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# MITOCHONDRIAL DISEASE AUSTRALIAN STUDY 2018





The International Centre for Community-Driven Research

## SECTION 1: INTRODUCTION AND METHODOLOGY

- Mitochondrial disease is a heterogeneous group of diseases that have dysfunctional mitochondrial respiratory changes that are caused by mutations to nuclear or mitochondrial DNA. The disease may affect single organ or may affect multiple organs, and usually affect organs that have the highest energy needs such as muscles, brain, eyes and heart.
- The prevalence of mitochondrial disease is estimated at 11.5 per 100,000, however this may underestimate the prevalence with reports of one in 200 healthy births having a mitochondrial DNA mutation.
- Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by the International Centre for Community-Driven Research (ICCDR).
- The aim of PEEK is to conduct patient experience studies across several disease areas using a protocol that will allow for comparisons over time (both quantitative and qualitative components).
- PEEK studies give us a clear picture and historical record of what it is like to be a patient at a given point in time, and by asking patients about their expectations, PEEK studies give us a way forward to support patients and their families with treatments, information and care.
- This PEEK study was generously sponsored by the Mito Foundation (Australia). The sponsor had no input into the methodology, analysis or reporting.



In this PEEK study, 50 people with mitochondrial disease or their carers, throughout Australia participated in the study that included a structured interview and quantitative questionnaire. This study in mitochondrial disease is therefore the largest mixed methodology study in Australia. In addition, PEEK is a comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations.





The International Centre for Community-Driven Research

## SECTION 2: DEMOGRAPHICS

| Characteristic  | n= | Percentage of participants |
|---|----|----------------------------|
| <b>Participant type n=50</b>  |    |                            |
| Person with mitochondrial disease                                     | 44 | 88.00                      |
| Parent/care of someone with mitochondrial disease                     | 6  | 12.00                      |
| <b>Location: State n=50</b>   |    |                            |
| New South Wales   | 18 | 36.00                      |
| Victoria  | 12 | 24.00                      |
| Queensland  | 10 | 20.00                      |
| South Australia   | 5  | 10.00                      |
| Tasmania  | 3  | 6.00                       |
| Western Australia   | 2  | 4.00                       |
| <b>Geographical location n=50</b>                                     |    |                            |
| Major City  | 30 | 60.00                      |
| Inner Regional  | 13 | 26.00                      |
| Outer Regional  | 6  | 12.00                      |
| Remote  | 1  | 2.00                       |
| <b>Social Economic Indexes for Areas n=50 (1= most disadvantaged)</b> |    |                            |
| 1   | 3  | 6.00                       |
| 2   | 2  | 4.00                       |
| 3   | 4  | 8.00                       |
| 4   | 5  | 10.00                      |
| 5   | 3  | 6.00                       |
| 6   | 6  | 12.00                      |
| 7   | 3  | 6.00                       |
| 8   | 8  | 16.00                      |
| 9   | 13 | 26.00                      |
| 10  | 3  | 6.00                       |
| <b>Gender n=50</b>  |    |                            |
| Female  | 37 | 74.00                      |
| Male  | 13 | 26.00                      |
| <b>Age of participant n=50</b>  |    |                            |
| 25-34   | 6  | 12.00                      |
| 35-44   | 8  | 16.00                      |
| 45-54   | 13 | 26.00                      |
| 55-64   | 13 | 26.00                      |
| 65-74   | 5  | 10.00                      |
| 75-84   | 5  | 10.00                      |
| <b>Race n=49</b>  |    |                            |
| Caucasian/White   | 47 | 95.92                      |
| Australian  | 1  | 2.04                       |
| Portuguese  | 1  | 2.04                       |



| Characteristic  | n= | Percentage of Participants |
|---|----|----------------------------|
| <b>Highest level of education obtained n=50</b>                   |    |                            |
| Less than High School degree                                      | 2  | 4.00                       |
| High school degree or equivalent                                  | 13 | 26.00                      |
| Some College but no degree  | 10 | 20.00                      |
| Trade   | 1  | 2.00                       |
| Associate degree  | 3  | 6.00                       |
| Bachelor Degree   | 9  | 18.00                      |
| Graduate degree   | 12 | 24.00                      |
| <b>Employment status (can choose more than one category) n=50</b> |    |                            |
| Currently receiving Centrelink support                            | 11 | 22.00                      |
| Disabled, not able to work  | 17 | 34.00                      |
| Employed, working full time                                       | 10 | 20.00                      |
| Employed, working part time                                       | 6  | 12.00                      |
| Full/part time carer  | 4  | 8.00                       |
| Full/part time study  | 2  | 4.00                       |
| Not employed, looking for work                                    | 1  | 2.00                       |
| Retired   | 10 | 20.00                      |
| <b>My health Record Access n=50</b>                               |    |                            |
| No  | 26 | 52.00                      |
| Yes   | 5  | 10.00                      |
| I Don't know what "My health record" is                           | 11 | 22.00                      |
| Not Sure  | 8  | 16.00                      |
| <b>My health Record Use n=5</b>                                   |    |                            |
| Good  | 1  | 20.00                      |
| Acceptable  | 1  | 20.00                      |
| Poor  | 2  | 40.00                      |
| Very Poor   | 1  | 20.00                      |
| <b>Carer status n=50</b>  |    |                            |
| Carer to children   | 14 | 28.00                      |
| Carer to spouse   | 2  | 4.00                       |
| Carer to parents  | 2  | 4.00                       |
| I am not a carer  | 32 | 64.00                      |



| Disease description  | Number | Percentage of Participants |
|--|--------|----------------------------|
| <b>Syndrome</b>  |        |                            |
| CPEO   | 2      | 4.00                       |
| KSS  | 3      | 6.00                       |
| Leigh's syndrome   | 2      | 4.00                       |
| LHON   | 3      | 6.00                       |
| MELAS  | 11     | 22.00                      |
| MELAS/NARP/Leigh like  | 1      | 2.00                       |
| MERRF  | 1      | 2.00                       |
| NARP/MERRF   | 1      | 2.00                       |
| <b>Symptoms</b>  |        |                            |
| General mitochondrial disease diagnosis, described main symptoms | 11     | 22.00                      |
| <b>No description</b>  |        |                            |
| General mitochondrial disease diagnosis                          | 6      | 12.00                      |
| <b>Deficiency</b>  |        |                            |
| Alpha-methylacyl-CoA racemase deficiency                         | 1      | 2.00                       |
| Complex I and IV deficiency                                      | 2      | 4.00                       |
| Complex IV deficiency  | 1      | 2.00                       |
| COX deficiency   | 1      | 2.00                       |
| <b>Mutation</b>  |        |                            |
| m.3302 A>G   | 1      | 2.00                       |
| MT 3113 A-G  | 1      | 2.00                       |
| <b>Mixed</b>   |        |                            |
| MELAS, m.3233 A>G  | 1      | 2.00                       |
| Complex IV deficiency/ Leigh's Disease                           | 1      | 2.00                       |





| Characteristic                                  | n= | Percentage of participants |
|---|----|----------------------------|
| <b>SF36 General health</b>                      |    |                            |
| Higher general health                           | 22 | 56.00                      |
| Lower general health                            | 28 | 44.00                      |
| <b>SF36 Physical functioning</b>                |    |                            |
| Higher physical functioning                     | 22 | 56.00                      |
| Lower physical functioning                      | 28 | 44.00                      |
| <b>SF36 Emotional well-being</b>                |    |                            |
| Higher emotional well-being                     | 26 | 52.00                      |
| Lower emotional well-being                      | 24 | 48.00                      |
| <b>SF36 Social functioning</b>                  |    |                            |
| Higher social functioning                       | 20 | 40.00                      |
| Lower social functioning                        | 30 | 60.00                      |
| <b>Hearing problems</b>                         |    |                            |
| Hearing problems                                | 24 | 48.00                      |
| No hearing problems                             | 26 | 52.00                      |
| <b>Eye problems</b>                             |    |                            |
| Eye problems                                    | 34 | 68.00                      |
| No eye problems                                 | 16 | 32.00                      |
| <b>Location</b>                                 |    |                            |
| Metropolitan                                    | 30 | 60.00                      |
| Regional/rural                                  | 20 | 40.00                      |
| <b>Education</b>                                |    |                            |
| Trade or high school                            | 26 | 52.00                      |
| University                                      | 24 | 48.00                      |
| <b>Socio-Economic Indexes for Areas (SEIFA)</b> |    |                            |
| Higher SEIFA                                    | 27 | 54.00                      |
| Lower SEIFA                                     | 23 | 46.00                      |





## SECTION 3: SYMPTOMS & DIAGNOSIS

| Symptoms leading to diagnosis   | All participants |       | Metropolitan |       | Rural |       | SEIFA (High) |       | SEIFA (Low) |       |
|---|------------------|-------|--------------|-------|-------|-------|--------------|-------|-------------|-------|
|   | n=50             | %     | n=30         | %     | n=20  | %     | n=27         | %     | n=23        | %     |
| Participant describes fatigue and/or lack of stamina                    | 14               | 28.00 | 9            | 30.00 | 5     | 25.00 | 7            | 25.93 | 7           | 30.43 |
| Participant describes gastrointestinal distress                         | 11               | 22.00 | 7            | 23.33 | 4     | 20.00 | 5            | 18.52 | 6           | 26.09 |
| Participant describes failing to thrive as an infant                    | 8                | 16.00 | 5            | 16.67 | 3     | 15.00 | 5            | 18.52 | 3           | 13.04 |
| Participant describes not being able to use their legs/weakness in legs | 7                | 14.00 | 2            | 6.67  | 5     | 25.00 | 4            | 14.81 | 3           | 13.04 |
| Participant describes migraine (Stroke-like)                            | 7                | 14.00 | 5            | 16.67 | 2     | 10.00 | 1            | 3.70  | 6           | 26.09 |
| Participant describes hearing deficit or hearing loss                   | 6                | 12.00 | 3            | 10.00 | 3     | 15.00 | 3            | 11.11 | 3           | 13.04 |
| Participant describes blurred vision (to vision loss)                   | 6                | 12.00 | 3            | 10.00 | 3     | 15.00 | 3            | 11.11 | 3           | 13.04 |
| Participant describes muscle pains and aches                            | 6                | 12.00 | 2            | 6.67  | 4     | 20.00 | 2            | 7.41  | 4           | 17.39 |
| Participant describes having diabetes                                   | 5                | 10.00 | 3            | 10.00 | 2     | 10.00 | 2            | 7.41  | 3           | 13.04 |



