</b>

## Q18 Do you (or does your child) have an Individual Education Plan (IEP)?

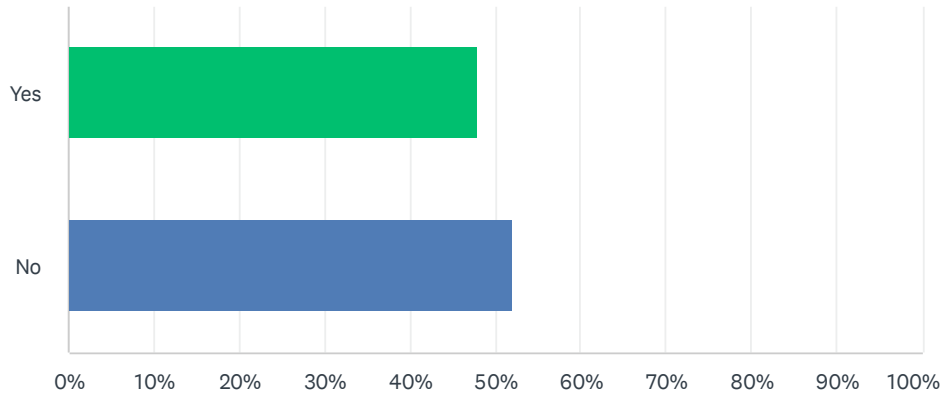
Answered: 76 Skipped: 8



ANSWER CHOICES	RESPONSES	
Yes	23.68%	18
No	76.32%	58
TOTAL		76

## Q19 Do you (or does your child) have an Education, Health and Care Plan (EHCP)?

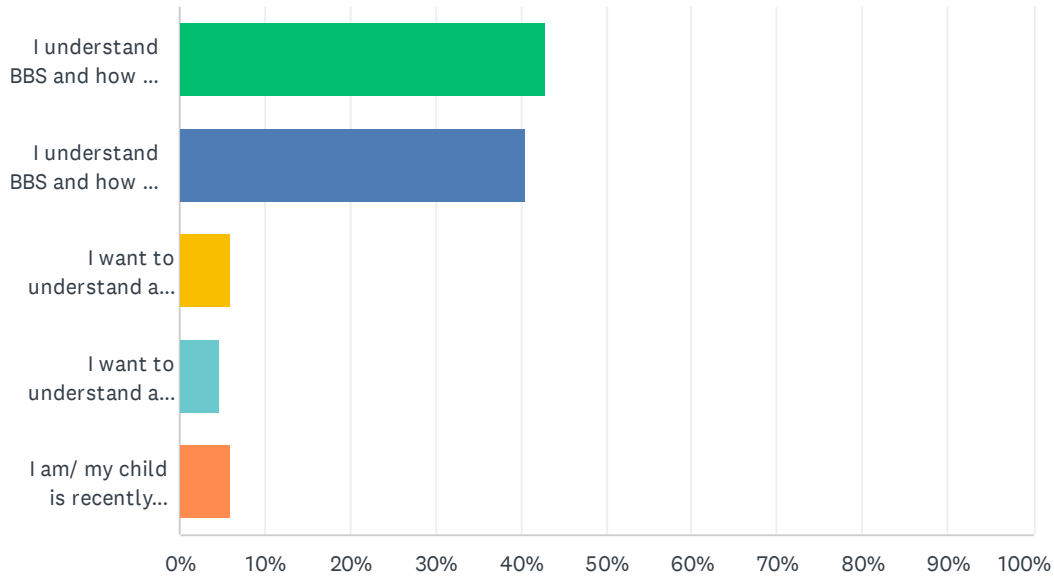
Answered: 75 Skipped: 9



ANSWER CHOICES	RESPONSES	
Yes	48.00%	36
No	52.00%	39
TOTAL		75

## Q20 Which of these statements best describes your/ your child's current situation?

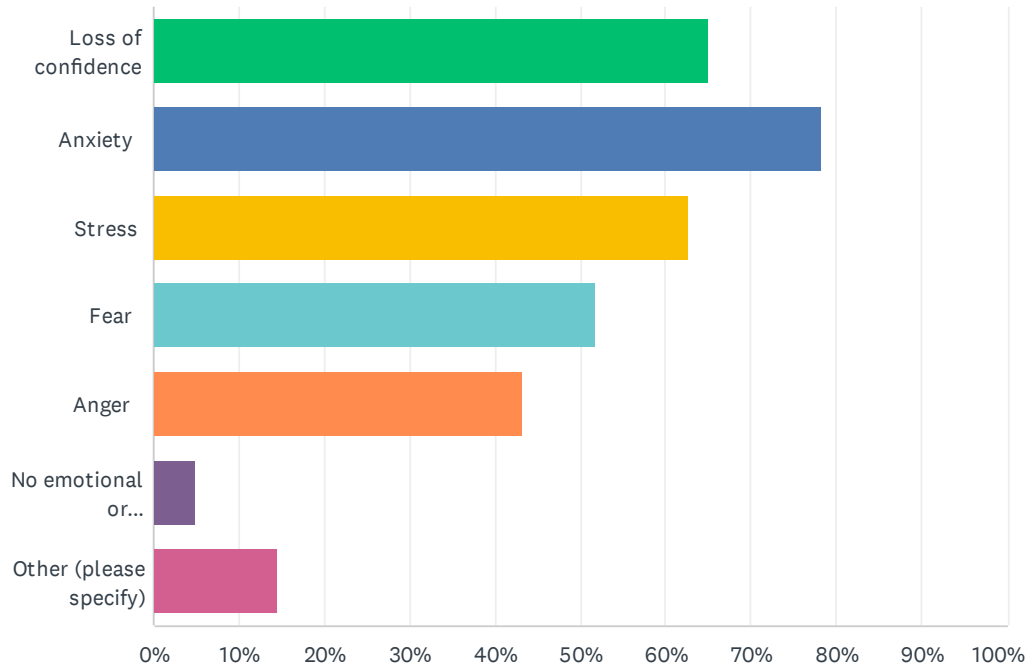
Answered: 84 Skipped: 0



ANSWER CHOICES	RESPONSES	
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.	42.86%	36
I understand BBS and how to manage it, and I know I can access help and support if I need it.	40.48%	34
I want to understand and manage BBS better, but I am unsure how to access the support I need.	5.95%	5
I want to understand and manage BBS better, but I have been unable to access the support I need.	4.76%	4
I am/ my child is recently diagnosed and still adjusting to life with BBS.	5.95%	5
<b>TOTAL</b>		<b>84</b>

