

Appendix 1: Questionnaire

Name: DOB:

Hospital ID#: Phone Number:

Diagnosis:

1. When and how was your child diagnosed?
.....
2. With what gender your child was raised before admission? Was it changed? Was also the name changed? When?
.....
3. Do you have any other child affected? Anyone else in your family?
.....
4. Which institutions were you referred to for your child's condition? If you changed your doctor in the process, was it your choice?
.....
5. Do you think you have enough knowledge about your child's disease?
.....
6. Does your child know about his/her condition?
.....
7. Do you talk to your child about the condition?
.....
8. There are many terms used to refer to this condition. Which ones do you know?
.....
9. Which department is the one most involved in your child's management? Do you know the terms your doctors use?
.....
10. Do different doctors use different terms?
.....
11. Which term do you prefer to use when talking to your husband/wife?
.....
12. Which term do you prefer to use when talking to your child's doctor?
.....
13. Which term do you prefer to use when talking to your relatives or friends?
.....
14. Do you have a suggestion for a more proper term?
.....
15. Have you ever heard of the terms listed below?
.....

DSD, intersex, dubious genitals, ambiguous genitals