| Symptoms leading to diagnosis   | All participants |       | High school or trade |       | University |       | Hearing impairment |       | Eye or visual impairment |       |
|---|------------------|-------|----------------------|-------|------------|-------|--------------------|-------|--------------------------|-------|
|   | n=50             | %     | n=26                 | %     | n=24       | %     | n=24               | %     | n=34                     | %     |
| Participant describes fatigue and/or lack of stamina                    | 14               | 28.00 | 7                    | 26.92 | 7          | 29.17 | 9                  | 37.50 | 11                       | 32.35 |
| Participant describes gastrointestinal distress                         | 11               | 22.00 | 3                    | 11.54 | 8          | 33.33 | 9                  | 37.50 | 7                        | 20.59 |
| Participant describes failing to thrive as an infant                    | 8                | 16.00 | 6                    | 23.08 | 2          | 8.33  | 2                  | 8.33  | 6                        | 17.65 |
| Participant describes not being able to use their legs/weakness in legs | 7                | 14.00 | 3                    | 11.54 | 4          | 16.67 | 3                  | 12.50 | 5                        | 14.71 |
| Participant describes migraine (Stroke-like)                            | 7                | 14.00 | 4                    | 15.38 | 3          | 12.50 | 4                  | 16.67 | 5                        | 14.71 |
| Participant describes hearing deficit or hearing loss                   | 6                | 12.00 | 0                    | 0.00  | 6          | 25.00 | 6                  | 25.00 | 3                        | 8.82  |
| Participant describes blurred vision (to vision loss)                   | 6                | 12.00 | 3                    | 11.54 | 3          | 12.50 | 3                  | 12.50 | 5                        | 14.71 |
| Participant describes muscle pains and aches                            | 6                | 12.00 | 3                    | 11.54 | 3          | 12.50 | 2                  | 8.33  | 4                        | 11.76 |
| Participant describes having diabetes                                   | 5                | 10.00 | 0                    | 0.00  | 5          | 20.83 | 5                  | 20.83 | 2                        | 5.88  |



| Symptoms leading to diagnosis   | All participants |       | Physical function (High) |       | Physical function (Low) |       | Emotional well-being (High) |       | Emotional well-being (Low) |       |
|---|------------------|-------|--------------------------|-------|-------------------------|-------|-----------------------------|-------|----------------------------|-------|
|   | n=50             | %     | n=22                     | %     | n=28                    | %     | n=26                        | %     | n=24                       | %     |
| Participant describes fatigue and/or lack of stamina                    | 14               | 28.00 | 9                        | 40.91 | 5                       | 17.86 | 8                           | 30.77 | 6                          | 25.00 |
| Participant describes gastrointestinal distress                         | 11               | 22.00 | 6                        | 27.27 | 5                       | 17.86 | 6                           | 23.08 | 5                          | 20.83 |
| Participant describes failing to thrive as an infant                    | 8                | 16.00 | 2                        | 9.09  | 6                       | 21.43 | 4                           | 15.38 | 4                          | 16.67 |
| Participant describes not being able to use their legs/weakness in legs | 7                | 14.00 | 3                        | 13.64 | 4                       | 14.29 | 4                           | 15.38 | 3                          | 12.50 |
| Participant describes migraine (Stroke-like)                            | 7                | 14.00 | 4                        | 18.18 | 3                       | 10.71 | 2                           | 7.69  | 5                          | 20.83 |
| Participant describes hearing deficit or hearing loss                   | 6                | 12.00 | 5                        | 22.73 | 1                       | 3.57  | 4                           | 15.38 | 2                          | 8.33  |
| Participant describes blurred vision (to vision loss)                   | 6                | 12.00 | 3                        | 13.64 | 3                       | 10.71 | 5                           | 19.23 | 1                          | 4.17  |
| Participant describes muscle pains and aches                            | 6                | 12.00 | 1                        | 4.55  | 5                       | 17.86 | 2                           | 7.69  | 4                          | 16.67 |
| Participant describes having diabetes                                   | 5                | 10.00 | 5                        | 22.73 | 0                       | 0.00  | 3                           | 11.54 | 2                          | 8.33  |

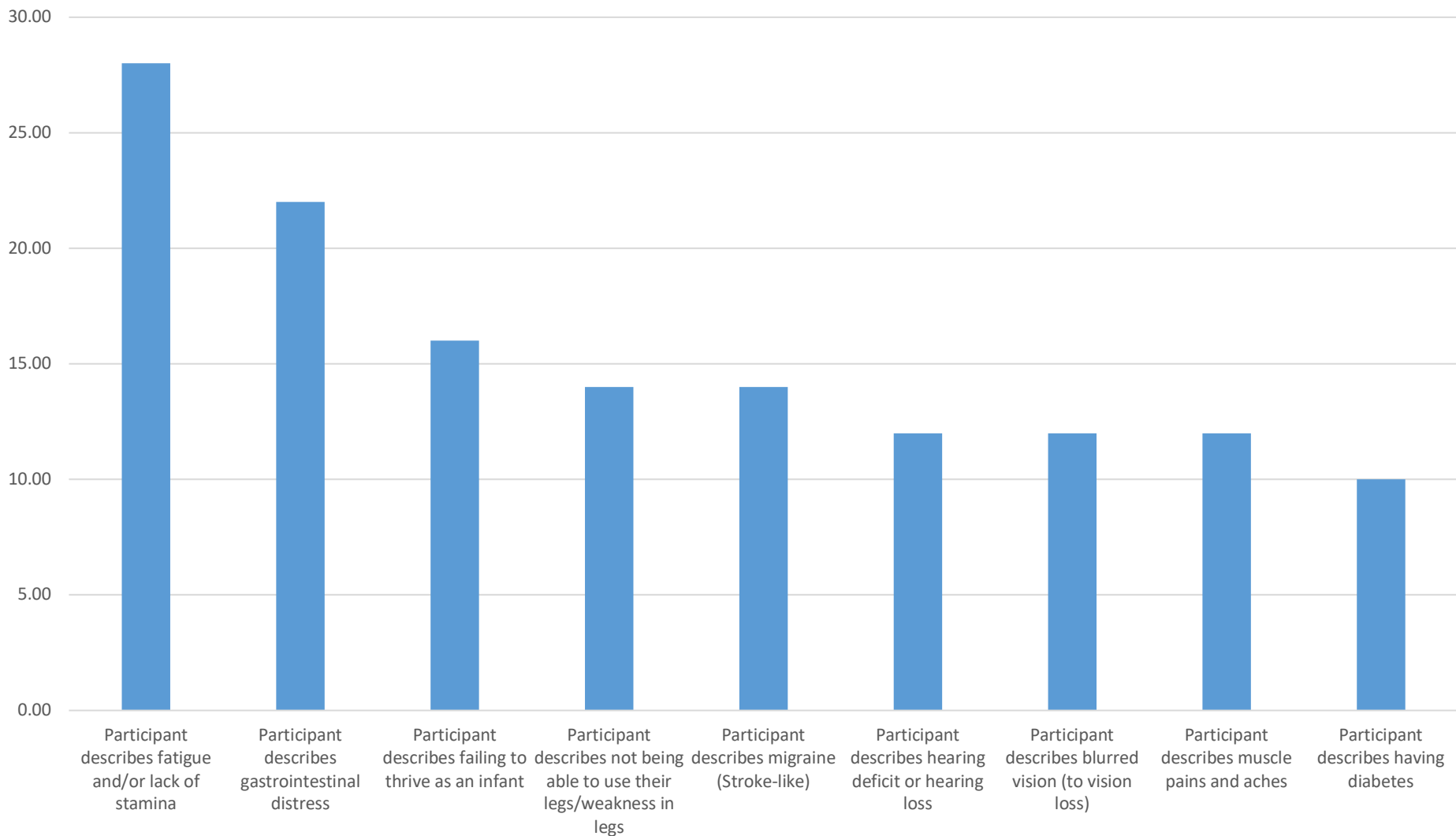


| Symptoms leading to diagnosis   | All participants |       | Social functioning (High) |       | Social functioning (Low) |       | General health (High) |       | General health (Low) |       |
|---|------------------|-------|---------------------------|-------|--------------------------|-------|-----------------------|-------|----------------------|-------|
|   | n=50             | %     | n=20                      | %     | n=30                     | %     | n=22                  | %     | n=28                 | %     |
| Participant describes fatigue and/or lack of stamina                    | 14               | 28.00 | 8                         | 40.00 | 6                        | 20.00 | 7                     | 31.82 | 7                    | 25.00 |
| Participant describes gastrointestinal distress                         | 11               | 22.00 | 4                         | 20.00 | 7                        | 23.33 | 6                     | 27.27 | 5                    | 17.86 |
| Participant describes failing to thrive as an infant                    | 8                | 16.00 | 3                         | 15.00 | 5                        | 16.67 | 3                     | 13.64 | 5                    | 17.86 |
| Participant describes not being able to use their legs/weakness in legs | 7                | 14.00 | 4                         | 20.00 | 3                        | 10.00 | 5                     | 22.73 | 2                    | 7.14  |
| Participant describes migraine (Stroke-like)                            | 7                | 14.00 | 2                         | 10.00 | 5                        | 16.67 | 0                     | 0.00  | 7                    | 25.00 |
| Participant describes hearing deficit or hearing loss                   | 6                | 12.00 | 3                         | 15.00 | 3                        | 10.00 | 4                     | 18.18 | 2                    | 7.14  |
| Participant describes blurred vision (to vision loss)                   | 6                | 12.00 | 2                         | 10.00 | 4                        | 13.33 | 3                     | 13.64 | 3                    | 10.71 |
| Participant describes muscle pains and aches                            | 6                | 12.00 | 2                         | 10.00 | 4                        | 13.33 | 2                     | 9.09  | 4                    | 14.29 |
| Participant describes having diabetes                                   | 5                | 10.00 | 2                         | 10.00 | 3                        | 10.00 | 4                     | 18.18 | 1                    | 3.57  |