## Q21 What are the emotional and psychological impacts of having BBS? Tick any/ all that apply

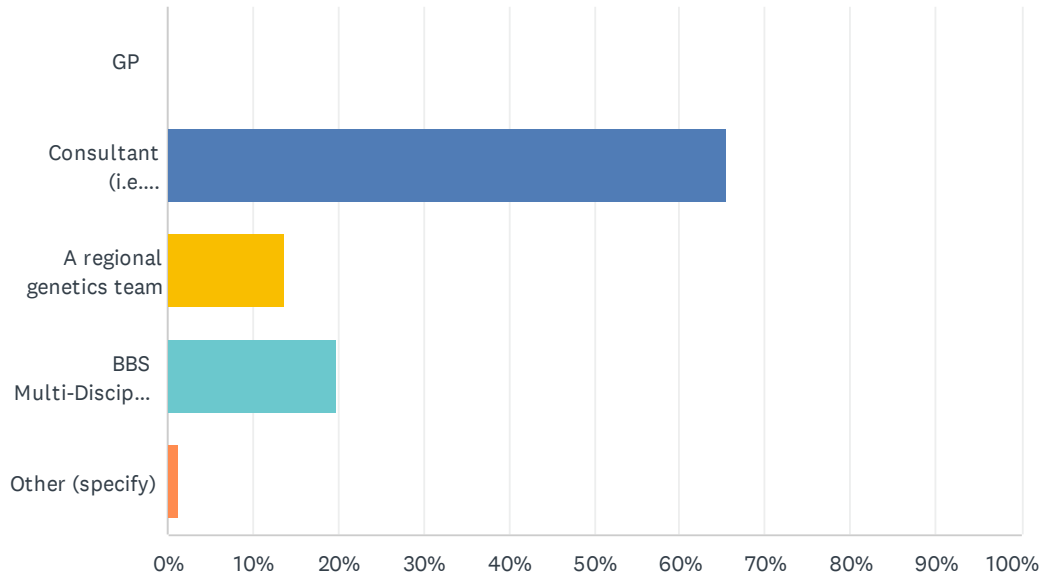
Answered: 83 Skipped: 1



ANSWER CHOICES	RESPONSES	
Loss of confidence	65.06%	54
Anxiety	78.31%	65
Stress	62.65%	52
Fear	51.81%	43
Anger	43.37%	36
No emotional or psychological impact	4.82%	4
Other (please specify)	14.46%	12
Total Respondents: 83		

## Q22 Please indicate who provided the diagnosis of BBS (if you can't remember leave blank)

Answered: 81 Skipped: 3

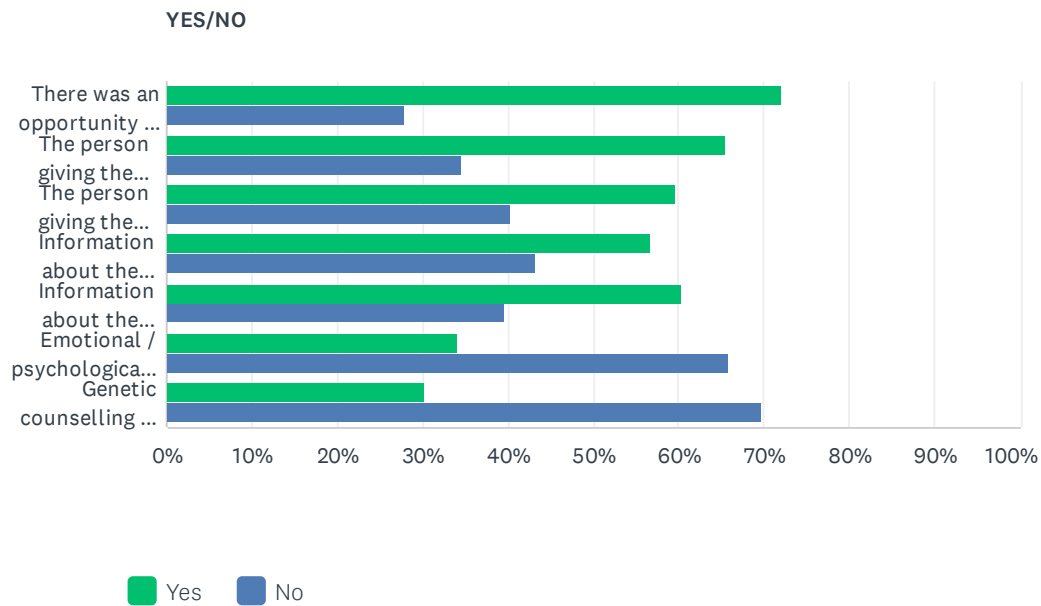


ANSWER CHOICES	RESPONSES	
GP	0.00%	0
Consultant (i.e. Geneticist, Ophthalmologist, Neurologist, Nephrologist)	65.43%	53
A regional genetics team	13.58%	11
BBS Multi-Disciplinary Clinic	19.75%	16
Other (specify)	1.23%	1
<b>TOTAL</b>		<b>81</b>



## Q23 With reference to when you received your diagnosis please indicate by selecting either 'Yes' or 'No' which statements apply to you.

