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| --- | --- | --- | --- |
| **Number of variables** | **Name of variables** | **Label of variables** | **Codes of variables** |
| 1 | ID | Number observation |  |
| 2 | Age | Age (years) |  |
| 3 | Age of the diagnosis | Age (years) |  |
| 4 | Age of communication of the diagnosis | Age (years) |  |
| 5 | 3 | Question Nr. 3 of the questionnaire | * 1. = Between 5 and 10 years
	2. = Between 11 and 12 years
	3. = Between 13 and 14 years
	4. = Between 15 and 16 years
	5. = Between 17 and 18 years
	6. = After the age of 18
	7. = It would be better not to know
 |
| 6 | 4 | Question Nr. 4 of the questionnaire | 1. = Mother
2. = Father
3. = Both parents
4. = Pediatrics
5. = Infant Neuropsychiatrist
6. = Gynecologist
7. = Psychologist
8. = Geneticist
9. = Pediatric endocrinologist
10. = Adult endocrinologist
11. = Andrologist/Urologist
12. = Primary Care Physician
13. = Other (specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_
 |
| 7 | 5 | Question Nr. 5 of the questionnaire | 1. = Mother
2. = Father
3. = Both parents
4. = Pediatrics
5. = Infant Neuropsychiatrist
6. = Psychologist
7. = Geneticist
8. = Endocrinologist
9. = Andrologist/Urologist
10. = Primary Care Physician
11. = A multidisciplinary team made up of all these figures
12. = Other (specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_
 |
| 8 | 6 | Question Nr. 6 of the questionnaire | 1. = No
2. = Pediatrics
3. = Infant Neuropsychiatrist
4. = Gynecologist
5. = Psychologist
6. = Geneticist
7. = Pediatric endocrinologist
8. = Adult endocrinologist
9. = Andrologist/Urologist
10. = Primary Care Physician
11. = Other (specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_
 |
| 9 | 7 | Question Nr. 7 of the questionnaire | 1. = No
2. = Pediatrics
3. = Infant Neuropsychiatrist
4. = Gynecologist
5. = Psychologist
6. = Geneticist
7. = Pediatric endocrinologist
8. = Adult endocrinologist
9. = Andrologist/Urologist
10. = Primary Care Physician
11. = A multidisciplinary team made up of all these figures
12. = Other (specify): \_\_\_\_\_\_\_\_\_\_\_\_\_\_
 |
| 10 | 8 | Question Nr. 8 of the questionnaire | Likert scale from 1 (=Not at all) to 5 (=Very much) |
| 11 | 9 | Question Nr. 9 of the questionnaire | Likert scale from 1 (=Not at all) to 5 (=Very much) |
| 12 | 10 | Question Nr. 10 of the questionnaire | 1. = No, I did not feel this type of need.
2. = Yes, because the communication of the diagnosis received was unclear
3. = Yes, because I felt the need to have a different opinion
4. = Yes, because I felt the need to explore some aspects of the condition in more detail
5. = Other (please specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_
 |
| 13 | 11 | Question Nr. 11 of the questionnaire | 1. = Consulting a specialist
2. = Researching on the Internet
3. = Consulting scientific journals
4. = Consulting a medical encyclopedia
5. = Consulting texts
6. = Asking relatives/friends/acquaintances
7. = Talking to someone with the same condition
8. = Contacting an association of patients with SK
9. = Other (specify):\_\_\_\_\_\_\_\_\_\_\_\_\_
 |
| 13 | 12 | Question Nr. 12 of the questionnaire | 1. = Spouse/Partner
2. = Close relatives (parents/brothers)
3. = Most relatives (extended family members)
4. = Family friends
5. = My friends
6. = Colleagues
7. = Wider friends
8. = None
9. = Other (specify):\_\_\_\_\_\_\_\_\_\_\_
 |
| 14 | 13 | Question Nr. 13 of the questionnaire | 1. = Spouse/partner
2. = Close relatives (parents/brothers)