| Symptoms leading to diagnosis   | All participants |       | Under 18 |       | 24-44 |       | 45-54 |       | 55-64 |       | 65-74+ |       |
|---|------------------|-------|----------|-------|-------|-------|-------|-------|-------|-------|--------|-------|
|   | n=50             | %     | n=6      | %     | n=14  | %     | n=9   | %     | n=11  | %     | n=10   | %     |
| Participant describes fatigue and/or lack of stamina                    | 14               | 28.00 | 1        | 16.67 | 4     | 28.57 | 3     | 33.33 | 2     | 18.18 | 4      | 40.00 |
| Participant describes gastrointestinal distress                         | 11               | 22.00 | 1        | 16.67 | 4     | 28.57 | 2     | 22.22 | 2     | 18.18 | 2      | 20.00 |
| Participant describes failing to thrive as an infant                    | 8                | 16.00 | 4        | 66.67 | 1     | 7.14  | 1     | 11.11 | 2     | 18.18 | 0      | 0.00  |
| Participant describes not being able to use their legs/weakness in legs | 7                | 14.00 | 1        | 16.67 | 0     | 0.00  | 1     | 11.11 | 4     | 36.36 | 1      | 10.00 |
| Participant describes migraine (Stroke-like)                            | 7                | 14.00 | 1        | 16.67 | 4     | 28.57 | 2     | 22.22 | 0     | 0.00  | 0      | 0.00  |
| Participant describes hearing deficit or hearing loss                   | 6                | 12.00 | 0        | 0.00  | 4     | 28.57 | 1     | 11.11 | 1     | 9.09  | 0      | 0.00  |
| Participant describes blurred vision (to vision loss)                   | 6                | 12.00 | 0        | 0.00  | 1     | 7.14  | 2     | 22.22 | 2     | 18.18 | 1      | 10.00 |
| Participant describes muscle pains and aches                            | 6                | 12.00 | 0        | 0.00  | 1     | 7.14  | 0     | 0.00  | 2     | 18.18 | 3      | 30.00 |
| Participant describes having diabetes                                   | 5                | 10.00 | 0        | 0.00  | 3     | 21.43 | 1     | 11.11 | 1     | 9.09  | 0      | 0.00  |

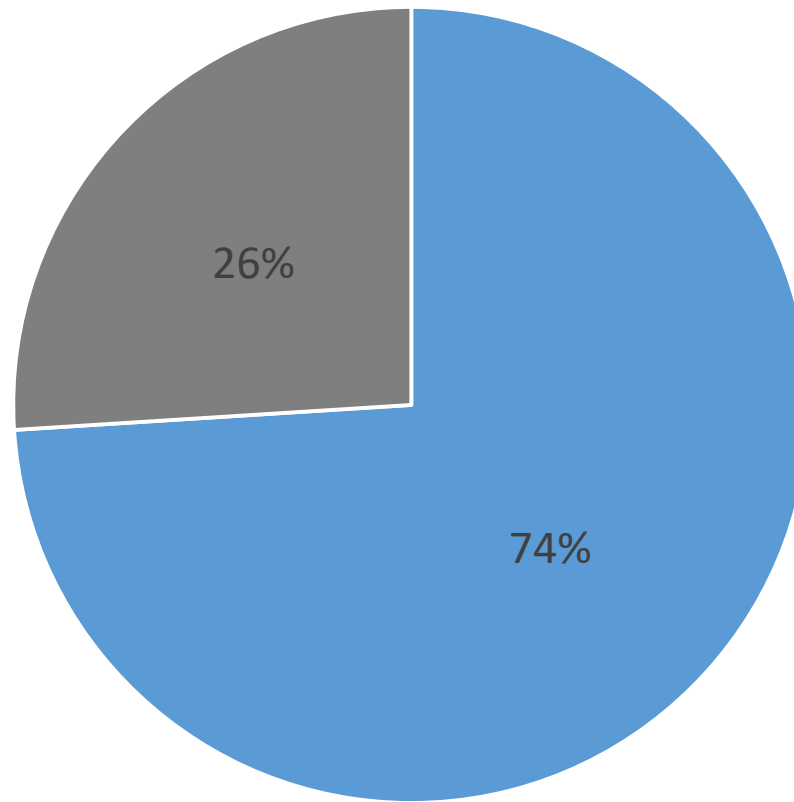






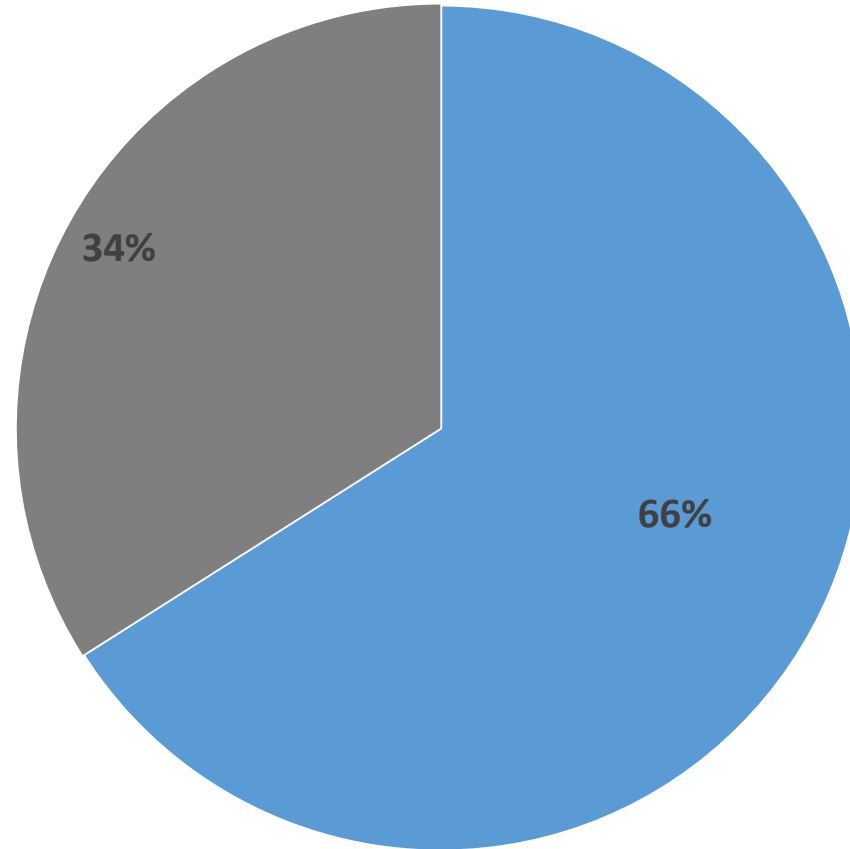
| Conditions misdiagnosed or suspected before diagnosis             | All participants |      |
|---|------------------|------|
|   | n=50             | %    |
| Muscular dystrophy suspected or misdiagnosed                      | 3                | 6.00 |
| Rheumatoid arthritis suspected suspected or misdiagnosed          | 3                | 6.00 |
| Diagnosed through other investigation or treatment/therapy regime | 2                | 4.00 |
| Multiple sclerosis suspected suspected or misdiagnosed            | 1                | 2.00 |
| Fibromyalgia suspected or misdiagnosed                            | 1                | 2.00 |
| Chronic fatigue syndrome suspected or misdiagnosed                | 1                | 2.00 |





- No hereditary condition noted as part of diagnosis
- Participant describes a hereditary component in relation to diagnosis





- Description of a long (more than a year) or complicated path to diagnosis
- Initially diagnosis was mitochondrial disease (relatively straight forward)



| Understanding of disease at diagnosis  | All participants |       |
|--|------------------|-------|
|  | n=50             | %     |
| Participant describes knowing nothing about mitochondrial disease at diagnosis   | 31               | 62.00 |
| Participant describes knowing about mitochondrial disease as the time to diagnosis was relatively long, giving them time to educate themselves | 8                | 16.00 |
| Participant describes knowing very little about mitochondrial disease at diagnosis   | 7                | 14.00 |
| Participant describes knowing about mitochondrial disease before diagnosis (scientific background)   | 2                | 4.00  |
| Participant describes no-one knowing much about mitochondrial disease and the uncertainty of the diagnosis                                     | 2                | 4.00  |



| Understanding of prognosis   | All participants |       |
|--|------------------|-------|
|  | n=50             | %     |
| Participant describes prognosis not being discussed  | 26               | 52.00 |
| Participant describes poor prognosis - decline in physical function                                | 9                | 18.00 |
| Participant describes a relatively stable disease/controlled (may have some exacerbations)         | 7                | 14.00 |
| Participant describes poor prognosis - reduced life expectancy and/or rapid progression of disease | 6                | 12.00 |



| Understanding of testing for genes, biomarkers or mutations   | All participants |       |
|---|------------------|-------|
|   | n=50             | %     |
| Participant understands that the test determines treatment option(s)  | 6                | 12.00 |
| Participant understands that the test is used for diagnosis of mitochondrial disease  | 5                | 10.00 |
| Participant understands that the test is to see if there are any deletions  | 4                | 8.00  |
| Participant understands that the test can not help them but may help others in the future   | 4                | 8.00  |
| Participant understands that the test can not target treatment as there are no treatments available or that there was no clinical indication following the test | 4                | 8.00  |



