**Table 3. Sample break-up of interview participants by gender**

|  |  |
| --- | --- |
| Sickle cell carriers (women)  (n) 11 | SC carriers (men)  (n) 14 |
| wp1, wp2, wp5, wp7 wp8, wp9,  wp11, wp20, wp26, wp35 ,  wp41 | Mp6, mp12, mp13, mp15,  mp16, mp22, mp27, mp30,  mp33, mp34, mp40,  mp42, mp43; MP 57 |
| Thalasaemia trait (women)  (n) 22 | Thalassaemia trait (men)  (n) 10 |
| wp3, wp4 , wp10 , wp14 , wp17, wp23, wp24, wp28, wp29, wp31, wp32, wp36, wp38, wp39, wp44, wp45 ; wp 47; wp48 ; wp49 ; wp50 ; wp52 ; wp53 | Mp18, mp19, mp21,  MP25, MP37; MP46 ; MP51 ; MP 54; MP55, Mp56 |
| **(N) Total** =  **57** (33 women + 24 men)  SC carriers = 25  thal carriers = 32 |  |

The sample consisted of 33 women and 24 men who were either SC (25) or thalassaemia (32) carriers (Table 3). In principle, we excluded children under 16 years and people who had the condition – with the exception of one man in his early 50s who was diagnosed as having HB As and, later, re-diagnosed as having a complex sickle beta thal disorder.

The age range of the participants was 17- 70 years (Table 4), allowing us to explore the potential significance of the biographical circumstances under which their carrier status was diagnosed. Apart from 6 students, a majority of the participants were engaged in occupations ranging from academics, business, banking, sales, school teaching, taxi driving, catering, healthcare, a couple who had retired and a few who were not working due to unrelated health reasons or had never worked outside home.

**Table 4: Age distribution of the interview participants**

|  |  |
| --- | --- |
| Age group | No of participants |
| 17-24 years | 6 |
| 25- 35 | 17 |
| 36-45 | 14 |
| 46-55 | 14 |
| 56-65 | 5 |
| 66 and above | 1 |
| Total | 57 |

In two families, a child with SCD had undergone a bone marrow transplant while a third had lost a child following a transplant; one family had refused the option, while another had stored cord blood for a future transplant. Two women were undergoing fertility treatment, one of whom had a baby during the life of the project. Sadly, one of the participants died due to an unrelated illness, before the research was completed.

52 interviews took place at the participant’s home, and the remaining 5 rest were conducted either at a community centre or a friend’s residence, each lasting between one and a half to two hours and were recorded digitally (except in one case where permission was denied). Each participant was interviewed once, though in 12 cases, more than one member of a family was interviewed. Hence, 27 of the 57 interviews involved a range of intra and intergenerational relationships within a family, as reflected in Table 5. Since a majority of the participants were recruited through our voluntary sector collaborators and likely to be biased towards the ideas and practices of these organisations, we made an effort at snowballing outside these networks and interviewed 10 participants (WP4; WP5; WP10; WP35; WP36; FP44;WP49; WP50; MP51; MP57) . For issues of parity caused by the parallel recruitment strategy to another study being conducted at York, at some of these sites, we offered a cash gift in addition to a certificate of participation to each participant.

**Table 5: Family interviews**

|  |  |
| --- | --- |
| **Identifier** | **Relationship/s** |
| WP11, MP12 | Mother – son |
| WP20, MP21 | Mother -son |
| WP8, MP27, MP30  MP27, MP30 | Mother-sons  Half brothers |
| WP17, MP18 | Daughter-father |
| WP47, WP48 | Mother-daughter |
| WP23, MP25  WP24 | Wife-husband  Sister-in-law |
| MP37, WP38 | Husband- wife |
| WP50, MP51 | Wife-husband |
| WP45, MP56 | Wife-husband |
| WP53, MP55  MP56 | Mother-son  cousins |
| WP36, WP49 | Cousins |
| MP 19, WP29 | Uncle -niece |

The participants represented five broad ethnic backgrounds African (9), African-Caribbean (18); South Asian (19); Greek, Cypriot, Turkish (9) and white/mixed heritage (2) with complex family histories and plural ethnic identities operating transnationally (Table 6). Even though a majority of the participants (34) were above 36 years of age, only 13 (of 57) were born outside the UK.

6 participants chose to be interviewed in Urdu/Punjabi (these were translated and transcribed), SC and some of the South Asian participants switched between Urdu and English, given the context of the conversation. Only in once instance, where the participant insisted on speaking in English rather than Urdu/Punjabi, the content was, at times, difficult to follow, requiring going back to the recording. In certain cases, the presence or absence of transnational kinship networks contributed significantly to the understanding and experience of being a carrier, irrespective of where the participant was born and brought up. The only white participant, a thalassaemia carrier, tried to forge a possible Mediterranean link through her grandmother who she thought had a ‘strange, Jewish sounding name’. Even though SC followed self- ascribed descriptions within categories, it was important to probe the links with dominant assumptions about the trait/condition being associated with particular ethnic groups, the biographical salience of the trait at a demotic level. For example, it was important to analyse why even though FP4 acknowledged her ‘mixed race’ and would tick the White/Caribbean box on a census form, she did not feel that she was ‘half black’ or ‘half Caribbean’ – since she had only recently discovered who her biological father was and had no emotional family/kinship ties with his side of the family.