

**Table 1. Parental survey.**

| <b>Parental survey:</b> |                                                                                |              |
|-------------------------|--------------------------------------------------------------------------------|--------------|
| <b>1</b>                | <b>Parental demographics</b>                                                   | <b>n=110</b> |
|                         | Mothers                                                                        | 73%          |
|                         | Fathers                                                                        | 27%          |
| <b>2</b>                | <b>Parental age</b>                                                            |              |
|                         | 18-24                                                                          | 3%           |
|                         | 25-30                                                                          | 25%          |
|                         | 30-35                                                                          | 38%          |
|                         | 35-45                                                                          | 33%          |
|                         | 45-50                                                                          | 1%           |
| <b>3</b>                | <b>Number of children</b>                                                      |              |
|                         | 1st child                                                                      | 48%          |
|                         | 2nd child                                                                      | 32%          |
|                         | 3rd child                                                                      | 13%          |
|                         | 4th child                                                                      | 7%           |
| <b>4</b>                | <b>Highest level of education</b>                                              |              |
|                         | Primary school                                                                 | 1%           |
|                         | Secondary school                                                               | 5%           |
|                         | ITE <sup>[1]</sup>                                                             | 11%          |
|                         | Polytechnic                                                                    | 21%          |
|                         | University                                                                     | 43%          |
|                         | Postgraduate                                                                   | 19%          |
| <b>5</b>                | <b>Housing</b>                                                                 |              |
|                         | HDB flat <sup>[2]</sup>                                                        | 93%          |
|                         | Condominium                                                                    | 4%           |
|                         | Landed property                                                                | 2%           |
| <b>6</b>                | <b>Location</b>                                                                |              |
|                         | Postnatal nursery                                                              | 100%         |
|                         | <b>Previous children (if you have multiple children, for the last child):</b>  | <b>n=57</b>  |
| <b>7</b>                | <b>Did they receive newborn screening for metabolic disorders?</b>             |              |
|                         | Yes                                                                            | 28%          |
|                         | No                                                                             | 32%          |
|                         | I don't know                                                                   | 40%          |
| <b>8</b>                | <b>What was your experience with newborn screening for metabolic disorders</b> |              |
|                         | Satisfactory                                                                   | 23%          |
|                         | Poor                                                                           | 5%           |

|           |                                                                                                                                                                                                                                                                              |              |
|-----------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------|
|           | I don't know                                                                                                                                                                                                                                                                 | 72%          |
|           | <b>Knowledge of Spinal Muscular Atrophy and Newborn Screen</b>                                                                                                                                                                                                               | <b>n=110</b> |
| <b>9</b>  | <b>Have you heard of the condition Spinal Muscular Atrophy?</b>                                                                                                                                                                                                              |              |
|           | Yes                                                                                                                                                                                                                                                                          | 34%          |
|           | No                                                                                                                                                                                                                                                                           | 66%          |
| <b>10</b> | <b>Are you aware that treatment is available for Spinal Muscular Atrophy?</b>                                                                                                                                                                                                |              |
|           | Yes                                                                                                                                                                                                                                                                          | 23%          |
|           | No                                                                                                                                                                                                                                                                           | 77%          |
| <b>11</b> | <b>Are you aware that early diagnosis of Spinal Muscular Atrophy and early treatment leads to improved outcomes?</b>                                                                                                                                                         |              |
|           | Yes                                                                                                                                                                                                                                                                          | 44%          |
|           | No                                                                                                                                                                                                                                                                           | 56%          |
| <b>12</b> | <b>Early diagnosis and treatment of Spinal Muscular Atrophy leads to improved outcomes. Newborn screen is done by a heel prick blood test together with the existing newborn screening test for babies taken in the first few days of life.</b>                              |              |
|           | Yes                                                                                                                                                                                                                                                                          | 85%          |
|           | No                                                                                                                                                                                                                                                                           | 4%           |
|           | I don't know                                                                                                                                                                                                                                                                 | 11%          |
| <b>13</b> | <b>The treatment for Spinal Muscular Atrophy is costly. Funding for this may or may not be readily available.</b>                                                                                                                                                            |              |
|           | <b>With this knowledge, would you screen your child for Spinal Muscular Atrophy?</b>                                                                                                                                                                                         |              |
|           | Yes                                                                                                                                                                                                                                                                          | 69%          |
|           | No                                                                                                                                                                                                                                                                           | 6%           |
|           | I don't know                                                                                                                                                                                                                                                                 | 25%          |
| <b>14</b> | <b>Early diagnosis via newborn screening results in diagnosis and improved treatment but may limit access to private health insurance (not government/public funded healthcare resources). With this knowledge, would you screen your child for Spinal Muscular Atrophy?</b> |              |
|           | Yes                                                                                                                                                                                                                                                                          | 65%          |
|           | No                                                                                                                                                                                                                                                                           | 8%           |
|           | I don't know                                                                                                                                                                                                                                                                 | 27%          |
| <b>15</b> | <b>How much would you pay for Spinal Muscular Atrophy newborn screen?</b>                                                                                                                                                                                                    |              |
|           | <\$50                                                                                                                                                                                                                                                                        | 35%          |
|           | \$50-70                                                                                                                                                                                                                                                                      | 32%          |
|           | \$70-100                                                                                                                                                                                                                                                                     | 20%          |

