Table 1. Questionnaire used to collect patient experiences with care transition

**Tell us about your experience with transitioning from pediatric to adult care!**

1. When was your congenital heart condition diagnosed? Age: \_\_\_\_\_\_\_\_\_\_\_\_

(*If it was diagnosed in your adulthood [18 or older], skip to question 4.)*

2. When was the last time you saw a pediatric cardiologist? Age: \_\_\_\_\_\_\_\_\_\_\_\_

3. Were the information in the following areas discussed in pediatric cardiology care

before transitioning into adult cardiology care (Use "✔ " to indicate your answer)?

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Education Domain | Yes, thoroughly | Yes, somewhat | Yes,  a little | No |
| Knowledge about heart condition |  |  |  |  |
| The importance of taking medication |  |  |  |  |
| The importance of receiving adult care |  |  |  |  |
| Physical activity |  |  |  |  |
| Sexual health & Reproduction |  |  |  |  |
| Substance use |  |  |  |  |
| Coping strategies for emotional stress |  |  |  |  |
| Employment & Benefits |  |  |  |  |
| Legal changes about decision making |  |  |  |  |
| Insurance changes |  |  |  |  |

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4. Have there been any gaps in your cardiology care? \_\_ Yes \_\_ No

*If Yes, for how long?* \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

5. In your adulthood, have you seen a cardiologist who specializes in ***adult***

*congenital heart disease*? \_\_ Yes \_\_ No

*If Yes, for how long?*  \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

6. Was transitioning into or finding a cardiologist who specializes in ***adult***

*congenital heart disease* a difficult process for you? \_\_ Yes \_\_ No

If Yes, what made it difficult (Select all that apply)?

|  |  |
| --- | --- |
| Reasons | Use "✔ " |
| Letting go of long-standing relationships with pediatric providers |  |
| Feeling not ready for transition |  |
| Accessing/finding qualified practitioners |  |
| Insurance issues |  |
| Unfamiliarity with or negative expectations about adult care services |  |
| Other: |  |

7. Do you wish that you were better prepared for transitioning from pediatric to adult cardiology care? \_\_ Yes \_\_ No