## Healthcare for children under 18 years of age

**This survey is intended for a parent/carer of someone with Down syndrome to complete, sharing their views and/or supporting their family member with Down syndorme to share their views.**
**This covers up to adulthood, we have a separate survey we would ask adults with Down syndrome to complete and also parents of adults to consider completing please.**

* 1. How do you describe yourself/in what capacity are you completing this survey?

- [ ] I am a parent/carer of someone with Down syndrome and am answering with my views
- [ ] I am completing with someone with Down syndrome and supporting them to share their views
- [ ] I am a family relative of someone with Down syndrome
- [ ] I am a friend to someone/some people with Down syndrome
- [ ] Other (please specify)

2. What is your gender?

- ◯ Female
- ◯ Male
- ◯ Prefer not to say
- ◯ Other (specify)

3. What is your age?

- ◯ Under 18
- ◯ 18-25
- ◯ 25-40
- ◯ 40-50
- ◯ 50-60
- ◯ 60+
- ◯ Prefer not to say

4. What ethnicity are you?

- [ ] Asian or Asian British
- [ ] Black, Black British, Caribbean or African
- [ ] Mixed or multiple ethnic groups
- [ ] White
- [ ] Other ethnic group
- [ ] Prefer not to answer
- [ ] Other (please specify)

* 5. Where do you live?

- ◯ Scotland
- ◯ Northern Ireland
- ◯ Wales
- ◯ North East England
- ◯ North West England
- ◯ Yorkshire and the Humber
- ◯ East Midlands
- ◯ West Midlands
- ◯ East England
- ◯ London
- ◯ South East England
- ◯ South West England
- ◯ Channel Islands

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* 6. How old is the family member/friend with Down syndrome?

- ◯ Under 1
- ◯ 1-4
- ◯ 5-10
- ◯ 11-18
- ◯ 19-25
- ◯ 25-40
- ◯ 40-50
- ◯ 50-60
- ◯ 60+

* 7. Where does your family member/friend with Down syndrome live?

- ◯ Scotland
- ◯ Northern Ireland
- ◯ Wales
- ◯ North East England
- ◯ North West England
- ◯ Yorkshire and the Humber
- ◯ East Midlands
- ◯ West Midlands
- ◯ East England
- ◯ London
- ◯ South East England
- ◯ South West England
- ◯ Channel Islands

8. What gender is your family member/friend with Down syndrome?

- ◯ Female
- ◯ Male
- ◯ Prefer not to say
- ◯ Other (please specify)

[ ]

9. What ethnicity is your family member/friend with Down syndrome?

- [ ] Asian or Asian British
- [ ] Black, Black British, Caribbean or African
- [ ] Mixed or multiple ethnic groups
- [ ] White
- [ ] Other ethnic group
- [ ] Prefer not to answer
- [ ] Other (please specify)

## Healthcare for children under 18 years of age

### Pre and antenatal (care focused on the health of the mother and foetus and the first 28 days)

10. When did you find out your child has Down syndrome?

- ◯ Confirmed pre-natal diagnosis
- ◯ A high-chance pre-natal result and chose no further testing
- ◯ Post-natal
- ◯ Adopted or fostering

11. Maternity experience - how was the diagnosis delivered to you?

- ☐ Negatively
- ☐ Neutrally
- ☐ Positively

12. Was your pregnancy managed by a named midwife or team for continuity of care?

- ◯ Yes
- ◯ No
- ◯ Don't know

13. If you had a high chance or confirmed diagnosis whilst pregnant, did you get offered additional scans during the pregnancy?

- ◯ Yes
- ◯ No
- ◯ Don't know
- ◯ Not applicable

14. If you had a high chance/confirmed diagnosis whilst pregnant, before birth did you meet any specialist to allow early care planning e.g. paediatricians, cardiac or gastrointestinal surgeons?

- ☐ Yes
- ☐ No
- ☐ Don't know
- ☐ Not applicable

15. If yes, please specify specialist(s)

16. Did you have Placental Dysfuntcion?

- ◯ Yes
- ◯ No
- ◯ Don't know
- ◯ Not applicable

17. What type of birth did you have?

- ◯ Spontaneous
- ◯ Induction
- ◯ Planned c-section
- ◯ Emergency c-section

18. Were you offered emotional or psychological support and early access to psychological support (both formal and informal)?