|           |                                                                                                                                                                                                                                                                                                                                            |     |
|-----------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----|
|           | \$100-200                                                                                                                                                                                                                                                                                                                                  | 11% |
|           | >\$200                                                                                                                                                                                                                                                                                                                                     | 2%  |
| <b>16</b> | <b>If the Spinal Muscular Atrophy newborn screen is positive, you will be given an appointment with a specialist familiar with SMA and confirmatory genetic testing will be offered. How much would you pay for confirmatory genetic testing?</b>                                                                                          |     |
|           | < 100                                                                                                                                                                                                                                                                                                                                      | 50% |
|           | 100-300                                                                                                                                                                                                                                                                                                                                    | 31% |
|           | 300-500                                                                                                                                                                                                                                                                                                                                    | 7%  |
|           | 500-1000                                                                                                                                                                                                                                                                                                                                   | 1%  |
|           | >1000                                                                                                                                                                                                                                                                                                                                      | 11% |
| <b>17</b> | <b>If the Spinal Muscular Atrophy newborn screen is positive, you will be given an appointment with a specialist familiar with SMA and confirmatory genetic testing (via a blood test) will need to be done. Genetic test findings inform on diagnosis and treatment, but has risk on psychological stress and insurance implications.</b> |     |
|           | <b>Do you think the confirmatory genetic test should be automatically done as a reflex upon receipt of a positive screen?</b>                                                                                                                                                                                                              |     |
|           | Yes                                                                                                                                                                                                                                                                                                                                        | 54% |
|           | No                                                                                                                                                                                                                                                                                                                                         | 8%  |
|           | I have no opinion on this                                                                                                                                                                                                                                                                                                                  | 38% |
| <b>18</b> | <b>When, in your opinion, is the ideal time to learn about availability of Spinal Muscular Atrophy newborn screen?</b>                                                                                                                                                                                                                     |     |
|           | Before pregnancy via public health messaging                                                                                                                                                                                                                                                                                               | 29% |
|           | Clinic visit during pregnancy: first trimester visit                                                                                                                                                                                                                                                                                       | 17% |
|           | Clinic visit during pregnancy: second trimester visit                                                                                                                                                                                                                                                                                      | 9%  |
|           | Clinic visit during pregnancy: third trimester visit                                                                                                                                                                                                                                                                                       | 19% |
|           | Delivery suite when in labour                                                                                                                                                                                                                                                                                                              | 2%  |
|           | In the ward after baby is born                                                                                                                                                                                                                                                                                                             | 24% |
| <b>19</b> | <b>If your child screens positive for SMA, it could mean that you and your spouse are genetic carriers for this condition.</b>                                                                                                                                                                                                             |     |
|           | <b>Would you have preferred to know your SMA carrier status before pregnancy?</b>                                                                                                                                                                                                                                                          |     |
|           | Yes                                                                                                                                                                                                                                                                                                                                        | 78% |
|           | No                                                                                                                                                                                                                                                                                                                                         | 22% |

<sup>[1]</sup> ITE: Institute of Technical Education

<sup>[2]</sup> HDB flat: public housing