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**Living with Sickle Cell or Beta-Thalassaemia Trait**

**DRAFT SUMMARY INTERVIEW TOPIC GUIDE**

**1. Biographical details**

Tell me about yourself:

Background (Ethnic Origin, Age, Religion, Occupation)

Family, partner and children

Knowledge of own and family carrier status

**2. Awareness of being a sickle cell or thalassaemia carrier**

When did you first know you were a sickle cell/thalassaemia carrier?

What were circumstances? Was it planned or accidental?

Were you expecting to be told you were a trait carrier?

Who told you? How did you find out?

What was your first feeling/reaction?

Did you tell anyone else? If so how did they react?

How did you feel towards their reaction?

Are you glad you found out?

**3. Prior Knowledge/Awareness of Sickle Cell/Thalassaemia Carriers**

Had you heard about sickle cell/thalassaemia before you knew about being a carrier?

What did you know?

How useful was this previous understanding?

What was your understanding then of the consequences of carrying a trait?

How have these changed over time?

What, do you know about sickle cell or thalassaemia now?

Is there anything you know now that you wished you had known in the past?

Did it change how you thought about yourself or your family?

(*Probe:* Spoiled identity, family relationships, social identity)

How has this changed over time and at particular times in the life course?

When has such information being important?

(And useful?)

When has knowing your carrier status being less helpful?

(And less useful?)

**4. Living with sickle cell or thalassaemia trait**

How do you feel about being a carrier?

Is there anything about being a carrier that confuses you?

Does your family know?

Why/why not?

And if family members know what is their reaction?

How did you decide you to tell?

When did you tell your partner? How did they react?

Have you told your children? If not, when do you think you will do this?

Do you feel under pressure to tell others in your family?

How do you explain this?

Have you told others, such as friends and peers? Why/why not?

Has carrying as trait made any difference to how you feel about yourself or how you view yourself?

How has this changed over time?

What difference has carrying a trait made to your life?

Do you think the impact is different for men and women?

different age groups?

different faith groups?

different ethnic groups?

Do you think other people treat your differently because you have a trait?

Do you think being a trait carrier has affected your health in any way?

Do you think knowledge influences people’s choice of marriage partner?

Would it/has it influenced your choice?

**5. Screening and testing**

Is screening worthwhile?

If yes, when should people be screened?

Are there any possible disadvantages of screening?

What information should be available to people?

Are you glad you found out you were a carrier?

Do you know if your partner has been tested?

Why/why not? How did this come about?

Did you discuss it?

Did/would you encourage them?

Did your knowledge of your carrier status influence your partner’s decision?

Have your children been tested?

Why/why not? And if yes, how did this come about?

Would you encourage children to be tested

When is best time to do this?

Would you encourage other family members to be tested?

If disagreements occurred about testing within a family how should these be negotiated? Partner testing, testing of children/other family members.

**6. Any Other Issues**

Imagine you could tell people who devise policies on sickle cell and thalassaemia carriers what to do.

What would you tell them?

Would you advise people to be tested?

What advice would you give to someone recently identified as a trait carrier?

Any other questions (about being a sickle cell/thalassaemia carrier)?

Any other comments?