- ◯ Yes
- ◯ No
- ◯ Don't know

19. Did the hospital arrange any of the following whilst pregnant/post birth?

- ☐ Spoke to paediatric team
- ☐ Breastfeeding support
- ☐ Early contact with other services
- ☐ Put in touch with local Down syndrome group
- ☐ Given details of national Down syndrome group

## Healthcare for children under 18 years of age

### Early Years

20. Does/did your child Down syndrome have a congenital heart defect?

- ◯ Yes
- ◯ No
- ◯ Don't know

21. If yes, did the heart defect require surgery?

- ◯ Yes surgery was done and fully corrected the defect
- ◯ Yes the surgery was done but did not fully correct the defect
- ◯ No surgery was not required
- ◯ Under review
- ◯ Don't know

22. If yes to the above question, which kind of defect(s)?

- ☐ Atrioventricular septal defect (AVSD)
- ☐ Ventricular Septal Defect (VSD)
- ☐ Persistent Ductus Arteriosus (PDS)
- ☐ Tetralogy of Fallot
- ☐ Other

23. Does/did your child have a congenital bowel (gut) defect?

- ◯ Yes
- ◯ No
- ◯ Don't know

24. If yes, what kind of defect (you can select more then one)

- ☐ Hirschsprung disease
- ☐ Duodenal obstruction
- ☐ Imperforate anus
- ☐ Tracheoesophageal fistula
- ☐ Other (please specify)

25. Is your child on the GP Learning Disability Register?

- ◯ Yes
- ◯ No
- ◯ Don't know

26. During their first year, which healthcare teams did/does your child see regularly (at least once)?

- ☐ Neonatologist
- ☐ Midwife
- ☐ Hospital inpatient paediatrician
- ☐ Community paediatrician
- ☐ GP (General Practitioner)
- ☐ Gastroenterologist (bowel/gut doctors)
- ☐ Cardiologist (heart doctor)
- ☐ Haematologist (blood doctor)
- ☐ Psychiatrist
- ☐ Neurologist
- ☐ ENT doctor
- ☐ Orthopaedic Doctor (bone and joint doctor)
- ☐ Sleep clinic (including for sleep apnoea checks)
- ☐ Health Visiting Service
- ☐ Early Intervention Service
- ☐ Breastfeeding Team
- ☐ Audiologist (hearing team)
- ☐ Vision Team
- ☐ Portage (home teaching)
- ☐ Physiotherapy
- ☐ Speech and Language Therapist
- ☐ Occupational Therapy
- ☐ Feeding Team
- ☐ Learning Disability Nurser
- ☐ Psychologist
- ☐ Continence Nurse
- ☐ Specialist Nurse e.g. Eplilepsy, Asthma, Gastro etc
- ☐ Other (please specify)

## Healthcare for children under 18 years of age

### Child (1-17) years

27. If older than 1 year, which healthcare teams does/did your child now see regularly (at least once a year)?

- [ ] Hospital inpatient Paediatrician
- [ ] Community Paediatrician
- [ ] GP (General Practitioner)
- [ ] Gastroenterologist (bowel/gut doctors)
- [ ] Cardiologist (Heart doctor)
- [ ] Haematologist (Blood doctor)
- [ ] Psychiatrist
- [ ] Neurologist
- [ ] ENT doctor
- [ ] Orthopaedic Doctor (bone and joint doctor)
- [ ] Sleep clinic
- [ ] Health Visiting Service
- [ ] Audiologist (hearing team)
- [ ] Vision Team
- [ ] Portage (home teaching)
- [ ] Physiotherapy
- [ ] Speech and Language Therapist (NHS)
- [ ] Occupational Therapy
- [ ] Feeding Team
- [ ] Learning Disability Nurse
- [ ] Psychologist
- [ ] Continence Nurse
- [ ] Specialist Nurser e.g. Epilepsy, Asthma, Gastro etc
- [ ] Other (please specify)