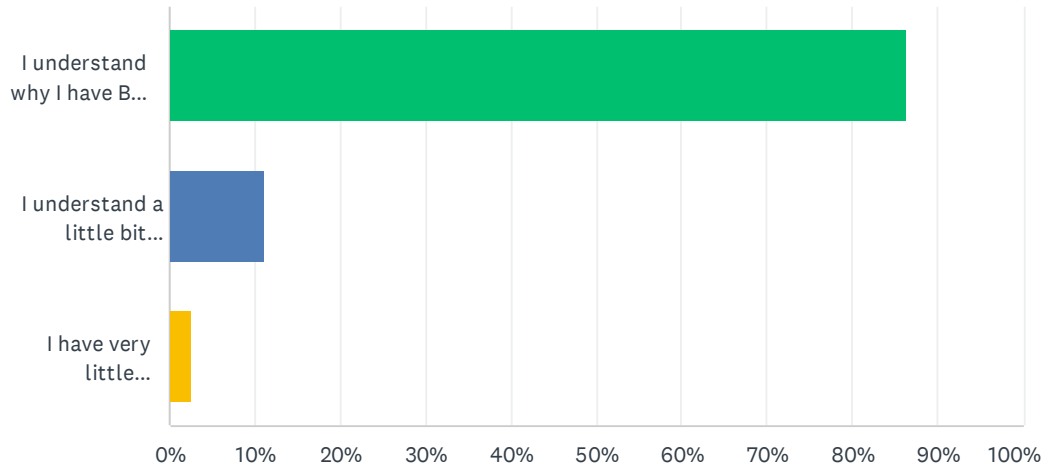
Answered: 83 Skipped: 1



YES/NO	YES	NO	TOTAL
There was an opportunity to ask questions during the diagnosis	72.15% 57	27.85% 22	79
The person giving the diagnosis had a good knowledge of the condition	65.38% 51	34.62% 27	78
The person giving the diagnosis had a good understanding of how I/ my child might be feeling	59.74% 46	40.26% 31	77
Information about the ongoing support was made available	56.76% 42	43.24% 32	74
Information about the support available from BBS UK was provided	60.26% 47	39.74% 31	78
Emotional / psychological support was offered	34.21% 26	65.79% 50	76
Genetic counselling was offered	30.26% 23	69.74% 53	76

## Q24 Do you understand your genetic diagnosis? Tick the box to indicate which statement applies to you

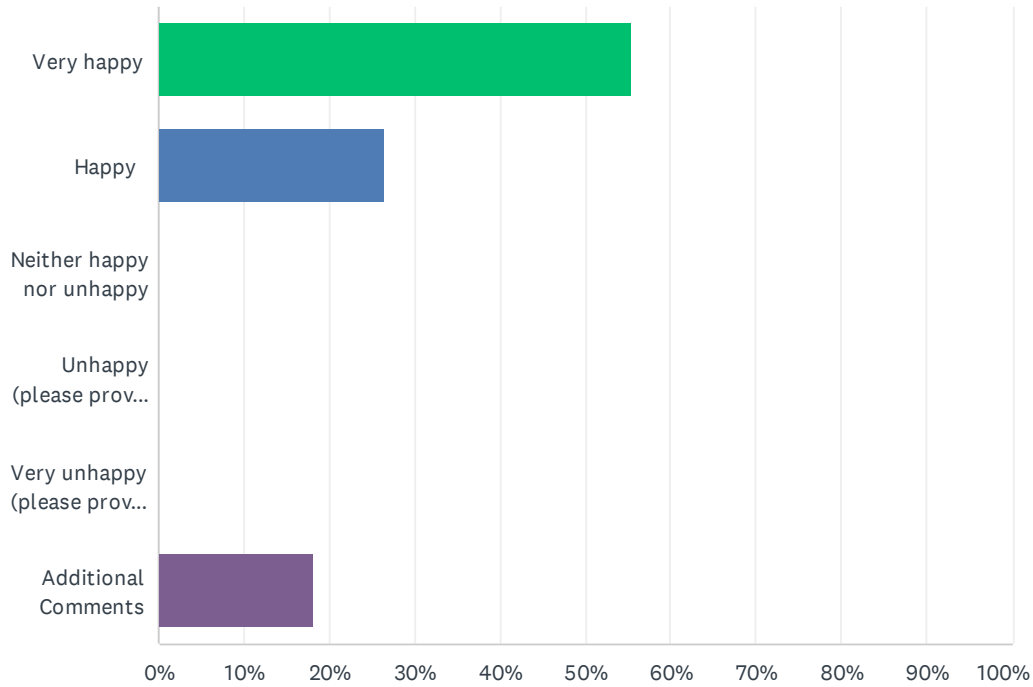
Answered: 81 Skipped: 3



ANSWER CHOICES	RESPONSES	
I understand why I have BBS and I am clear about the risks of it being passed on if I have children	86.42%	70
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	11.11%	9
I have very little understanding about why I have BBS	2.47%	2
<b>TOTAL</b>		<b>81</b>

