HAEMOGLOBINOPATHIES (excluding carrier states) QUESTIONNAIRE
Australian Paediatric Surveillance Unit

Please ring Dr Elizabeth Argent on 02 9382 1729 if you have any difficulty with this questionnaire.

REPORTING CLINICIAN
1. APSU Dr Code/Name □ □ □ □ / ...........................................
2. Month/Year of Report ........ / ........

PATIENT
3. First 2 letters of first name □ □
4. First 2 letters of surname □ □
5. Date of Birth □ □ / □ □ / □ □
6. Sex □ M □ F
7. Post code □ □ □ □ □ □ □ □
8. Date questionnaire completed □ □ / □ □ / □ □
9. Is the child of Aboriginal or Torres Strait Islander origin □ Yes □ No □ Don’t know

If this patient is primarily cared for by another physician whom you believe will report the case, please write the other physician’s name and complete questionnaire details above this line and return to the APSU. If no other report is received for this child we will contact you for information requested in the remainder of the questionnaire. Please keep the patient’s name and other details on your APSU file.

Instructions: Please answer each question by placing a tick in the appropriate box or writing your response in the space provided.

CLINICAL DETAILS
10. What is the nature of the haemoglobinopathy/haemoglobin disorder?
    □ β-thalassaemia major
    □ Hb E/β-thalassaemia
    □ Hb SS disease (sickle cell anaemia)
    □ Hb S/β-thalassaemia
    □ Hb SC disease
    □ Hb H disease
    □ Hb Barts disease
    □ Hb CC disease
    □ Hb EE disease
    □ Other, please specify ............................................. □ Don’t know

11. Date of diagnosis □ □ / □ □ / □ □

12. Is the child currently alive? □ Yes □ No □ Don’t know

13. If the child has died,
    a. date of death ........ / ........ / ...................................................... □ Don’t know
    b. cause of death ................................................................. □ Don’t know
    c. was the child stillborn? □ Yes □ No □ Don’t know
    d. intrauterine foetal death? □ Yes □ No □ Don’t know

14. Presentation at diagnosis
    a. Antenatal diagnosis □ Yes □ No □ Don’t know
    b. Anaemia/ Pallor □ Yes □ No □ Don’t know
    c. Sepsis □ Yes □ No □ Don’t know
    d. Haemolysis □ Yes □ No □ Don’t know
    e. Aplastic crisis □ Yes □ No □ Don’t know
    f. Hepatomegaly &/or splenomegaly □ Yes □ No □ Don’t know
    g. Sequestration crisis □ Yes □ No □ Don’t know
    h. Vaso-occlusive crisis □ Yes □ No □ Don’t know
    i. Other, please specify ........................................................................................................

15. Is the child currently being treated for this condition?  
- Yes 
- No 
- Don’t know 
- Not applicable

16. Please indicate treatment(s) the child has received for haemoglobinopathy (tick all that apply) 
- a. Medication(s), please specify ……………………………………………………………………………
- b. Regular transfusion program
- c. Intermittent transfusions when symptomatic
- d. Exchange transfusion
- e. Other, please specify ……………………………………………………………………………
- f. Don’t know
- g. Not applicable

17. Has the child received a bone marrow transplant?  
- Yes 
- No 
- Don’t know 
- Not applicable

18. Is a bone marrow transplant planned?  
- Yes 
- No 
- Don’t know 
- Not applicable

FAMILY HISTORY DETAILS
19. Are the parents consanguineous?  
- Yes 
- No 
- Don’t know

20. If there is consanguinity, please specify relationship (if known)………………………………………………………………………….

21. Are there other family members with the same condition?  
- Yes 
- No 
- Don’t know

22. Please list the relationship to the child of any other affected family members………………………………………………………………………….

23. Is the Mother’s Hb EPG result or other relevant diagnostic information known?  
- Yes 
- No  (please specify)…………………………………………………………………………

24. Was the mother aware her Hb EPG result prior to this pregnancy?  
- Yes 
- No 
- Don’t know 
- Not Applicable

25. Is the Father’s Hb EPG result or other relevant diagnostic information known?  
- Yes 
- No  (please specify)…………………………………………………………………………

26. Was the Father aware his Hb EPG result prior to this pregnancy?  
- Yes 
- No 
- Don’t know 
- Not Applicable

27. What is the mother’s ethnic background?…………………………………………………………………………
- Don’t know

28. What is the father’s ethnic background?…………………………………………………………………………
- Don’t know

29. In which country was the child born?  
- Australia 
- Other (please specify) …………………

ANTENATAL ASSESSMENT OF THIS PREGNANCY
30. Was the mother screened antenatally for haemoglobinopathy with a Hb EPG?  
- Yes 
- No 
- Don’t know

31. Was the infant tested antenatally for a haemoglobinopathy?  
- Yes 
- No 
- Don’t know 
- If YES, what testing was undertaken?…………………………………………………………………………

32. Was information about the risk of haemoglobinopathy discussed with the mother and/or father during the pregnancy?  
- Yes 
- No 
- Don’t know

33. Do the parents propose to seek antenatal diagnosis in subsequent pregnancies?  
- Yes 
- No 
- Don’t know 
- Not planning further pregnancies

34. If no further pregnancies are planned, was this decision influenced by the diagnosis of this affected child?  
- Yes 
- No 
- Don’t know 
- Not applicable

Please return this questionnaire in the addressed reply-paid envelope. Thankyou for your assistance with this study.