28. In your child's early years, did they receive:

- [ ] Speech and Language Therapy (SaLT)
- [ ] Occupational therapy
- [ ] Physiotherapy

29. If not, what reasons were given?

30. If yes, was it sufficient for your child's needs?

31. If yes, for how long did you have to wait to access services? (months)

| | |
|---|---|
| SaLT | |
| Occupational Therapy | |
| Physiotherapy | |

32. If you did not receive any services, what reasons were given?

33. If your child is over the age of 14 has he/she seen the GP for an Annual Health Check once a year?

- ◯ Yes, every year
- ◯ Not as often as once a year
- ◯ A long time ago
- ◯ Never
- ◯ Don't know

## Healthcare for children under 18 years of age

**Now we would like to understand how confident you have felt with your health professional's knowledge in caring for someone with Down syndrome. We will explore your opinion on a number of health professionals you may have seen. Please tick N/A if not seen a particular professional or had any experience of particular condition.**

34. People with Down syndrome have some conditions more commonly than people without Down syndrome, e.g. hypothyroidism. What is your experience of the level of awareness of these professionals for these conditions? (1 being not very aware, 5 being very aware)

| | 1 | 2 | 3 | 4 | 5 | N/A |
|---|---|---|---|---|---|---|
| Thyroid Function Blood Test | ○ | ○ | ○ | ○ | ○ | ○ |
| Cardiovascular examination (e.g. listening to heart) | ○ | ○ | ○ | ○ | ○ | ○ |
| Sleep discussion, including possible sleep apnoea assessment if indicated | ○ | ○ | ○ | ○ | ○ | ○ |
| Throat and neck examination | ○ | ○ | ○ | ○ | ○ | ○ |
| Vision and hearing check (or confrmation these are being checked) | ○ | ○ | ○ | ○ | ○ | ○ |
| Immunisations- including influenza and Pneumococcal Vaccinations | ○ | ○ | ○ | ○ | ○ | ○ |
| Communication needs | ○ | ○ | ○ | ○ | ○ | ○ |
| Medication review | ○ | ○ | ○ | ○ | ○ | ○ |
| Lifestyle factors such as smoking, alcohol consumption, nutrition and exercise | ○ | ○ | ○ | ○ | ○ | ○ |
| Secual health | ○ | ○ | ○ | ○ | ○ | ○ |
| Foot care | ○ | ○ | ○ | ○ | ○ | ○ |
| Continence | ○ | ○ | ○ | ○ | ○ | ○ |
| Weight, height, blood pressure and heart rate | ○ | ○ | ○ | ○ | ○ | ○ |
| Mental health and emotional wellbeing, | ○ | ○ | ○ | ○ | ○ | ○ |

| | | | | | | |
|---|---|---|---|---|---|---|
| including mood and anxiety | | | | | | |
| Well woman awareness (cervical and breast care screening) | | | | | | |
| Well man awareness (testicular and prostate health) | | | | | | |
| Consideration should also be given to the carer's health and well being. | | | | | | |

35. How would you rate these health professionals in terms of their understanding of how to best help people with Down syndrome? (1 is poor, 5 is excellent)

| | 1 | 2 | 3 | 4 | 5 | N/A |
|---|---|---|---|---|---|---|
| GP | | | | | | |
| Paediatric | | | | | | |
| Heart | | | | | | |
| Vision | | | | | | |
| Hearing | | | | | | |
| Gastro (bowel) | | | | | | |
| Dental | | | | | | |
| Speech and Languate Therapy | | | | | | |
| Occupational Therapy | | | | | | |

36. Please provide any examples of best practice you've had with these professionals

| | |
|---|---|
| GP | |
| Paediatric | |
| Heart | |
| Vision | |
| Hearing | |
| Gastro (bowel) | |
| Dental | |
| Speech and Language Therapy | |
| Occupational Therapy | |

37. Please provide any examples of poor/inadequate practice you've had with these professionals

| | |
|---|---|
| GP | |
| Paediatric | |
| Heart | |
| Vision | |
| Hearing | |
| Gastro (bowel) | |
| Dental | |
| Speech and Language Therapy | |
| Occupational Therapy | |