## Understanding of tests for genes, biomarkers or mutations



The International Centre for Community-Driven Research

## SECTION 4: DECISION-MAKING

| Conversations about treatment   | All participants |       | Metropolitan |       | Rural |       | SEIFA (High) |       | SEIFA (Low) |       |
|---|------------------|-------|--------------|-------|-------|-------|--------------|-------|-------------|-------|
|   | n=50             | %     | n=30         | %     | n=20  | %     | n=27         | %     | n=23        | %     |
| Participant describes being told about supplements, such as Coenzyme Q10 and ATP support      | 19               | 38.00 | 11           | 36.67 | 8     | 40.00 | 9            | 33.33 | 10          | 43.48 |
| Participant describes being told that there is no treatment for mitochondrial disease         | 16               | 32.00 | 10           | 33.33 | 6     | 30.00 | 9            | 33.33 | 7           | 30.43 |
| Participant describes having little to no discussion about treatment options during diagnosis | 9                | 18.00 | 5            | 16.67 | 4     | 20.00 | 5            | 18.52 | 4           | 17.39 |
| Participant describes having a discussion about lifestyle changes, e.g. diet and exercise     | 9                | 18.00 | 6            | 20.00 | 3     | 15.00 | 5            | 18.52 | 4           | 17.39 |





| Conversations about treatment   | All participants |       | High school or trade |       | University |       | Hearing impairment |       | Eye or visual impairment |       |
|---|------------------|-------|----------------------|-------|------------|-------|--------------------|-------|--------------------------|-------|
|   | n=50             | %     | n=26                 | %     | n=24       | %     | n=24               | %     | n=34                     | %     |
| Participant describes being told about supplements, such as Coenzyme Q10 and ATP support      | 19               | 38.00 | 11                   | 42.31 | 8          | 33.33 | 9                  | 37.50 | 15                       | 44.12 |
| Participant describes being told that there is no treatment for mitochondrial disease         | 16               | 32.00 | 5                    | 19.23 | 11         | 45.83 | 10                 | 41.67 | 10                       | 29.41 |
| Participant describes having little to no discussion about treatment options during diagnosis | 9                | 18.00 | 5                    | 19.23 | 4          | 16.67 | 3                  | 12.50 | 5                        | 14.71 |
| Participant describes having a discussion about lifestyle changes, e.g. diet and exercise     | 9                | 18.00 | 4                    | 15.38 | 5          | 20.83 | 3                  | 12.50 | 7                        | 20.59 |



| Conversations about treatment   | All participants |       | Physical function (High) |       | Physical function (Low) |       | Emotional well-being (High) |       | Emotional well-being (Low) |       |
|---|------------------|-------|--------------------------|-------|-------------------------|-------|-----------------------------|-------|----------------------------|-------|
|   | n=50             | %     | n=22                     | %     | n=28                    | %     | n=26                        | %     | n=24                       | %     |
| Participant describes being told about supplements, such as Coenzyme Q10 and ATP support      | 19               | 38.00 | 9                        | 40.91 | 10                      | 35.71 | 10                          | 38.46 | 9                          | 37.50 |
| Participant describes being told that there is no treatment for mitochondrial disease         | 16               | 32.00 | 7                        | 31.82 | 9                       | 32.14 | 8                           | 30.77 | 8                          | 33.33 |
| Participant describes having little to no discussion about treatment options during diagnosis | 9                | 18.00 | 4                        | 18.18 | 5                       | 17.86 | 5                           | 19.23 | 4                          | 16.67 |
| Participant describes having a discussion about lifestyle changes, e.g. diet and exercise     | 9                | 18.00 | 3                        | 13.64 | 6                       | 21.43 | 6                           | 23.08 | 3                          | 12.50 |

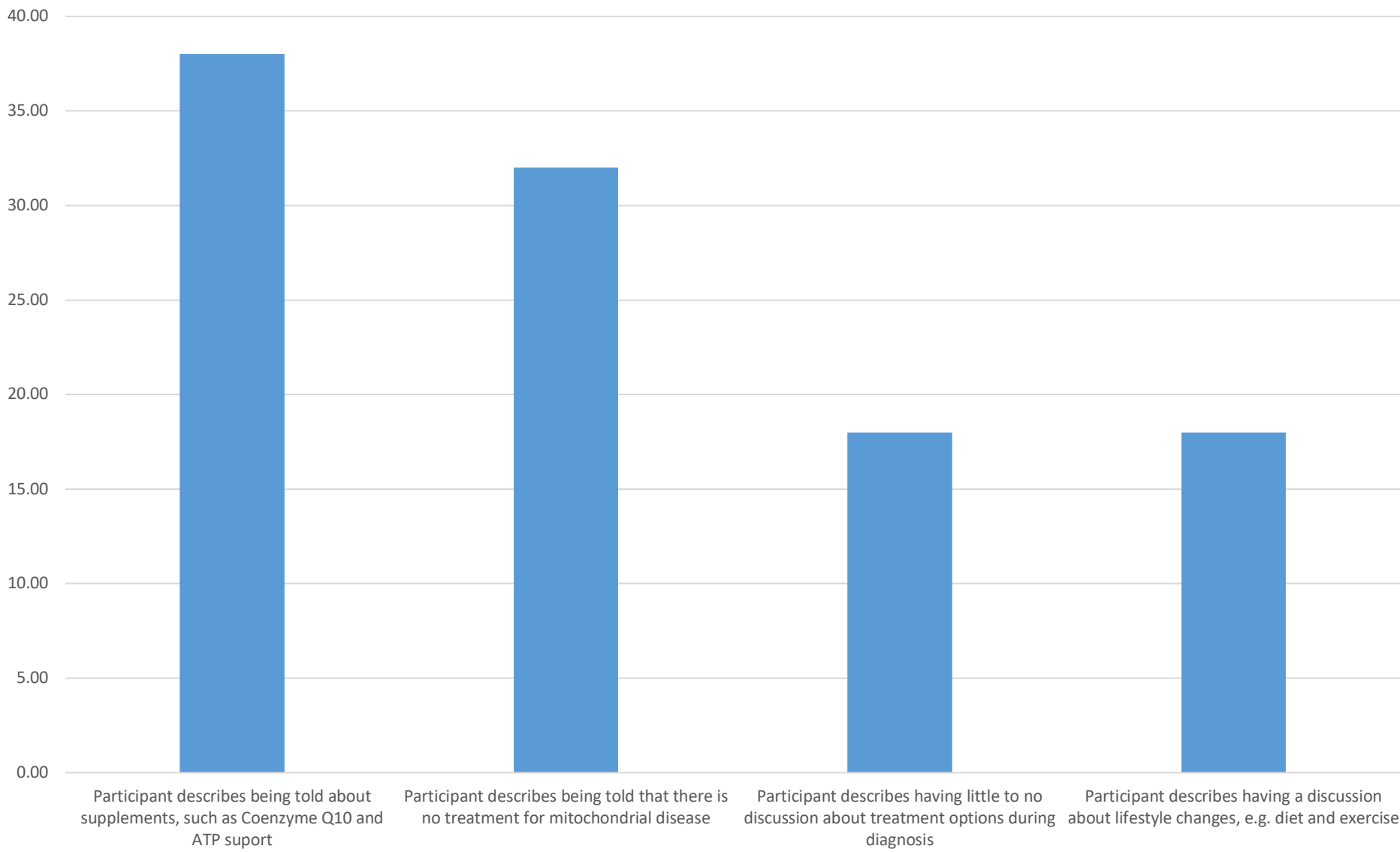


| Conversations about treatment   | All participants |       | Social functioning (High) |       | Social functioning (Low) |       | General health (High) |       | General health (Low) |       |
|---|------------------|-------|---------------------------|-------|--------------------------|-------|-----------------------|-------|----------------------|-------|
|   | n=50             | %     | n=20                      | %     | n=30                     | %     | n=22                  | %     | n=28                 | %     |
| Participant describes being told about supplements, such as Coenzyme Q10 and ATP support      | 19               | 38.00 | 9                         | 45.00 | 10                       | 33.33 | 9                     | 40.91 | 10                   | 35.71 |
| Participant describes being told that there is no treatment for mitochondrial disease         | 16               | 32.00 | 6                         | 30.00 | 10                       | 33.33 | 8                     | 36.36 | 8                    | 28.57 |
| Participant describes having little to no discussion about treatment options during diagnosis | 9                | 18.00 | 5                         | 25.00 | 4                        | 13.33 | 4                     | 18.18 | 5                    | 17.86 |
| Participant describes having a discussion about lifestyle changes, e.g. diet and exercise     | 9                | 18.00 | 4                         | 20.00 | 5                        | 16.67 | 4                     | 18.18 | 5                    | 17.86 |



| Conversations about treatment   | All participants |       | Under 18 |       | 24-44 |       | 45-54 |       | 55-64 |       | 65-74+ |       |
|---|------------------|-------|----------|-------|-------|-------|-------|-------|-------|-------|--------|-------|
|   | n=50             | %     | n=6      | %     | n=14  | %     | n=9   | %     | n=11  | %     | n=10   | %     |
| Participant describes being told about supplements, such as Coenzyme Q10 and ATP support      | 19               | 38.00 | 5        | 83.33 | 4     | 28.57 | 2     | 22.22 | 5     | 45.45 | 3      | 30.00 |
| Participant describes being told that there is no treatment for mitochondrial disease         | 16               | 32.00 | 0        | 0.00  | 2     | 14.29 | 5     | 55.56 | 6     | 54.55 | 3      | 30.00 |
| Participant describes having little to no discussion about treatment options during diagnosis | 9                | 18.00 | 0        | 0.00  | 5     | 35.71 | 1     | 11.11 | 1     | 9.09  | 2      | 20.00 |
| Participant describes having a discussion about lifestyle changes, e.g. diet and exercise     | 9                | 18.00 | 2        | 33.33 | 2     | 14.29 | 1     | 11.11 | 2     | 18.18 | 2      | 20.00 |





| Considerations when making decisions about treatment  | All participants |       | Metropolitan |       | Rural |       | SEIFA (High) |       | SEIFA (Low) |       |
|---|------------------|-------|--------------|-------|-------|-------|--------------|-------|-------------|-------|
|   | n=50             | %     | n=30         | %     | n=20  | %     | n=27         | %     | n=23        | %     |
| Participant describes considering a combination of the benefits and side effects                              | 10               | 20.00 | 5            | 16.67 | 5     | 25.00 | 4            | 14.81 | 6           | 26.09 |
| Participant describes their main consideration as the side effects  | 6                | 12.00 | 5            | 16.67 | 1     | 5.00  | 4            | 14.81 | 2           | 8.70  |
| Participant describes their main consideration as the evidence to support the use of the treatment (Efficacy) | 10               | 20.00 | 5            | 16.67 | 5     | 25.00 | 5            | 18.52 | 5           | 21.74 |
| Participant describes their main consideration as the cost of the treatment                                   | 9                | 18.00 | 7            | 23.33 | 2     | 10.00 | 5            | 18.52 | 4           | 17.39 |
| Participant describes considering the impact on their lifestyle, including work                               | 6                | 12.00 | 5            | 16.67 | 1     | 5.00  | 6            | 22.22 | 0           | 0.00  |
| Participant describes taking the advice from the specialist with no specific considerations                   | 5                | 10.00 | 4            | 13.33 | 1     | 5.00  | 3            | 11.11 | 2           | 8.70  |
| Participant describes considering their quality of life when deciding on a treatment                          | 5                | 10.00 | 2            | 6.67  | 3     | 15.00 | 2            | 7.41  | 3           | 13.04 |