## Q25 How happy are you with the ongoing care you receive from the BBS Clinics service?

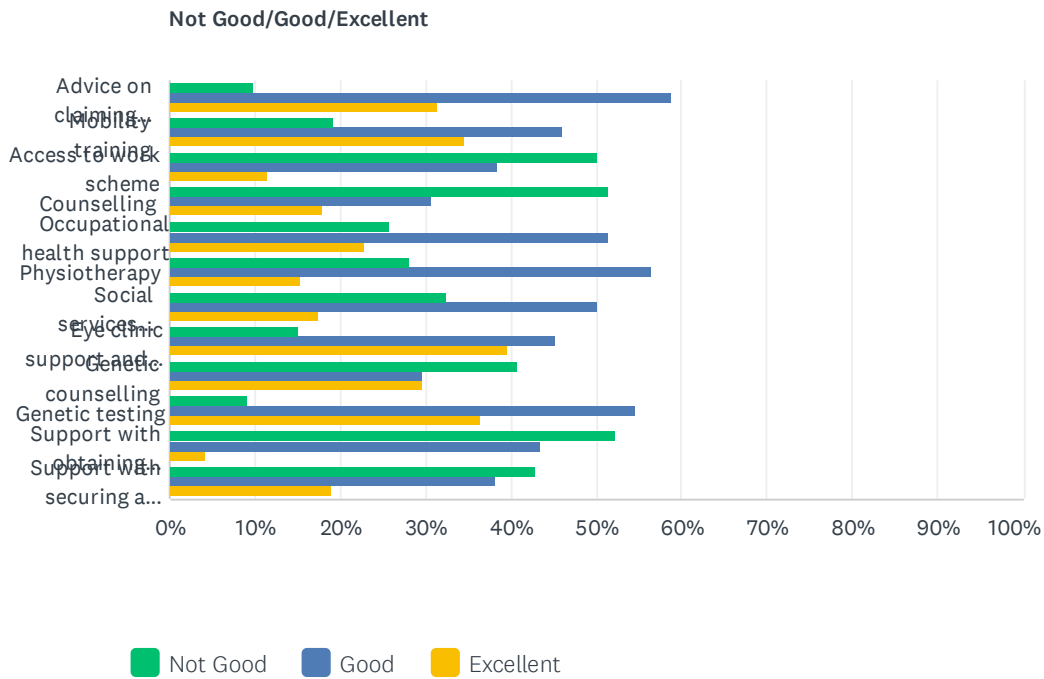
Answered: 83 Skipped: 1



ANSWER CHOICES	RESPONSES	
Very happy	55.42%	46
Happy	26.51%	22
Neither happy nor unhappy	0.00%	0
Unhappy (please provide an explanation why using the additional comments section below)	0.00%	0
Very unhappy (please provide an explanation why using the additional comments section below)	0.00%	0
Additional Comments	18.07%	15
<b>TOTAL</b>		<b>83</b>

Q26 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.

Answered: 76 Skipped: 8

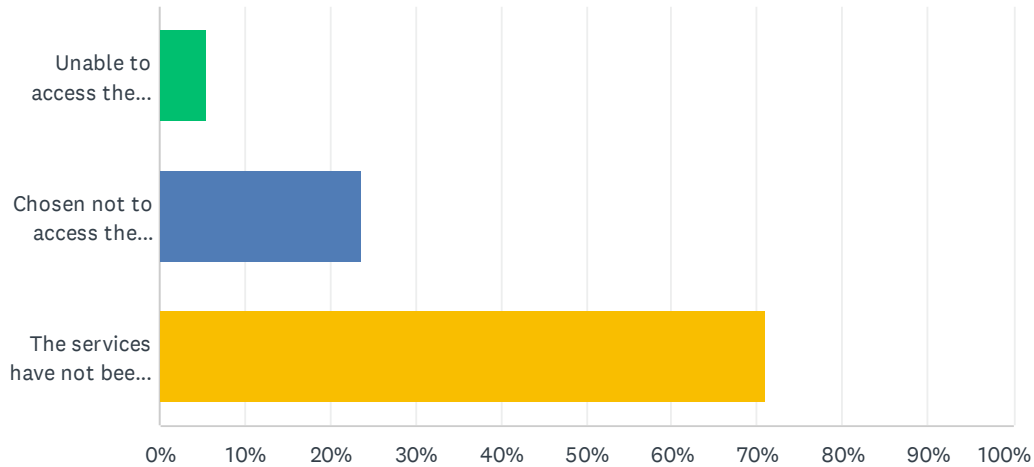


## BBS UK Membership Audit

Not Good/Good/Excellent				
	NOT GOOD	GOOD	EXCELLENT	TOTAL
Advice on claiming benefits	9.80% 5	58.82% 30	31.37% 16	51
Mobility training	19.23% 10	46.15% 24	34.62% 18	52
Access to work scheme	50.00% 13	38.46% 10	11.54% 3	26
Counselling	51.28% 20	30.77% 12	17.95% 7	39
Occupational health support	25.71% 9	51.43% 18	22.86% 8	35
Physiotherapy	28.21% 11	56.41% 22	15.38% 6	39
Social services support	32.50% 13	50.00% 20	17.50% 7	40
Eye clinic support and sign posting (ECLO)	15.09% 8	45.28% 24	39.62% 21	53
Genetic counselling	40.74% 11	29.63% 8	29.63% 8	27
Genetic testing	9.09% 4	54.55% 24	36.36% 16	44
Support with obtaining employment	52.17% 12	43.48% 10	4.35% 1	23
Support with securing a volunteer placement	42.86% 9	38.10% 8	19.05% 4	21