38. Have you ever attended a Down syndrome clinic/provider?

- ◯ Yes
- ◯ No

39. If yes, please provide thoughts on your experience

40. In the last 12 months, how many times has your child seen a GP?

- ◯ None
- ◯ 1-3
- ◯ 4-6
- ◯ 6-12
- ◯ More than 12

41. In the last 12 months, how many trips to A&E has your child had?

- ◯ None
- ◯ 1-3
- ◯ 4-5
- ◯ More than 5

42. In the last 12 months, has your child had to stay in hospital for any reason?

- ◯ Yes
- ◯ No
- ◯ Don't know

43. In the last 12 months how many nights, in total, has your child stayed in hospital for any reason?

- ◯ 1-7 nights
- ◯ 8-14 nights
- ◯ 14+ nights
- ◯ None

44. Please tick the following conditions your child has, if diagnosed by a doctor

- ☐ Thyroid disorder
- ☐ Seizures/epilepsy
- ☐ Blood cancer (e.g. leukemia, lymphoma)
- ☐ Low white cells e.g. lymphopenia
- ☐ Other cancer
- ☐ Immuno-compormised (e.g. on cancer treatment)
- ☐ Obstructive sleep apnoea
- ☐ Obesity
- ☐ Hypertension
- ☐ Diabetes
- ☐ Cerebrovascular disease
- ☐ Coronary heart disease
- ☐ Chronic liver disease
- ☐ Chronic renal disease
- ☐ Chronic renal disease
- ☐ Chronic lung disease (e.g. asthma, emphysema, COPD)
- ☐ Celiac disease
- ☐ Gastroesophageal (acid) reflux (GERD)
- ☐ Constipation
- ☐ Irritable bowel sundrome (IBS)
- ☐ Allergies (e.g. reaction to past vaccines, food, mould)
- ☐ Food intolerances
- ☐ Alopecia

45. Does your child with Down syndrome have a current diagnosis of any behavioural and/or psychiatric condition (for example, autism spectrum disorder)?

- ◯ Yes
- ◯ No
- ◯ Don't know
- ◯ Awaiting diagnosis

46. If yes, please indicate all that apply

- ☐ Autism spectrum disorder
- ☐ Depression
- ☐ ADHD/ADD
- ☐ Anxiety
- ☐ Other (please specify)
- ☐ Obsessive compulsive disorder (OCD)
- ☐ Behaviour problems
- ☐ Psychosis
- ☐ Challenging Behaviours

47. Does your child have Epilepsy, if so, when did the seizures/Epilepsy begin?

- ◯ Before age of 10 years
- ◯ Age 10 years or older
- ◯ Don't know
- ◯ Does not have Epilepsy

48. What medications (or other treatments) is your child with Down syndrome normally on?

- ☐ On no medication
- ☐ Current flu vaccine
- ☐ Thyroxine/thyroid medication
- ☐ Steriods (oral)
- ☐ Reflux medication
- ☐ Constipation medication
- ☐ Long term antibiotics
- ☐ Inhalers
- ☐ Nebulizers
- ☐ Blood pressure medicine
- ☐ Antipsychotics for psychosis or to manager behaviour (e.g. Risperidone)
- ☐ ADHD medications
- ☐ Antidepressants
- ☐ Anti Epileptic medications
- ☐ Melatonin
- ☐ CPAP/APAP/BIPAP
- ☐ Other (please specify)

49. What supplements (or other treatments) is your child normally on?

- ☐ On no supplements
- ☐ Vitamin C
- ☐ Vitamin D
- ☐ Multivitamin
- ☐ Fish oil/Omega 3
- ☐ Other (please specify)
- ☐ Curcumin/Turmeric
- ☐ EGCG/Green tea extract
- ☐ TNI (Targeted Nutritional Intervention)
- ☐ Probiotics

50. Any other information you would like to share around healthcare

51. If you are happy for us to contact you with regard to this survey, the Down Syndrome Act and guidance, please share your details.

**Name**

**Email Address**