**Supplementary table 1- Details about PedsQLTM questionnaires**

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| --- | --- | --- | --- | --- |
| **Questionnaire** | **Domains** | **Items** | **Scoring** | **Score analysis** |
| PedsQLTM 4.0 Generic Core Scales | Physical functioning | 8 items | Patients scored HRQOL questions based on their condition over the previous month, from zero (never a problem) to 4 (“almost always a problem). Mean score for each domain was the sum of the items divided by the number of items answered | Responses were reverse scored and linearly transformed to 0-100 with higher scores indicating better HRQOL |
| Emotional functioning | 5 items |
| Social functioning | 5 items |
| School functioning | 5 items |
| Psychosocial functioning | 15 | Sum of the items in the emotional, social, and school functioning scales was divided by the number of items answered.  |
| Total HRQOL | 23 | Sum of all items over the number answered. |
| PedsQLTM Cognitive Functioning | Cognitive functioning | 6 items | Mean score was the sum of the items divided by the number of items answered | Responses were reverse scored and linearly transformed to 0-100 with higher scores indicating better HRQOL |
| PedsQLTM 3.0 Cardiac Module | Heart problems | 7 items | Mean score for each domain was the sum of the items divided by the number of items answered | Responses were reverse scored and linearly transformed to 0-100 with higher scores indicating better HRQOL |
| Treatment problems | 5 items |
| Perceived physical appearance | 3 items |
| Treatment anxiety | 4 items |
| Cognitive problems | 5 items |
| Communication  | 3 items |

**Supplementary file 1: Qualitative interview guide for ACHD patients**

1. In your view, what is quality of life?
2. How do you see your disease i.e. Congenital Heart Disease and surgery?
3. How does the community and society view your Congenital Heart Disease and surgery?
4. What is the most disturbing or bothersome aspect of your surgery?
5. How do you deal with these issues and problems?
6. What are some of the concerns which are very important for you to discuss for your future years?
7. What do you think are the needs of Congenital Heart Disease patients with surgery and what would you like to suggest to the health care professionals to address those needs?