## Healthcare for adults with Down syndrome

**This survey is intended for an adult with Down syndrome to complete, or a parent/carer, other family relative or friend of an adult with Down syndrome.**

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

- [ ] I have Down syndrome
- [ ] 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
- [ ] Other (please specify)
- [ ] I am a family relative of someone with Down syndrome
- [ ] I am a friend to someone/some people with Down syndrome

2. What is your gender?

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

* 3. What is your age?

- ◯ 18-24
- ◯ 25-39
- ◯ 40-49
- ◯ 50-59
- ◯ 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

## Healthcare for adults with Down syndrome

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

- ◯ 18-25
- ◯ 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 adults with Down syndrome

10. Do you know if you are on your GP/Doctor's Learning Disability Register?

- ◯ Yes
- ◯ No
- ◯ Don't know

11. Which healthcare teams do you see regularly (at least once in the last year)?

- ☐ GP (doctor)
- ☐ Gastroenterologist (bowel/gut doctors)
- ☐ Cardiologist (Heart doctor)
- ☐ Psychiatrist
- ☐ Neurologist
- ☐ Dementia Team/Clinic
- ☐ Ear Nose Throat doctor
- ☐ Orthopaedic Doctor (bone and joint doctor)
- ☐ Sleep clinic (including sleep apnoea checks)
- ☐ Audiologist (hearing team)
- ☐ Vision Team
- ☐ Learning Disability Nurse
- ☐ District Nurse
- ☐ Continence Nurse
- ☐ Specialist Nurse e.g. Epilepsy, Asthma, Gastro etc
- ☐ Psychologist
- ☐ Occupational Therapy
- ☐ Physiotherapy
- ☐ Speech and Language Therapist

## Healthcare for adults with Down syndrome

**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. If you have not seen any of the listed professionals, please tick N/A = Not/Applicable.**

12. Do you think that the following health professionals were/are able to understand your needs and provide the correct treatments and programmes you need?

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

13. How well do these health professional explain things to you when you meet them? (1 is poor, 5 is excellent)
If you do not see them, then please tick N/A = Not Applicable.

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

14. If you are a person with Down syndrome, how easy or hard is it to explain how you are feeling to a health professional? (1 is easy, 5 is hard)

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

15. Do you see a Doctor every year to check your health?

- ◯ Yes
- ◯ No

16. In the last 12 months, how many times have you seen a GP/Doctor?

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

17. In the last 12 months, how many trips to A&E have you had?

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

18. In the last 12 months, have you had to stay in hospital for any reason?

- ◯ Yes
- ◯ No
- ◯ Don't know

19. In the last 12 months how many nights, in total, have you stayed in hospital for any reason?

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

20. Please tick the following conditions if a doctor has advised you have the condition.

- ☐ 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)
- ☐ Alzheimer's disease/dementia
- ☐ Food intolerances
- ☐ Alopecia

21. Do you have a congenital bowel (gut) defect?

- ◯ Yes
- ◯ No
- ◯ Don't know

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

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

23. Do you have a current diagnosis of any behavioural and/or psychiatric condition (for example, autism spectrum disorder)?

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

24. 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

25. If you have Epilepsy, when did the seizures/Epilepsy begin?

- ◯ Before age of 30 years
- ◯ Age 30 years or older
- ◯ Don't know
- ◯ I do not have Epilepsy

26. What medications (or other treatments) are you 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)

27. What supplements (or other treatments) are you/the person with Down syndrome 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

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

29. 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**

# Healthcare for adults with Down syndrome

## Professionals Specialist questionniare

**Thank you for your interest in giving your views as a professional.  We kindly ask you proceed to our professional's only survey to share your experiences.**

**Professionals Survey (hyperlink)**

**If you are filling in this survey WITH someone (i.e. facilitating them sharing their voice) please return to the start of this survey and tick:**
**"*I am completing with someone with Down syndrome and supporting them to share their views*". RESTART SURVEY**

**Many thanks,**
**The NDSPG**