## Q27 If you haven't accessed any of the services referred to in Q26, please tell us why

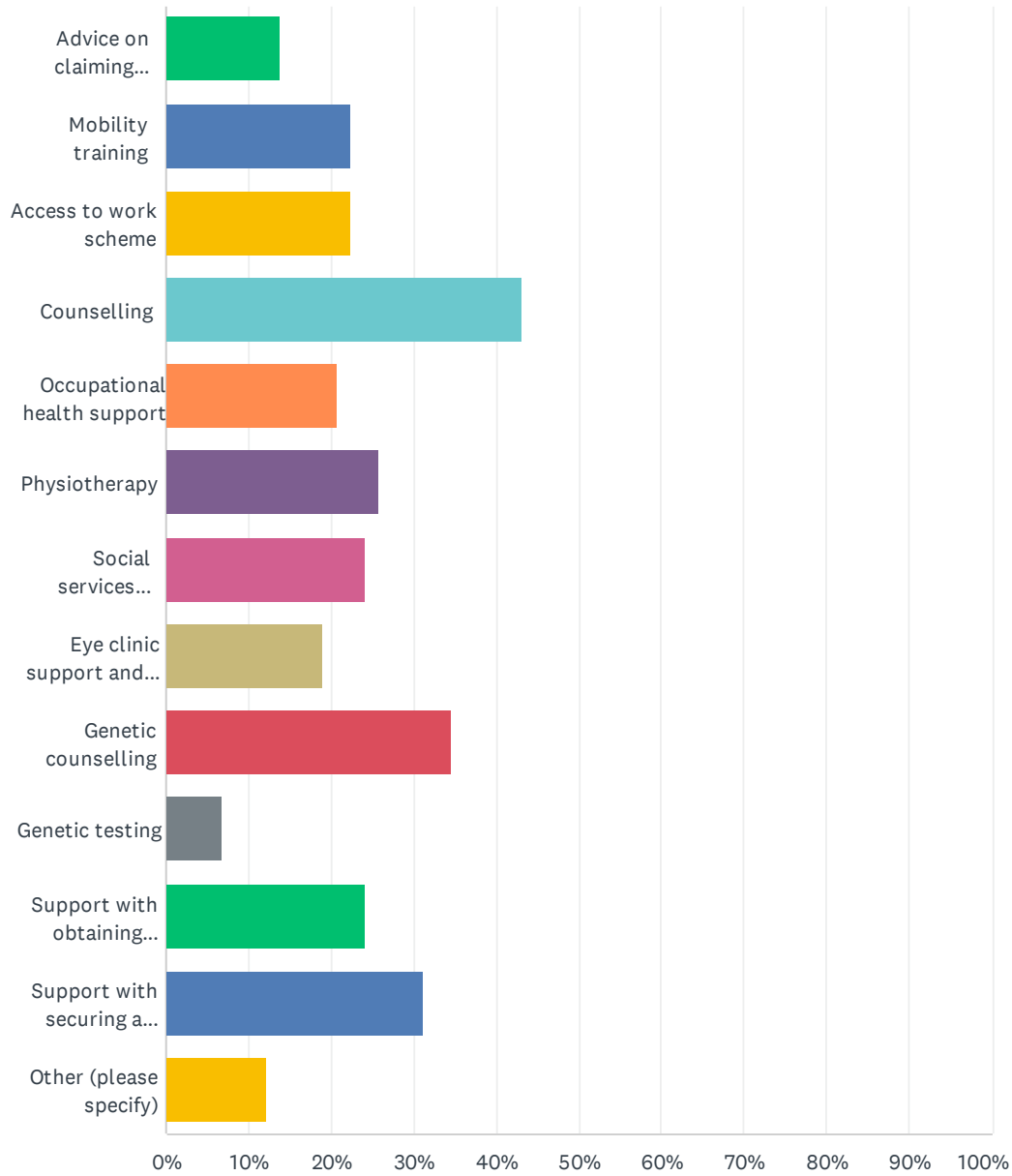
Answered: 55 Skipped: 29



ANSWER CHOICES	RESPONSES	
Unable to access the services	5.45%	3
Chosen not to access the services	23.64%	13
The services have not been offered to me	70.91%	39
<b>TOTAL</b>		<b>55</b>

## Q28 Of the services listed below, which have you NOT accessed but would like to?

Answered: 58 Skipped: 26



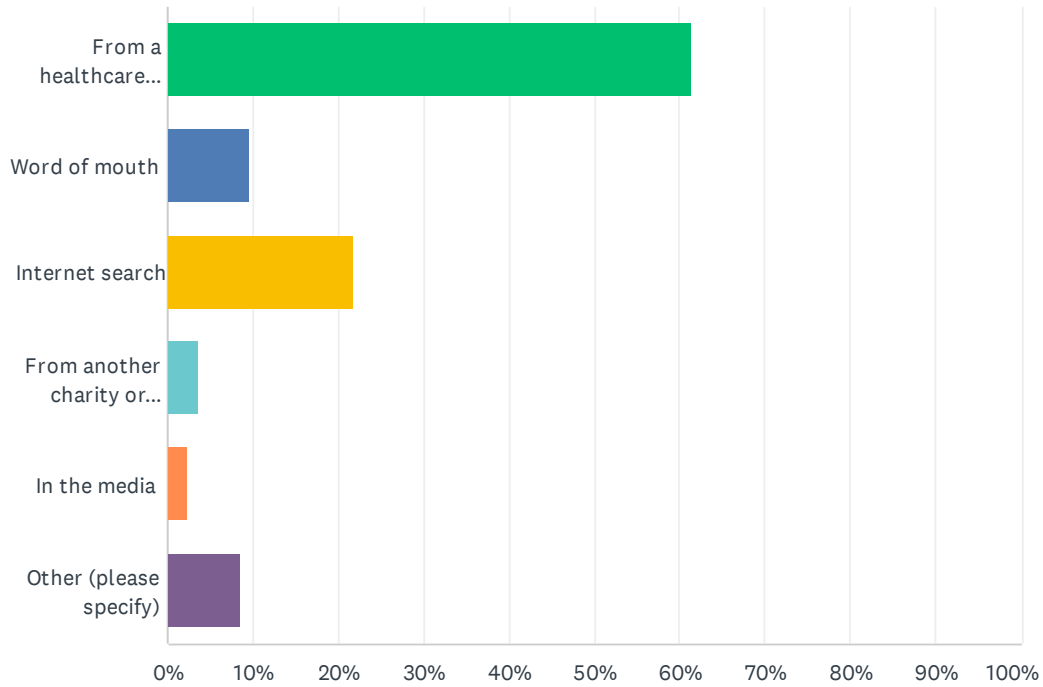
## BBS UK Membership Audit

ANSWER CHOICES	RESPONSES	
Advice on claiming benefits	13.79%	8
Mobility training	22.41%	13
Access to work scheme	22.41%	13
Counselling	43.10%	25
Occupational health support	20.69%	12
Physiotherapy	25.86%	15
Social services support	24.14%	14
Eye clinic support and signposting (ECLO)	18.97%	11
Genetic counselling	34.48%	20
Genetic testing	6.90%	4
Support with obtaining employment	24.14%	14
Support with securing a volunteer placement	31.03%	18
Other (please specify)	12.07%	7
Total Respondents: 58		



