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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) |