## Considerations when making decisions about treatment (Table a)

| Considerations when making decisions about treatment  | All participants |       | High school or trade |       | University |       | Hearing impairment |       | Eye or visual impairment |       |
|---|------------------|-------|----------------------|-------|------------|-------|--------------------|-------|--------------------------|-------|
|   | n=50             | %     | n=26                 | %     | n=24       | %     | n=24               | %     | n=34                     | %     |
| Participant describes considering a combination of the benefits and side effects                              | 10               | 20.00 | 7                    | 26.92 | 3          | 12.50 | 5                  | 20.83 | 7                        | 20.59 |
| Participant describes their main consideration as the side effects  | 6                | 12.00 | 2                    | 7.69  | 4          | 16.67 | 4                  | 16.67 | 3                        | 8.82  |
| Participant describes their main consideration as the evidence to support the use of the treatment (Efficacy) | 10               | 20.00 | 3                    | 11.54 | 7          | 29.17 | 6                  | 25.00 | 6                        | 17.65 |
| Participant describes their main consideration as the cost of the treatment                                   | 9                | 18.00 | 5                    | 19.23 | 4          | 16.67 | 4                  | 16.67 | 7                        | 20.59 |
| Participant describes considering the impact on their lifestyle, including work                               | 6                | 12.00 | 4                    | 15.38 | 2          | 8.33  | 3                  | 12.50 | 4                        | 11.76 |
| Participant describes taking the advice from the specialist with no specific considerations                   | 5                | 10.00 | 3                    | 11.54 | 2          | 8.33  | 2                  | 8.33  | 4                        | 11.76 |
| Participant describes considering their quality of life when deciding on a treatment                          | 5                | 10.00 | 2                    | 7.69  | 3          | 12.50 | 3                  | 12.50 | 2                        | 5.88  |



## Considerations when making decisions about treatment (Table b)

| Considerations when making decisions about treatment  | All participants |       | Physical function (High) |       | Physical function (Low) |       | Emotional well-being (High) |       | Emotional well-being (Low) |       |
|---|------------------|-------|--------------------------|-------|-------------------------|-------|-----------------------------|-------|----------------------------|-------|
|   | n=50             | %     | n=22                     | %     | n=28                    | %     | n=26                        | %     | n=24                       | %     |
| Participant describes considering a combination of the benefits and side effects                              | 10               | 20.00 | 4                        | 18.18 | 6                       | 21.43 | 5                           | 19.23 | 5                          | 20.83 |
| Participant describes their main consideration as the side effects  | 6                | 12.00 | 2                        | 9.09  | 4                       | 14.29 | 5                           | 19.23 | 1                          | 4.17  |
| Participant describes their main consideration as the evidence to support the use of the treatment (Efficacy) | 10               | 20.00 | 5                        | 22.73 | 5                       | 17.86 | 6                           | 23.08 | 4                          | 16.67 |
| Participant describes their main consideration as the cost of the treatment                                   | 9                | 18.00 | 2                        | 9.09  | 7                       | 25.00 | 6                           | 23.08 | 3                          | 12.50 |
| Participant describes considering the impact on their lifestyle, including work                               | 6                | 12.00 | 3                        | 13.64 | 3                       | 10.71 | 4                           | 15.38 | 2                          | 8.33  |
| Participant describes taking the advice from the specialist with no specific considerations                   | 5                | 10.00 | 3                        | 13.64 | 2                       | 7.14  | 1                           | 3.85  | 4                          | 16.67 |
| Participant describes considering their quality of life when deciding on a treatment                          | 5                | 10.00 | 0                        | 0.00  | 5                       | 17.86 | 2                           | 7.69  | 3                          | 12.50 |



## Considerations when making decisions about treatment (Table c)



| Considerations when making decisions about treatment  | All participants |       | Social functioning (High) |       | Social functioning (Low) |       | General health (High) |       | General health (Low) |       |
|---|------------------|-------|---------------------------|-------|--------------------------|-------|-----------------------|-------|----------------------|-------|
|   | n=50             | %     | n=20                      | %     | n=30                     | %     | n=22                  | %     | n=28                 | %     |
| Participant describes considering a combination of the benefits and side effects                              | 10               | 20.00 | 4                         | 20.00 | 6                        | 20.00 | 5                     | 22.73 | 5                    | 17.86 |
| Participant describes their main consideration as the side effects  | 6                | 12.00 | 3                         | 15.00 | 3                        | 10.00 | 1                     | 4.55  | 5                    | 17.86 |
| Participant describes their main consideration as the evidence to support the use of the treatment (Efficacy) | 10               | 20.00 | 4                         | 20.00 | 6                        | 20.00 | 3                     | 13.64 | 7                    | 25.00 |
| Participant describes their main consideration as the cost of the treatment                                   | 9                | 18.00 | 4                         | 20.00 | 5                        | 16.67 | 2                     | 9.09  | 7                    | 25.00 |
| Participant describes considering the impact on their lifestyle, including work                               | 6                | 12.00 | 3                         | 15.00 | 3                        | 10.00 | 2                     | 9.09  | 4                    | 14.29 |
| Participant describes taking the advice from the specialist with no specific considerations                   | 5                | 10.00 | 2                         | 10.00 | 3                        | 10.00 | 2                     | 9.09  | 3                    | 10.71 |
| Participant describes considering their quality of life when deciding on a treatment                          | 5                | 10.00 | 0                         | 0.00  | 5                        | 16.67 | 1                     | 4.55  | 4                    | 14.29 |

