**Patient interview**

Questionnaire Number:

Patient Registration Number:

Date of Interview: Location of interview:

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| **Patient Information** |
| 1. **Gender**  Male Female | **Age of Patient (Years/Months):** |
| 2. **Age at diagnosis (Years/Months):** | **Age starting regular transfusions (Years/Months):**  |
| 3. **Patient Height (cm):** | **Patient Weight (Kg):** |
| 3. **Other diagnoses (If known):** UnknownHIV Hepatitis B Hepatitis C Diabetes Osteoporosis HypersplenismHypothyroidism Hypoparathyroidism Cardiomyopathy  |

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| **Respondent Information** |
| 4**. Gender** Male Female | **Age (Years/Months):** |
| 5**. Occupation:** | **Relationship to patient:**Parent SupporterOther (Specify) |
| 6.**a) What district do you live in?****b) Is there another transfusion centre closer to you?****c) If YES why do you not use that centre ?** Stigma Better service Other (Specify) |
| 7. **Why does somebody accompany your child?**Distance Security Administrative barriers Too ill to travel alone Required for treatment Young child Other (specify):  |

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| **Socioeconomic Information** |
| 8**. Who is the primary income earner in the household?**  Patient Wife/Mother Husband/father Extended family Son/DaughterOther (Specify) |
| **What is the highest level of education of the…?****9. Patient** Graduate Secondary Primary Not attended/illiterate Other:**10. Primary income earner** Graduate Secondary Primary Not attended/illiterate Other**11. Head of household** Same as above Graduate Secondary Primary Not attended/illiterate Other**12. Spouse of the head of household**Graduate Secondary Primary Not attended/illiterate Other |
| 13. **Are you currently formally employed?** | - Yes, formal work - Go to 16- No, informal work –Go to 16- On leave - Retired- School / University - Housework - Combination (Specify)- Other (Specify) |
| **14. Is your reason for not working related to your child’s thalassaemia?**  | Yes No |
| **15. If YES: When were you last working (mm/yy)** |  |
| **16. What is your personal income per month**  |  |
| **17. What is the estimated income of your household per month currently?** |   |
| **18. What was the estimated income of your house per month before your child was diagnosed with thalassaemia?** |   |
|  If 16 and 17 differ:**19. Is the change related to your child’s thalassaemia**  |  Yes No |

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| **Treatment costs** |
| **Costs related to Transfusion**  |
| **20. How often does your child undergo transfusion?** | Fortnightly Monthly Other (Specify) |
| **21**. **How long does it take you to get there? (One way)**­­\_\_\_\_\_\_\_\_\_\_Hours walking \_\_\_\_\_\_\_\_\_\_Hours with transport ­­­­­­\_\_\_\_\_\_\_\_\_\_Other: |
| 22. **What is the total turnaround time Door to Door from leaving your home to getting back to your home after transfusion?** |  |
| **23. a) From your home to the hospital and back to your home again how much does it cost to take transport?****b) How many days do you spend in hospital for transfusion** |  |
| **24. How much do you spend on food on the road when coming for transfusion?** |  |
| **25. a) Does anyone else ever attend transfusion? Who?** **b) What extra costs do they have? For food and travel / visit** |  |
| **26. Do you have any accommodation costs when coming for your child’s transfusion?**  | No Yes **How much?** |

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| **Costs related to follow up tests – ICT clinics, Cardiac echo monitoring, Abdominal USS, Hearing clinic, Visual clinic, Ferritin elsewhere** |
| **27. Do you ever have to visit a health facility in relation to thalassaemia in addition to transfusion?** | Yes \_\_\_\_\_\_\_\_\_/yearNo |
| **28. Do you have to pay any additional costs for these?** | Yes No |
| **29. How much for…?**­­Fees\_\_\_\_\_\_\_\_\_\_ Tests\_\_\_\_\_\_\_\_\_\_ Drugs\_\_\_\_\_\_\_\_\_\_ Other\_\_\_\_\_\_\_\_\_\_ | Total /Visit\_\_\_\_\_\_\_\_\_\_ |
| **30.** **How long does one of these visits take on average, including time on the road and waiting time? (total turnaround time)** |  |