## Q29 How did you hear about BBS UK?

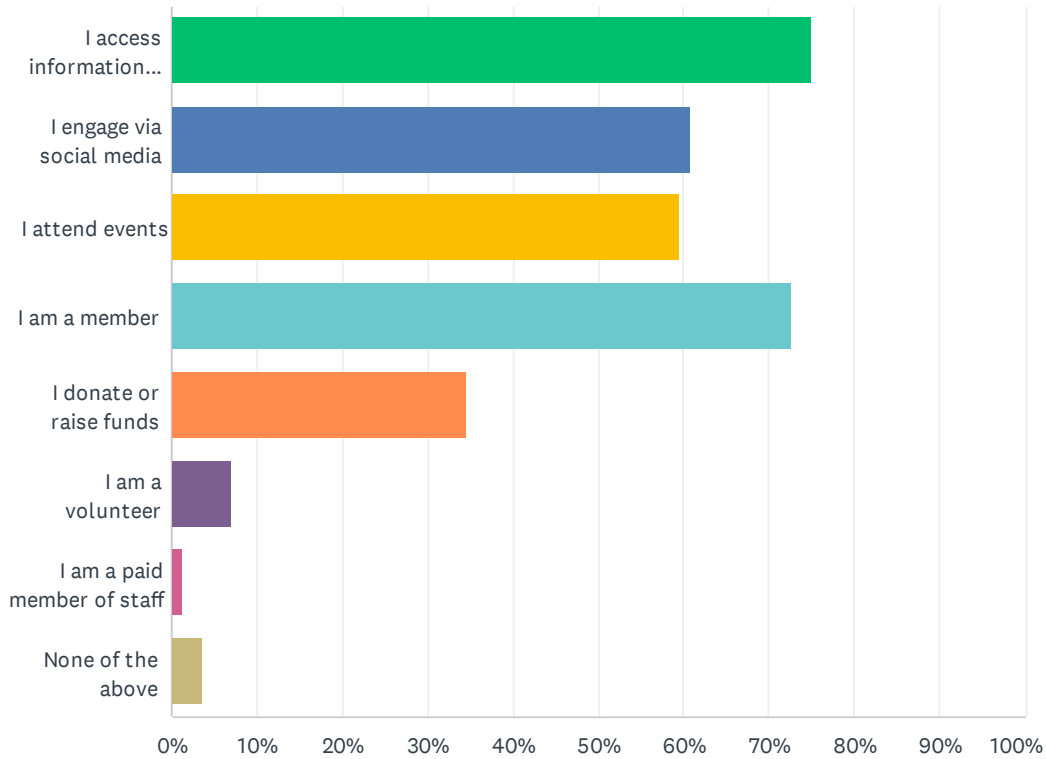
Answered: 83 Skipped: 1



ANSWER CHOICES	RESPONSES	
From a healthcare professional	61.45%	51
Word of mouth	9.64%	8
Internet search	21.69%	18
From another charity or support group	3.61%	3
In the media	2.41%	2
Other (please specify)	8.43%	7
Total Respondents: 83		

### Q30 In what ways have you engaged with BBS UK (Tick any/ all that apply)

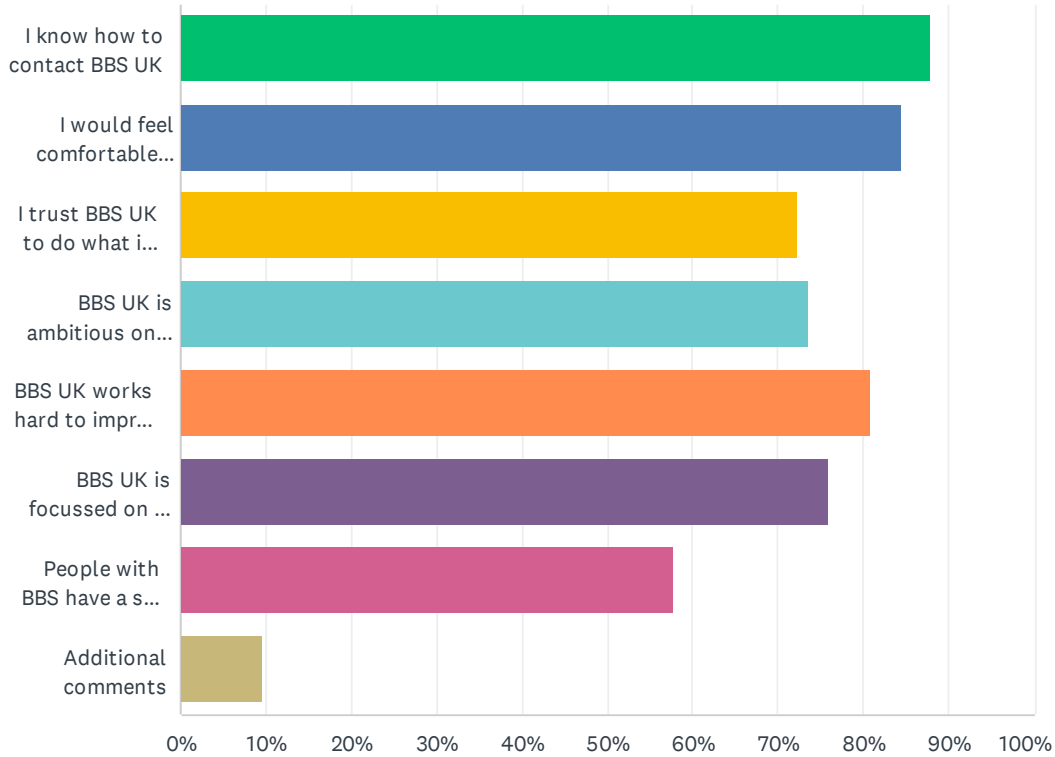
Answered: 84 Skipped: 0



ANSWER CHOICES	RESPONSES	
I access information and/or support	75.00%	63
I engage via social media	60.71%	51
I attend events	59.52%	50
I am a member	72.62%	61
I donate or raise funds	34.52%	29
I am a volunteer	7.14%	6
I am a paid member of staff	1.19%	1
None of the above	3.57%	3
Total Respondents: 84		