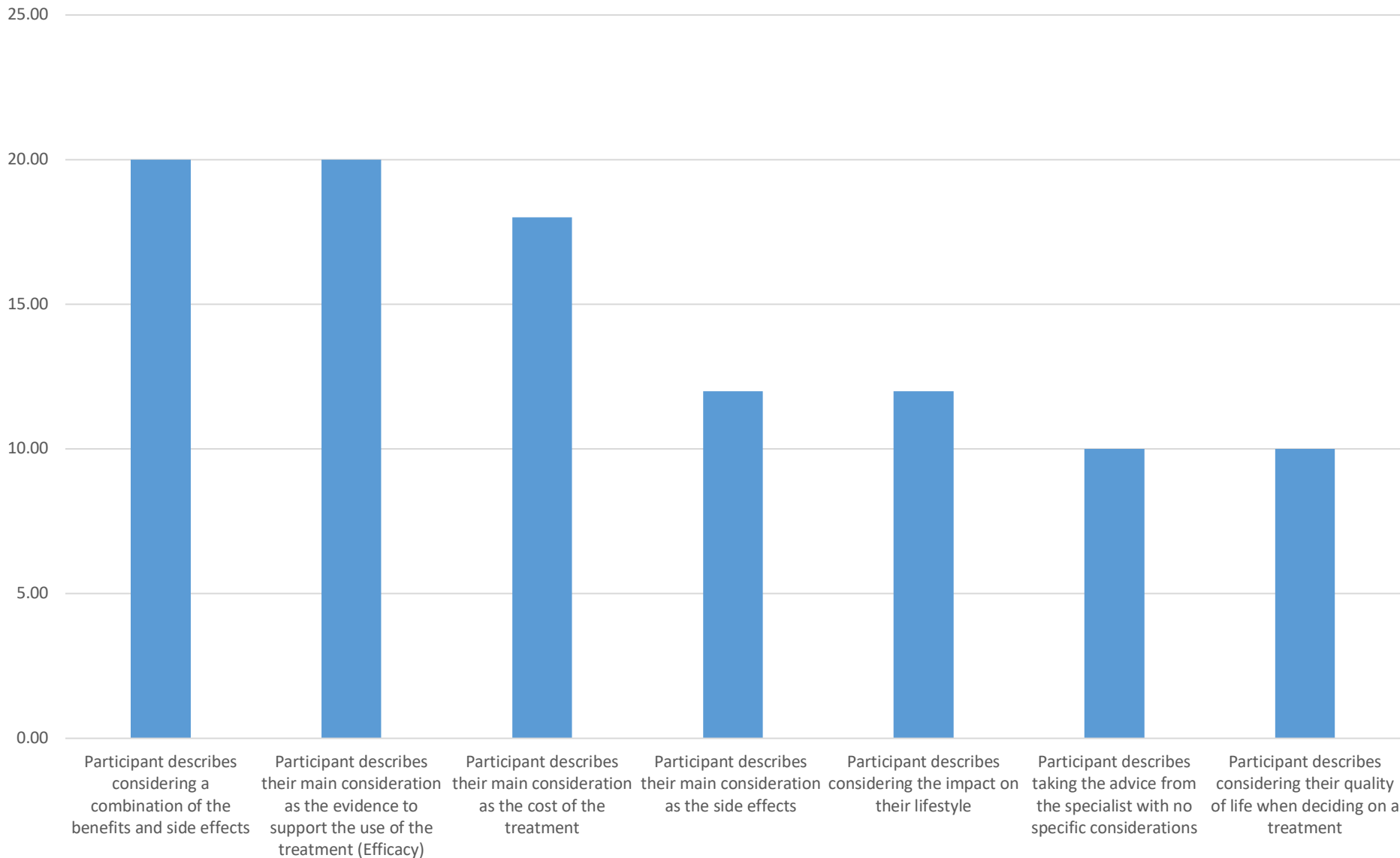


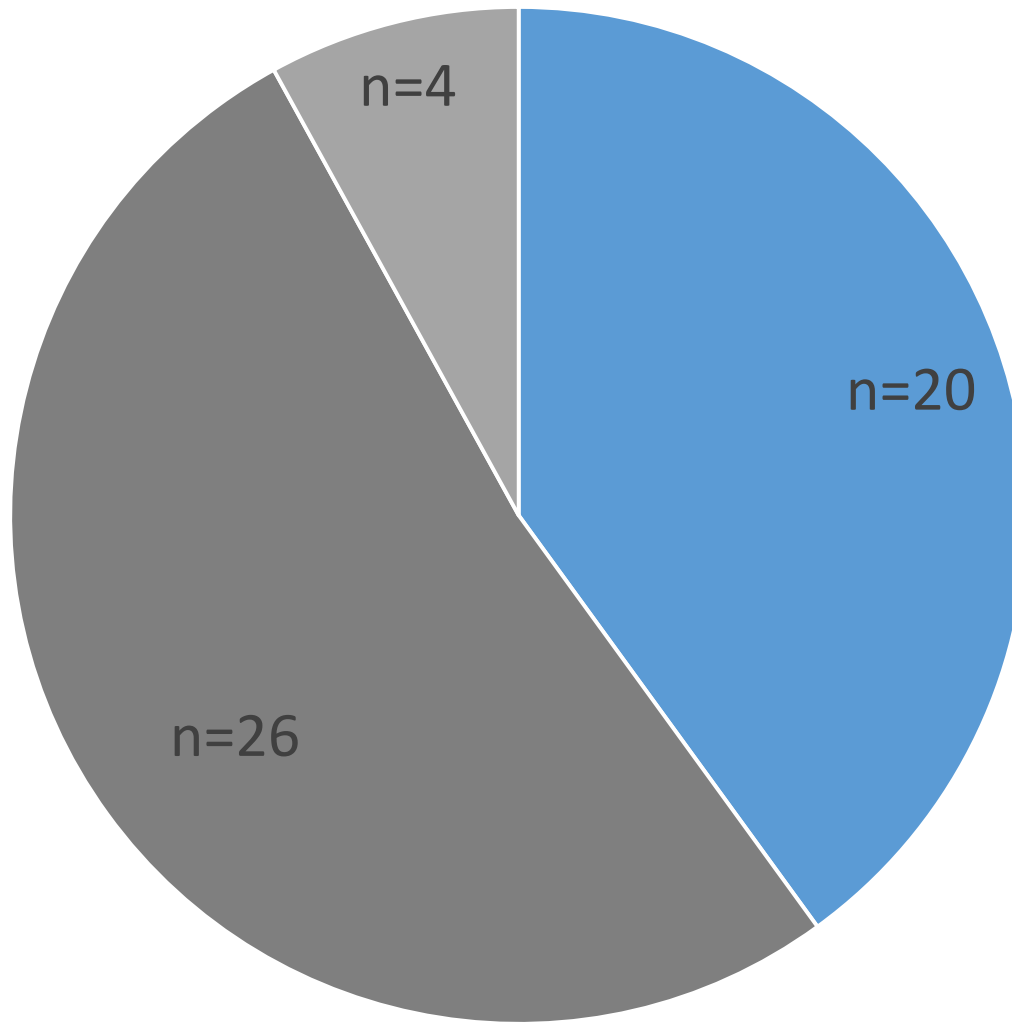
## Considerations when making decisions about treatment (Table d)

| Considerations when making decisions about treatment  | All participants |       | Under 18 |       | 24-44 |       | 45-54 |       | 55-64 |       | 65-74+ |       |
|---|------------------|-------|----------|-------|-------|-------|-------|-------|-------|-------|--------|-------|
|   | n=50             | %     | n=6      | %     | n=14  | %     | n=9   | %     | n=11  | %     | n=10   | %     |
| Participant describes considering a combination of the benefits and side effects                              | 10               | 20.00 | 3        | 50.00 | 4     | 28.57 | 1     | 11.11 | 1     | 9.09  | 1      | 10.00 |
| Participant describes their main consideration as the side effects  | 6                | 12.00 | 1        | 16.67 | 4     | 28.57 | 1     | 11.11 | 0     | 0.00  | 0      | 0.00  |
| Participant describes their main consideration as the evidence to support the use of the treatment (Efficacy) | 10               | 20.00 | 1        | 16.67 | 4     | 28.57 | 1     | 11.11 | 3     | 27.27 | 1      | 10.00 |
| Participant describes their main consideration as the cost of the treatment                                   | 9                | 18.00 | 2        | 33.33 | 4     | 28.57 | 1     | 11.11 | 1     | 9.09  | 1      | 10.00 |
| Participant describes considering the impact on their lifestyle, including work                               | 6                | 12.00 | 1        | 16.67 | 0     | 0.00  | 1     | 11.11 | 2     | 18.18 | 2      | 20.00 |
| Participant describes taking the advice from the specialist with no specific considerations                   | 5                | 10.00 | 0        | 0.00  | 1     | 7.14  | 1     | 11.11 | 2     | 18.18 | 1      | 10.00 |
| Participant describes considering their quality of life when deciding on a treatment                          | 5                | 10.00 | 1        | 16.67 | 2     | 14.29 | 0     | 0.00  | 1     | 9.09  | 1      | 10.00 |



## Considerations when making decisions about treatment (Table e)





■ No ■ Yes ■ Unsure



| Does decision-making change over time?   | All participants |       | Metropolitan |       | Rural |       | SEIFA (High) |       | SEIFA (Low) |       |
|--|------------------|-------|--------------|-------|-------|-------|--------------|-------|-------------|-------|
|  | n=50             | %     | n=30         | %     | n=20  | %     | n=27         | %     | n=23        | %     |
| Participant describes decision-making changing as they have become more informed                     | 11               | 22.00 | 5            | 16.67 | 6     | 30.00 | 5            | 18.52 | 6           | 26.09 |
| Participant describes decision-making changing as they consider quality of life more                 | 7                | 14.00 | 2            | 6.67  | 5     | 25.00 | 2            | 7.41  | 5           | 21.74 |
| Participant describes decision-making not changing as they have not been given any treatment options | 5                | 10.00 | 3            | 10.00 | 2     | 10.00 | 2            | 7.41  | 3           | 13.04 |



| Does decision-making change over time?   | All participants |       | High school or trade |       | University |       | Hearing impairment |       | Eye or visual impairment |       |
|--|------------------|-------|----------------------|-------|------------|-------|--------------------|-------|--------------------------|-------|
|  | n=50             | %     | n=26                 | %     | n=24       | %     | n=24               | %     | n=34                     | %     |
| Participant describes decision-making changing as they have become more informed                     | 11               | 22.00 | 5                    | 19.23 | 6          | 25.00 | 5                  | 20.83 | 8                        | 23.53 |
| Participant describes decision-making changing as they consider quality of life more                 | 7                | 14.00 | 3                    | 11.54 | 4          | 16.67 | 5                  | 20.83 | 5                        | 14.71 |
| Participant describes decision-making not changing as they have not been given any treatment options | 5                | 10.00 | 3                    | 11.54 | 2          | 8.33  | 3                  | 12.50 | 5                        | 14.71 |



| Does decision-making change over time?   | All participants |       | Physical function (High) |       | Physical function (Low) |       | Emotional well-being (High) |       | Emotional well-being (Low) |       |
|--|------------------|-------|--------------------------|-------|-------------------------|-------|-----------------------------|-------|----------------------------|-------|
|  | n=50             | %     | n=22                     | %     | n=28                    | %     | n=26                        | %     | n=24                       | %     |
| Participant describes decision-making changing as they have become more informed                     | 11               | 22.00 | 7                        | 31.82 | 4                       | 14.29 | 4                           | 15.38 | 7                          | 29.17 |
| Participant describes decision-making changing as they consider quality of life more                 | 7                | 14.00 | 1                        | 4.55  | 6                       | 21.43 | 3                           | 11.54 | 4                          | 16.67 |
| Participant describes decision-making not changing as they have not been given any treatment options | 5                | 10.00 | 3                        | 13.64 | 2                       | 7.14  | 2                           | 7.69  | 3                          | 12.50 |



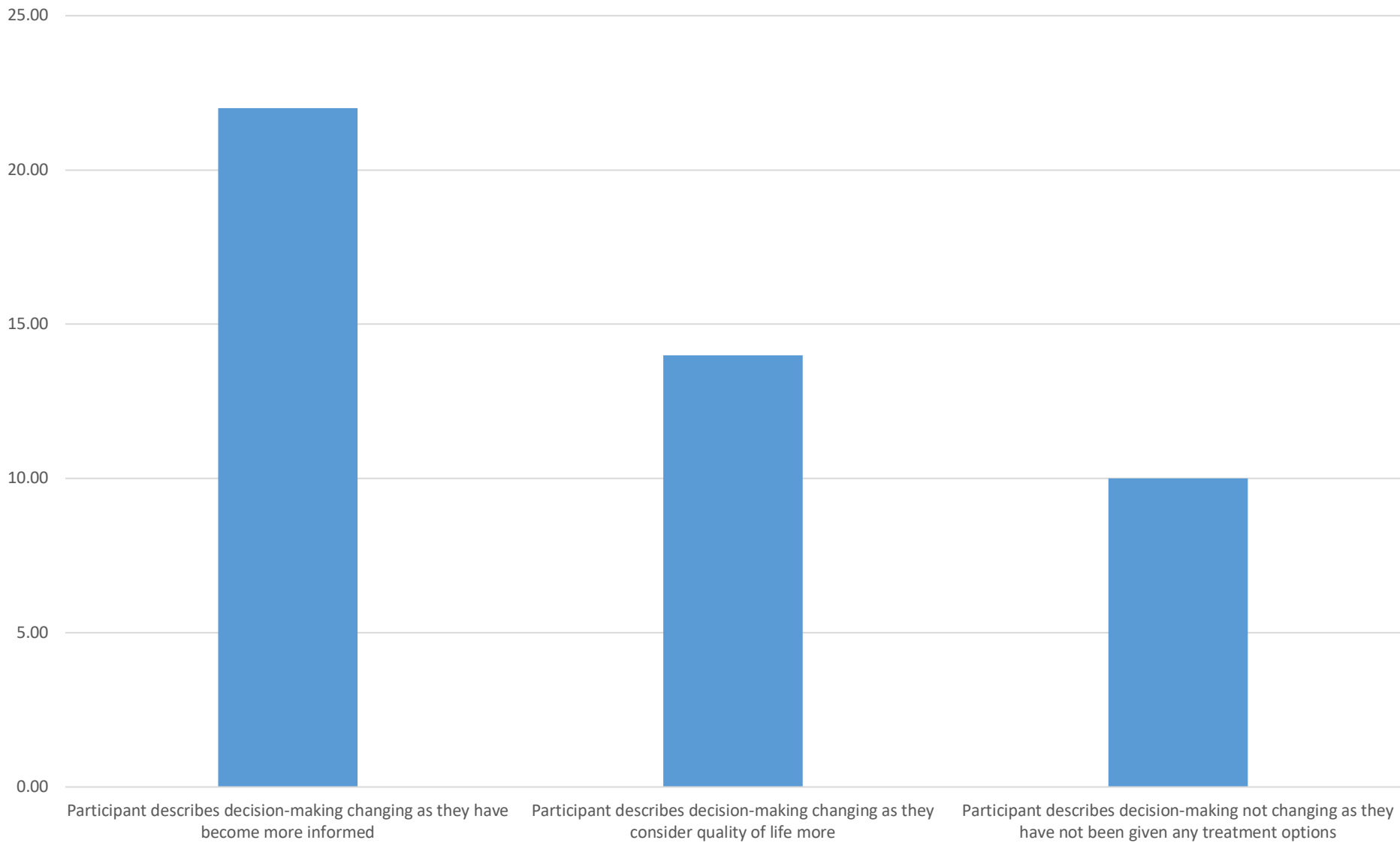
| Does decision-making change over time?   | All participants |       | Social functioning (High) |       | Social functioning (Low) |       | General health (High) |       | General health (Low) |       |
|--|------------------|-------|---------------------------|-------|--------------------------|-------|-----------------------|-------|----------------------|-------|
|  | n=50             | %     | n=20                      | %     | n=30                     | %     | n=22                  | %     | n=28                 | %     |
| Participant describes decision-making changing as they have become more informed                     | 11               | 22.00 | 6                         | 30.00 | 5                        | 16.67 | 3                     | 13.64 | 8                    | 28.57 |
| Participant describes decision-making changing as they consider quality of life more                 | 7                | 14.00 | 1                         | 5.00  | 6                        | 20.00 | 3                     | 13.64 | 4                    | 14.29 |
| Participant describes decision-making not changing as they have not been given any treatment options | 5                | 10.00 | 2                         | 10.00 | 3                        | 10.00 | 3                     | 13.64 | 2                    | 7.14  |