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| **Hospitalisation – Not including transfusion visits!** |
| **31. Has your child been hospitalized in the past 12 months related to thalassaemia?** | Yes \_\_\_\_\_\_\_\_\_/yearNo – Go to 46 |
| **32. How many days were they in hospital?** | \_\_\_\_\_\_\_\_\_\_Days |
| **33. How did you pay during the stay for …?**­­Fees\_\_\_\_\_\_\_\_\_\_ Tests\_\_\_\_\_\_\_\_\_\_ Drugs\_\_\_\_\_\_\_\_\_\_ Bed \_\_\_\_\_\_\_\_\_\_ Transport\_\_\_\_\_\_\_\_\_\_ Food\_\_\_\_\_\_\_\_\_\_Other\_\_\_\_\_\_\_\_\_\_ | Total /Visit\_\_\_\_\_\_\_\_\_\_ |
| **34. Did someone stay with your child while in hospital?** | YesNo – Go to 44 |
| **35. How many days did they sleep there?** | \_\_\_\_\_\_\_\_\_\_Days |
| **36. Where there any extra costs to stay in the hospital** Accommodation­\_\_\_\_\_\_\_\_\_\_ Food\_\_\_\_\_\_\_\_\_\_Transport\_\_\_\_\_\_\_\_\_\_\_ Other \_\_\_\_\_\_\_\_\_\_ | Yes Total \_\_\_\_\_\_\_\_\_\_No |
| **37. Did anyone else visit your child while in hospital** **a) How many people?****b) How many times?****c) Costs** Accommodation\_\_\_\_\_\_\_\_\_\_ Food\_\_\_\_\_\_\_\_\_\_Transport\_\_\_\_\_\_\_\_\_\_\_ Other \_\_\_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_\_\_People\_\_\_\_\_\_\_\_\_\_Person times\_\_\_\_\_\_\_\_\_\_Total |
| **38. How long were the visits including travelling time?** |  |

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| **Other costs**  |
| **Food supplements**  |
| **39. Do you buy any supplements for your child’s diet because of thalassaemia?** b) Fruits Drinks Vitamins/Herbs Meat Other (specify) | Yes No |
| **40. How much did you spend on these items in the last month?**  | \_\_\_\_\_\_\_\_\_\_Total/Month |
| **Other illnesses** |
| **41. Are there any additional costs for chronic illnesses related to thalassaemia that you have not already mentioned?** **­­**Fees\_\_\_\_\_\_\_\_\_\_ Tests\_\_\_\_\_\_\_\_\_\_ Drugs\_\_\_\_\_\_\_\_\_\_ Bed \_\_\_\_\_\_\_\_\_\_ Transport\_\_\_\_\_\_\_\_\_\_ Food\_\_\_\_\_\_\_\_\_\_Other\_\_\_\_\_\_\_\_\_\_ | Total\_\_\_\_\_\_\_\_\_\_/Month |
| **Coping costs**  |
| **42. Do you borrow any money to cover the costs of thalassaemia?** | Yes No Go to 55 |
| **If YES****43. a) Who did you borrow from** **b) How much?** | Family Neighbour Bank Other (specify) \_\_\_\_\_\_\_\_\_\_Total/year  |
| **44. What is the interest rate on the loan?** | \_\_\_\_\_\_\_\_\_\_%I am not expected to pay back the money |
| **45.a) Have you sold any of your property to finance the cost of thalassaemia?** | YesNo – Go to 56 |
| **b) What did you sell?****c) How much did you earn from the sale of your item(s)****d) What was the market value of these item(s)** | Land Livestock Vehicle Household item Farm produce Other (Specify)\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |

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| **Productivity loss -**  |
| **46. a) Has your child stopped going to school due to thalassaemia in the past year? – INCLUDES TRANSFUSION** **b) How long for?** | Yes No – Go to 49\_\_\_Months\_\_\_Weeks\_\_\_Days |
| **47. a) Does someone stay at home specifically to look after them?** **b) If YES: For how long?****c) Did they quit their income earning job to stay at home?** | Yes No - Go to\_\_\_Months\_\_\_Weeks\_\_\_DaysYes No |
| **48. How regularly did you work before your child was born with thalassaemia?** | Throughout the year Seasonal/part Day labour Other |
| **49. Did you have to change jobs after your child was born?**  | Yes No |
| **50. What is your main occupation**?  | Sales/service Agriculture Household Production/construction Combination (specify)Other (specify) |
| **51. How many hours did you work on average per day BEFORE your child was born?** | \_\_\_\_\_\_Hours  |
| **52. How many hours did you work on average per day AFTER your child was born?** | \_\_\_\_\_\_Hours  |
| **If 61 / 62 differ:****53. Is this change related to thalassaemia?** | YesNo |
| **54. a) Do you have other children of school age?****b) Do these children attend school regularly?** | Yes No – Go to 65Yes – Go to No  |
| **c) If NO: Why not?** | Housework No money for school Also sick Works for income to finance costs of thalassaemia Other (specify) |
| **55. a) Has thalassaemia affected your social/private life in any way?** **b) Has this resulted in financial burden**  | No – Go to Divorce/Separation Loss of job Dropped out of school Disruption of sexual life Other (specify)Yes No |