

Section 1 : Demographics

Q2: How old is the person with AS (in years)?

One choice in a range [0, 1, ..., 49, >=50]

Q3: In which region in France does the person with AS live?

One choice in a set of French regions



Figure 1 : French regions

Section 2 : Information about diagnosis

Q4 : How old was the person with AS when he/she was diagnosed with Angelman syndrome (in years)?

One choice in a range [0, 1, ..., 49, >=50]

Q5: What is the genotype?

One choice in a set [Deletion, Mutation, UPD, ICT, Unknown]

Section 3 : Check-up

Q6: Is the person with AS currently under the care of medical practitioner ? (multiple answers are possible)

- Not under the care of any practitioner
- Under the care of a general practitioner
- Under the care of one or more specialists (in the hospital-based physician)
- Under the care of one or more specialists (private practitioner)

Q7: If you have selected "one or more specialists (in the hospital)", check the hospital(s) in the list below (multiple answers are possible)?

One or many answers in a set of 44 hospitals

Q8: During the past year, how many medical appointments with specialists (neurologist, dentist, gastroenterologist, orthopedist, endocrinologist, etc.) did your child have ?

One choice in a range [0, 1, ..., 12, >12]

Q9: Does your child participate in regular therapy (at least once a month) ? Check as many as relevant from the list below.

- No paramedical check-up
- Occupational therapy
- Physiotherapy
- Speech Therapy
- Psychomotricity
- Other

Q10: If you ticked "Other" in the previous question, please list the therapy

Free answer

Section 4 : Impact on family life

Q11: Situation of the caregiver to the AS person (at the time of the survey with several possible choices)

- At home with family caregivers
- At home with professional caregivers
- In "special schools" (medico-social institute)
- Other

Q12: After the diagnosis of the person with AS, have you had to change your working habit ? (at the time of the survey, one choice)

- No change

- Change to part-time work
- Stop professional activity

Q13: Regarding seizures (in the past year), the AS person (one choice)

- Was not affected by seizures
- Had infrequent epileptic seizures but is not currently being treated
- Had controlled epileptic seizures with an appropriate treatment
- Had uncontrolled epileptic seizures and treatments have little or no effect

Q14: Regarding sleep (in the past year), the AS person with the syndrome (one choice)

- Was not affected by sleep disorders
- Had trouble sleeping and had no drug
- Had a good sleep with appropriate drugs
- Had sleep disorders and the treatments have little or no effect

Q15: Regarding behavior (in the past year), the person with the syndrome (one choice)

- Was not affected by challenging behaviors
- Sometimes exhibits challenging behaviors but is not currently on medication
- Behavior improved with appropriate medication
- Had behavioral problems and drugs have little or no effect

Q16: Is the person with AS currently on a special diet?

Choice between Yes or No

Q17: If yes to the previous question, please specify the diet?

Free answer

Q18: Does your child currently benefit from one or more medical device (eg: wheelchair, orthopedic shoes, seat, communication device, etc.) ?

Choice between Yes or No

Q19: If yes to the previous question, can you specify the medical device?

Free answer

Section 5 : Perspectives about registry, natural history, clinical trials

Q20: If a (patients) registry were available in France, would you be interested in participating in it (on behalf of the person with AS)?

Choice between Yes or No or I don't know

Q21: if a Natural History Study were available in France, would you be interested in participating in it (on behalf of the person with AS) ?

Choice between Yes or No or I don't know

Q22: "What improvement from a possible AS treatment would you expect ? Please rank the following items from the most important to the least." The scale is: from 1 (the most important item) to 6 (the least important item). The different items are the following : Behavior, Communication, Fine Motor, Gross Motor, Seizure, Sleep

	1 (the most important)	2	3	4	5	6 (the least important)
Behavior						
Communication						
Fine motor						
Gross motor						
Seizure control						
Sleep						