3. = Most relatives (extended family members)
4. = Family friends
5. = My friends
6. = Colleagues
7. = Acquaintances
8. = None
9. = Other (specify):\_\_\_\_\_\_\_\_\_
 |
| 15 | 14 | Question Nr. 14 of the questionnaire | 1. = Avoiding prejudice
2. = Avoiding discrimination
3. = To avoid misunderstandings
4. = Not to give worries
5. = Because I feel ashamed
6. = Because I don't think it is necessary
7. = Other (please specify):\_\_\_\_\_\_\_\_\_\_\_\_
 |
| 16 | 15 | Question Nr. 15 of the questionnaire | 1. = Infertility
2. = Metabolic diseases (obesity, diabetes, osteoporosis)
3. = Cardiovascular diseases (hypertension, heart problems, thrombosis)
4. = Development of sexual characteristics (development of mammary glands, reduced hairiness)
5. = Cognitive development (attention, learning)
6. = Problems in language development
7. = Psychological disorders
8. = Sexuality
9. = None of the above
 |
| 17 | 16.Infertility | Question Nr. 16 of the questionnaire | Likert scale from 1 (=Not at all) to 5 (=Very much) |
| 18 | 16. Metabolic diseases |
| 19 | 16. Cardiovascular diseases |
| 20 | 16.Development of sexual characteristics |
| 21 | 16. Cognitive development |
| 22 | 16. Problems in language development |
| 23 | 16.Psychological disorders |
| 24 | 16. Sexuality |
| 25 | 17. Fear | Question Nr. 17 of the questionnaire |
| 26 | 17. Sadness |
| 27 | 17. Discouragement |
| 28 | 17.Disappointment |
| 29 | 17. Anger |
| 30 | 17. Inferiority |
| 31 | 17. Humiliation |
| 32 | 17. Uncertainty |
| 33 | 17. Helplessness |
| 34 | 17. Diversity |
| 35 | 17. Anxiety |
| 36 | 17. Shame |
| 37 | 17. Demotivation |
| 38 | 18 | Question Nr. 18 of the questionnaire |
| 39 | 19 | Question Nr. 19 of the questionnaire | 1. = Yes
2. = No
 |
| 40 | 20 | Question Nr. 20 of the questionnaire | Likert scale from 1 (=Not at all) to 5 (=Very much) |
| 41 | 21 | Question Nr. 21 of the questionnaire |
| 42 | 22 | Question Nr. 22 of the questionnaire |
| 43 | 23 | Question Nr. 23 of the questionnaire |
| 44 | 24 | Question Nr. 24 of the questionnaire |
| 45 | 25 | Question Nr. 25 of the questionnaire |
| 46 | 26 | Question Nr. 26 of the questionnaire | 1. = Ability to procreate
2. = Psychological balance
3. = Physical appearance
4. = Sexual performance
5. = Intellectual capacity
6. = Communication skills
7. = Physical health
8. = I have never perceived myself as different
 |
| 47 | 27 | Question Nr. 27 of the questionnaire | 1. = Yes, because this allows you to find full understanding and acceptance.
2. = Yes, because it is heartening to know that you are not the only person with a given condition and helps you not feel alone.
3. = Yes, because I can have a role model
4. = Yes, because I can have a role model and gain support from it
5. = No, I don't think it is useful
6. = Other (please specify):\_\_\_\_\_\_\_\_\_\_\_\_\_\_
 |
| 48 | 28 | Question Nr. 28 of the questionnaire | 1. = Yes, I requested it myself
2. = Yes, it has been recommended to me
3. = Yes, it was suggested to me
4. = Yes, it was suggested to me
5. = I have never felt the need for it
6. = Other (specify):\_\_\_\_\_\_\_\_\_\_
 |
| 49 | 29 | Question Nr. 29 of the questionnaire | Likert scale from 1 (=Not at all) to 5 (=Very much) |
| 50 | 30 | Question Nr. 30 of the questionnaire | 1. = Yes
2. = No
 |
| 51 | 31 | Question Nr. 31 of the questionnaire | Likert scale from 1 (=Not at all) to 5 (=Very much) |
| 52 | 32 | Question Nr. 32 of the questionnaire | Likert scale from 1 (=Not at all) to 5 (=Very much) |