### Q31 Which of these statements do you agree with? (Tick any/ all that apply)

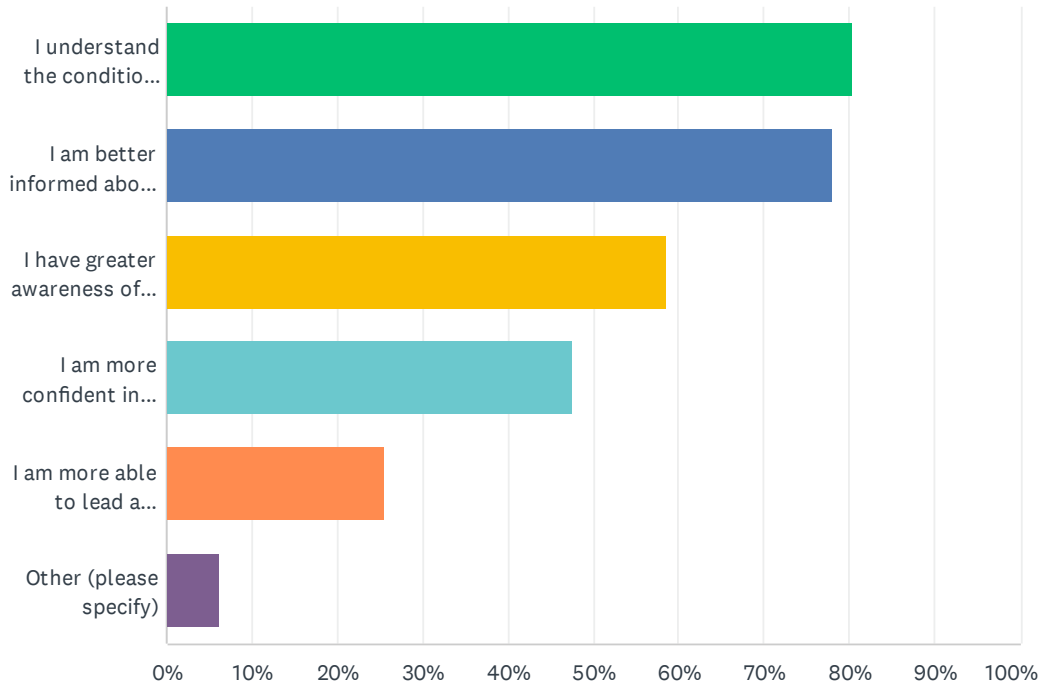
Answered: 83 Skipped: 1



ANSWER CHOICES	RESPONSES	
I know how to contact BBS UK	87.95%	73
I would feel comfortable getting in touch with BBS UK	84.34%	70
I trust BBS UK to do what it says it will do	72.29%	60
BBS UK is ambitious on behalf of people affected by the syndrome	73.49%	61
BBS UK works hard to improve the lives of those with BBS	80.72%	67
BBS UK is focussed on the wishes of its members and their everyday needs	75.90%	63
People with BBS have a say in what BBS UK does	57.83%	48
Additional comments	9.64%	8
Total Respondents: 83		

## Q32 Which of these statements reflect the difference BBS UK has made to you?

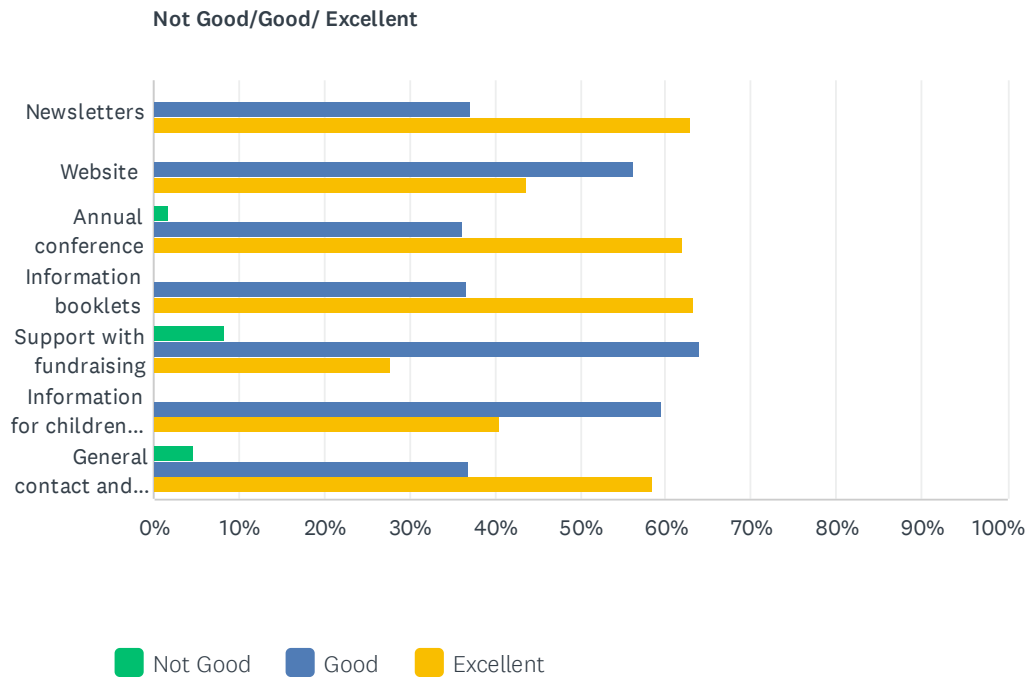
Answered: 82 Skipped: 2



ANSWER CHOICES	RESPONSES	
I understand the condition more fully	80.49%	66
I am better informed about research into the condition	78.05%	64
I have greater awareness of the support available	58.54%	48
I am more confident in managing the challenges of my / my child's condition including my/ my child's sight loss	47.56%	39
I am more able to lead a fulfilling life	25.61%	21
Other (please specify)	6.10%	5
Total Respondents: 82		

Q33 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.