| Does decision-making change over time?   | All participants |       | Under 18 |       | 24-44 |       | 45-54 |       | 55-64 |       | 65-74+ |       |
|--|------------------|-------|----------|-------|-------|-------|-------|-------|-------|-------|--------|-------|
|  | n=50             | %     | n=6      | %     | n=14  | %     | n=9   | %     | n=11  | %     | n=10   | %     |
| Participant describes decision-making changing as they have become more informed                     | 11               | 22.00 | 1        | 16.67 | 2     | 14.29 | 5     | 55.56 | 3     | 27.27 | 0      | 0.00  |
| Participant describes decision-making changing as they consider quality of life more                 | 7                | 14.00 | 1        | 16.67 | 2     | 14.29 | 0     | 0.00  | 3     | 27.27 | 1      | 10.00 |
| Participant describes decision-making not changing as they have not been given any treatment options | 5                | 10.00 | 0        | 0.00  | 3     | 21.43 | 1     | 11.11 | 1     | 9.09  | 0      | 0.00  |





## Does decision-making change over time? (% of all participants)



The International Centre for Community-Driven Research

# SECTION 5: TREATMENT

| Description of mild side effects   | All participants |       | Metropolitan |       | Rural |       | SEIFA (High) |       | SEIFA (Low) |       |
|--|------------------|-------|--------------|-------|-------|-------|--------------|-------|-------------|-------|
|  | n=50             | %     | n=30         | %     | n=20  | %     | n=27         | %     | n=23        | %     |
| Participant describes mild side effects as those that do not greatly impact activities of daily living                                 | 11               | 22.00 | 8            | 26.67 | 3     | 15.00 | 7            | 25.93 | 4           | 17.39 |
| Participant describes mild side effects as headaches   | 7                | 14.00 | 4            | 13.33 | 3     | 15.00 | 3            | 11.11 | 4           | 17.39 |
| Participant describes gastrointestinal problems (diarrhoea and cramping) as mild side effects  | 6                | 12.00 | 4            | 13.33 | 2     | 10.00 | 4            | 14.81 | 2           | 8.70  |
| Participant does not describe a mild side effect but talks about mitochondrial disease being part of everyday life (Particularly pain) | 6                | 12.00 | 4            | 13.33 | 2     | 10.00 | 4            | 14.81 | 2           | 8.70  |
| Participant had not had any mild side effects and could not answer (N/A)   | 6                | 12.00 | 3            | 10.00 | 3     | 15.00 | 2            | 7.41  | 4           | 17.39 |
| Participant describes mild side effects as something temporary, you can overcome in a short time period                                | 5                | 10.00 | 4            | 13.33 | 1     | 5.00  | 3            | 11.11 | 2           | 8.70  |
| Participant describes increased fatigue (and related irritability) as a mild side effect   | 5                | 10.00 | 4            | 13.33 | 1     | 5.00  | 4            | 14.81 | 1           | 4.35  |



| Description of mild side effects   | All participants |       | High school or trade |       | University |       | Hearing impairment |       | Eye or visual impairment |       |
|--|------------------|-------|----------------------|-------|------------|-------|--------------------|-------|--------------------------|-------|
|  | n=50             | %     | n=26                 | %     | n=24       | %     | n=24               | %     | n=34                     | %     |
| Participant describes mild side effects as those that do not greatly impact activities of daily living                                 | 11               | 22.00 | 5                    | 19.23 | 6          | 25.00 | 3                  | 12.50 | 8                        | 23.53 |
| Participant describes mild side effects as headaches   | 7                | 14.00 | 4                    | 15.38 | 3          | 12.50 | 5                  | 20.83 | 4                        | 11.76 |
| Participant describes gastrointestinal problems (diarrhoea and cramping) as mild side effects  | 6                | 12.00 | 4                    | 15.38 | 2          | 8.33  | 3                  | 12.50 | 4                        | 11.76 |
| Participant does not describe a mild side effect but talks about mitochondrial disease being part of everyday life (Particularly pain) | 6                | 12.00 | 4                    | 15.38 | 2          | 8.33  | 1                  | 4.17  | 5                        | 14.71 |
| Participant had not had any mild side effects and could not answer (N/A)   | 6                | 12.00 | 4                    | 15.38 | 2          | 8.33  | 3                  | 12.50 | 5                        | 14.71 |
| Participant describes mild side effects as something temporary, you can overcome in a short time period                                | 5                | 10.00 | 2                    | 7.69  | 3          | 12.50 | 3                  | 12.50 | 2                        | 5.88  |
| Participant describes increased fatigue (and related irritability) as a mild side effect   | 5                | 10.00 | 4                    | 15.38 | 1          | 4.17  | 2                  | 8.33  | 3                        | 8.82  |



| Description of mild side effects   | All participants |       | Physical function (High) |       | Physical function (Low) |       | Emotional well-being (High) |       | Emotional well-being (Low) |       |
|--|------------------|-------|--------------------------|-------|-------------------------|-------|-----------------------------|-------|----------------------------|-------|
|  | n=50             | %     | n=22                     | %     | n=28                    | %     | n=26                        | %     | n=24                       | %     |
| Participant describes mild side effects as those that do not greatly impact activities of daily living                                 | 11               | 22.00 | 6                        | 27.27 | 5                       | 17.86 | 8                           | 30.77 | 3                          | 12.50 |
| Participant describes mild side effects as headaches   | 7                | 14.00 | 3                        | 13.64 | 4                       | 14.29 | 4                           | 15.38 | 3                          | 12.50 |
| Participant describes gastrointestinal problems (diarrhoea and cramping) as mild side effects  | 6                | 12.00 | 1                        | 4.55  | 5                       | 17.86 | 4                           | 15.38 | 2                          | 8.33  |
| Participant does not describe a mild side effect but talks about mitochondrial disease being part of everyday life (Particularly pain) | 6                | 12.00 | 2                        | 9.09  | 4                       | 14.29 | 2                           | 7.69  | 4                          | 16.67 |
| Participant had not had any mild side effects and could not answer (N/A)   | 6                | 12.00 | 2                        | 9.09  | 4                       | 14.29 | 3                           | 11.54 | 3                          | 12.50 |
| Participant describes mild side effects as something temporary, you can overcome in a short time period                                | 5                | 10.00 | 1                        | 4.55  | 4                       | 14.29 | 3                           | 11.54 | 2                          | 8.33  |
| Participant describes increased fatigue (and related irritability) as a mild side effect   | 5                | 10.00 | 3                        | 13.64 | 2                       | 7.14  | 3                           | 11.54 | 2                          | 8.33  |