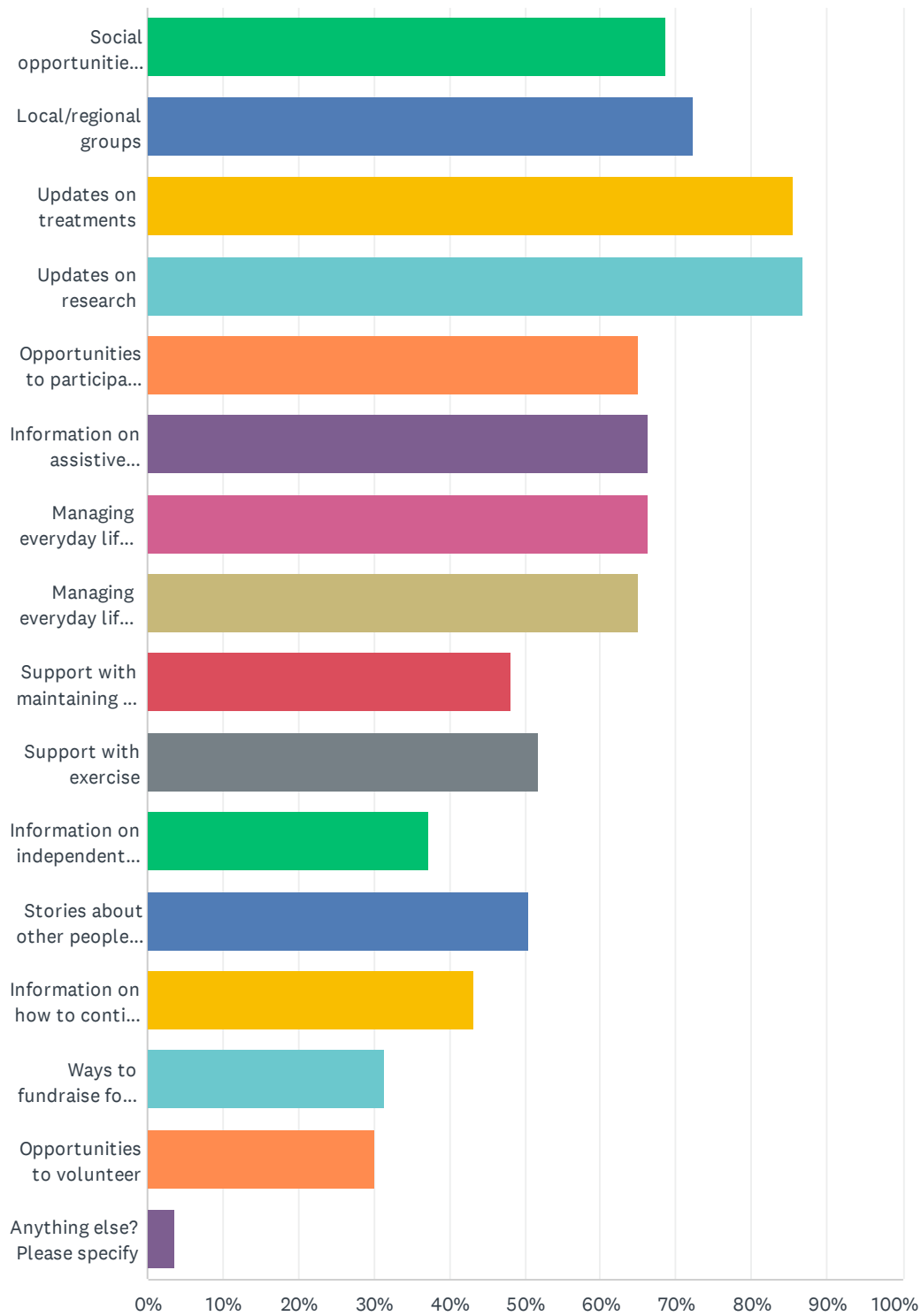
Answered: 79 Skipped: 5



Not Good/Good/ Excellent				
	NOT GOOD	GOOD	EXCELLENT	TOTAL
Newsletters	0.00% 0	37.14% 26	62.86% 44	70
Website	0.00% 0	56.25% 36	43.75% 28	64
Annual conference	1.72% 1	36.21% 21	62.07% 36	58
Information booklets	0.00% 0	36.62% 26	63.38% 45	71
Support with fundraising	8.33% 3	63.89% 23	27.78% 10	36
Information for children and young people	0.00% 0	59.52% 25	40.48% 17	42
General contact and support	4.62% 3	36.92% 24	58.46% 38	65

### Q34 Which of the following would be of interest (tick all that apply)

Answered: 83 Skipped: 1



## BBS UK Membership Audit

ANSWER CHOICES	RESPONSES	
Social opportunities and activities	68.67%	57
Local/regional groups	72.29%	60
Updates on treatments	85.54%	71
Updates on research	86.75%	72
Opportunities to participate in research	65.06%	54
Information on assistive technologies	66.27%	55
Managing everyday life with BBS	66.27%	55
Managing everyday life with sight loss	65.06%	54
Support with maintaining a healthy diet and lifestyle	48.19%	40
Support with exercise	51.81%	43
Information on independent living and getting around independently	37.35%	31
Stories about other people living with BBS	50.60%	42
Information on how to continue to work or study	43.37%	36
Ways to fundraise for, or donate to BBS UK	31.33%	26
Opportunities to volunteer	30.12%	25
Anything else? Please specify	3.61%	3
Total Respondents: 83		

Q35 Please provide any other comments or feedback you have for BBS  
UK here

Answered: 21 Skipped: 63