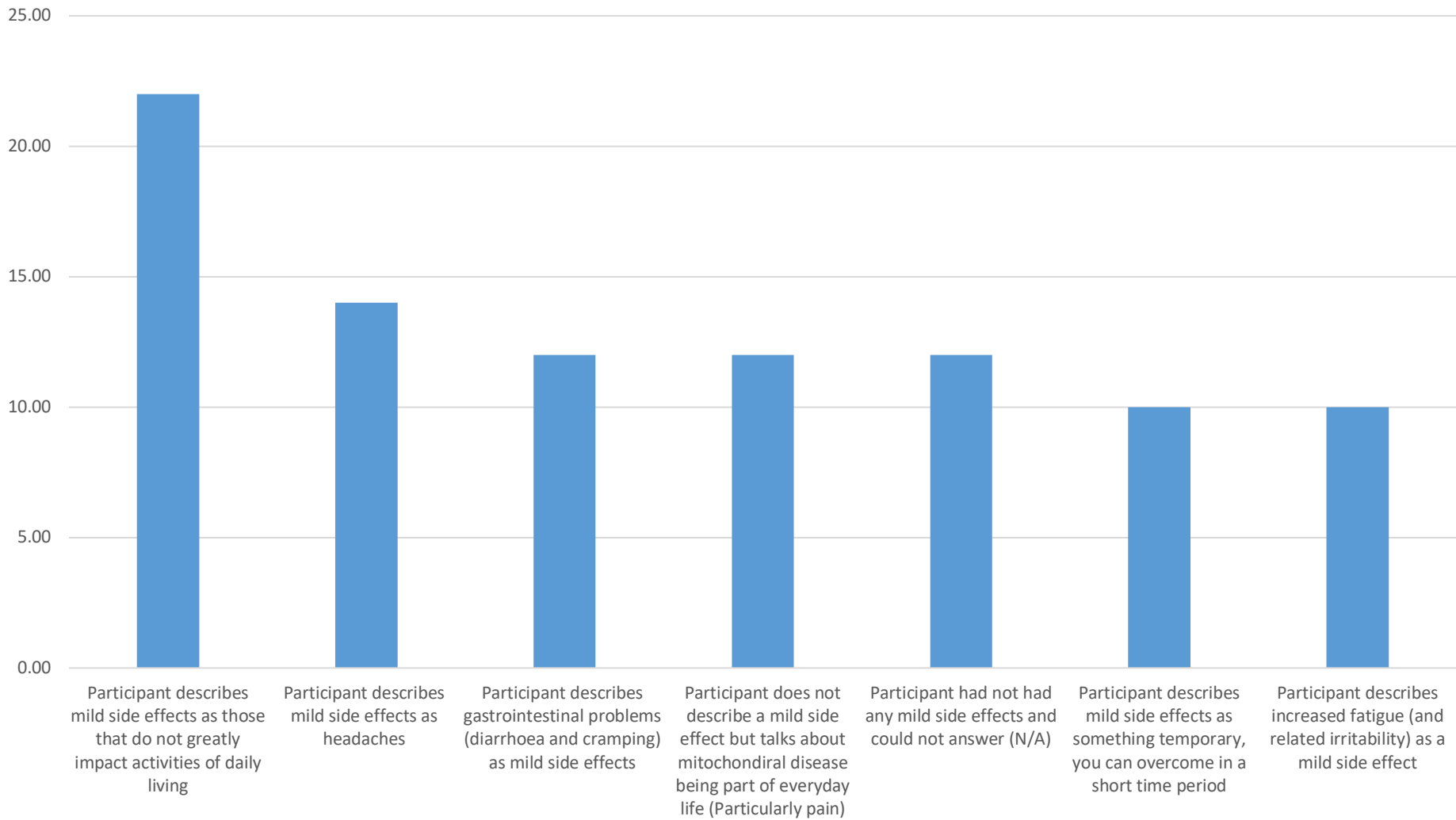
| Description of mild side effects   | All participants |       | Social functioning (High) |       | Social functioning (Low) |       | General health (High) |       | General health (Low) |       |
|--|------------------|-------|---------------------------|-------|--------------------------|-------|-----------------------|-------|----------------------|-------|
|  | n=50             | %     | n=20                      | %     | n=30                     | %     | n=22                  | %     | n=28                 | %     |
| Participant describes mild side effects as those that do not greatly impact activities of daily living                                 | 11               | 22.00 | 8                         | 40.00 | 3                        | 10.00 | 7                     | 31.82 | 4                    | 14.29 |
| Participant describes mild side effects as headaches   | 7                | 14.00 | 2                         | 10.00 | 5                        | 16.67 | 2                     | 9.09  | 5                    | 17.86 |
| Participant describes gastrointestinal problems (diarrhoea and cramping) as mild side effects  | 6                | 12.00 | 1                         | 5.00  | 5                        | 16.67 | 2                     | 9.09  | 4                    | 14.29 |
| Participant does not describe a mild side effect but talks about mitochondrial disease being part of everyday life (Particularly pain) | 6                | 12.00 | 0                         | 0.00  | 6                        | 20.00 | 2                     | 9.09  | 4                    | 14.29 |
| Participant had not had any mild side effects and could not answer (N/A)   | 6                | 12.00 | 2                         | 10.00 | 4                        | 13.33 | 3                     | 13.64 | 3                    | 10.71 |
| Participant describes mild side effects as something temporary, you can overcome in a short time period                                | 5                | 10.00 | 2                         | 10.00 | 3                        | 10.00 | 3                     | 13.64 | 2                    | 7.14  |
| Participant describes increased fatigue (and related irritability) as a mild side effect   | 5                | 10.00 | 3                         | 15.00 | 2                        | 6.67  | 3                     | 13.64 | 2                    | 7.14  |



| Description of mild side effects   | All participants |       | Under 18 |       | 24-44 |       | 45-54 |       | 55-64 |       | 65-74+ |       |
|--|------------------|-------|----------|-------|-------|-------|-------|-------|-------|-------|--------|-------|
|  | n=50             | %     | n=6      | %     | n=14  | %     | n=9   | %     | n=11  | %     | n=10   | %     |
| Participant describes mild side effects as those that do not greatly impact activities of daily living                                 | 11               | 22.00 | 2        | 33.33 | 2     | 14.29 | 5     | 55.56 | 1     | 9.09  | 1      | 10.00 |
| Participant describes mild side effects as headaches   | 7                | 14.00 | 1        | 16.67 | 3     | 21.43 | 0     | 0.00  | 2     | 18.18 | 1      | 10.00 |
| Participant describes gastrointestinal problems (diarrhoea and cramping) as mild side effects  | 6                | 12.00 | 2        | 33.33 | 4     | 28.57 | 0     | 0.00  | 0     | 0.00  | 0      | 0.00  |
| Participant does not describe a mild side effect but talks about mitochondrial disease being part of everyday life (Particularly pain) | 6                | 12.00 | 0        | 0.00  | 0     | 0.00  | 0     | 0.00  | 4     | 36.36 | 2      | 20.00 |
| Participant had not had any mild side effects and could not answer (N/A)   | 6                | 12.00 | 1        | 16.67 | 1     | 7.14  | 1     | 11.11 | 1     | 9.09  | 2      | 20.00 |
| Participant describes mild side effects as something temporary, you can overcome in a short time period                                | 5                | 10.00 | 0        | 0.00  | 2     | 14.29 | 2     | 22.22 | 0     | 0.00  | 1      | 10.00 |
| Participant describes increased fatigue (and related irritability) as a mild side effect   | 5                | 10.00 | 2        | 33.33 | 1     | 7.14  | 0     | 0.00  | 0     | 0.00  | 2      | 20.00 |







| Description of severe side effects  | All participants |       | Metropolitan |       | Rural |       | SEIFA (High) |       | SEIFA (Low) |       |
|---|------------------|-------|--------------|-------|-------|-------|--------------|-------|-------------|-------|
|   | n=50             | %     | n=30         | %     | n=20  | %     | n=27         | %     | n=23        | %     |
| Participant describes severe side effects as effects limiting their daily activities for an extended period of time   | 19               | 38.00 | 11           | 36.67 | 8     | 40.00 | 9            | 33.33 | 10          | 43.48 |
| Participant describes severe side effects as severe fatigue   | 9                | 18.00 | 4            | 13.33 | 5     | 25.00 | 5            | 18.52 | 4           | 17.39 |
| Participant describes severe side effects as an effect requiring hospitalisation or medical attention/permanent damage, or a life threatening effect or inability to function | 7                | 14.00 | 5            | 16.67 | 2     | 10.00 | 4            | 14.81 | 3           | 13.04 |
| Participant describes severe side effects as chronic headaches  | 4                | 8.00  | 2            | 6.67  | 2     | 10.00 | 2            | 7.41  | 2           | 8.70  |
| Participant describes severe side effects as loss of mobility or independence   | 4                | 8.00  | 1            | 3.33  | 3     | 15.00 | 2            | 7.41  | 2           | 8.70  |
| Participant describes severe side effects as diarrhoea or nausea that affects the whole body  | 3                | 6.00  | 1            | 3.33  | 2     | 10.00 | 1            | 3.70  | 2           | 8.70  |
| Participant describes severe side effects as cardiovascular issues such as shortness of breath and irregular heart rhythm   | 3                | 6.00  | 1            | 3.33  | 2     | 10.00 | 1            | 3.70  | 2           | 8.70  |



| Description of severe side effects  | All participants |       | High school or trade |       | University |       | Hearing impairment |       | Eye or visual impairment |       |
|---|------------------|-------|----------------------|-------|------------|-------|--------------------|-------|--------------------------|-------|
|   | n=50             | %     | n=26                 | %     | n=24       | %     | n=24               | %     | n=34                     | %     |
| Participant describes severe side effects as effects limiting their daily activities for an extended period of time   | 19               | 38.00 | 4                    | 15.38 | 15         | 62.50 | 12                 | 50.00 | 11                       | 32.35 |
| Participant describes severe side effects as severe fatigue   | 9                | 18.00 | 4                    | 15.38 | 5          | 20.83 | 4                  | 16.67 | 7                        | 20.59 |
| Participant describes severe side effects as an effect requiring hospitalisation or medical attention/permanent damage, or a life threatening effect or inability to function | 7                | 14.00 | 4                    | 15.38 | 3          | 12.50 | 5                  | 20.83 | 3                        | 8.82  |
| Participant describes severe side effects as chronic headaches  | 4                | 8.00  | 3                    | 11.54 | 1          | 4.17  | 2                  | 8.33  | 3                        | 8.82  |
| Participant describes severe side effects as loss of mobility or independence   | 4                | 8.00  | 2                    | 7.69  | 2          | 8.33  | 1                  | 4.17  | 3                        | 8.82  |
| Participant describes severe side effects as diarrhoea or nausea that affects the whole body  | 3                | 6.00  | 3                    | 11.54 | 0          | 0.00  | 1                  | 4.17  | 3                        | 8.82  |
| Participant describes severe side effects as cardiovascular issues such as shortness of breath and irregular heart rhythm   | 3                | 6.00  | 3                    | 11.54 | 0          | 0.00  | 0                  | 0.00  | 3                        | 8.82  |



| Description of severe side effects  | All participants |       | Physical function (High) |       | Physical function (Low) |       | Emotional well-being (High) |       | Emotional well-being (Low) |       |
|---|------------------|-------|--------------------------|-------|-------------------------|-------|-----------------------------|-------|----------------------------|-------|
|   | n=50             | %     | n=22                     | %     | n=28                    | %     | n=26                        | %     | n=24                       | %     |
| Participant describes severe side effects as effects limiting their daily activities for an extended period of time   | 19               | 38.00 | 12                       | 54.55 | 7                       | 25.00 | 11                          | 42.31 | 8                          | 33.33 |
| Participant describes severe side effects as severe fatigue   | 9                | 18.00 | 5                        | 22.73 | 4                       | 14.29 | 5                           | 19.23 | 4                          | 16.67 |
| Participant describes severe side effects as an effect requiring hospitalisation or medical attention/permanent damage, or a life threatening effect or inability to function | 7                | 14.00 | 1                        | 4.55  | 6                       | 21.43 | 3                           | 11.54 | 4                          | 16.67 |
| Participant describes severe side effects as chronic headaches  | 4                | 8.00  | 2                        | 9.09  | 2                       | 7.14  | 1                           | 3.85  | 3                          | 12.50 |
| Participant describes severe side effects as loss of mobility or independence   | 4                | 8.00  | 0                        | 0.00  | 4                       | 14.29 | 2                           | 7.69  | 2                          | 8.33  |
| Participant describes severe side effects as diarrhoea or nausea that affects the whole body  | 3                | 6.00  | 0                        | 0.00  | 3                       | 10.71 | 1                           | 3.85  | 2                          | 8.33  |
| Participant describes severe side effects as cardiovascular issues such as shortness of breath and irregular heart rhythm   | 3                | 6.00  | 1                        | 4.55  | 2                       | 7.14  | 2                           | 7.69  | 1                          | 4.17  |

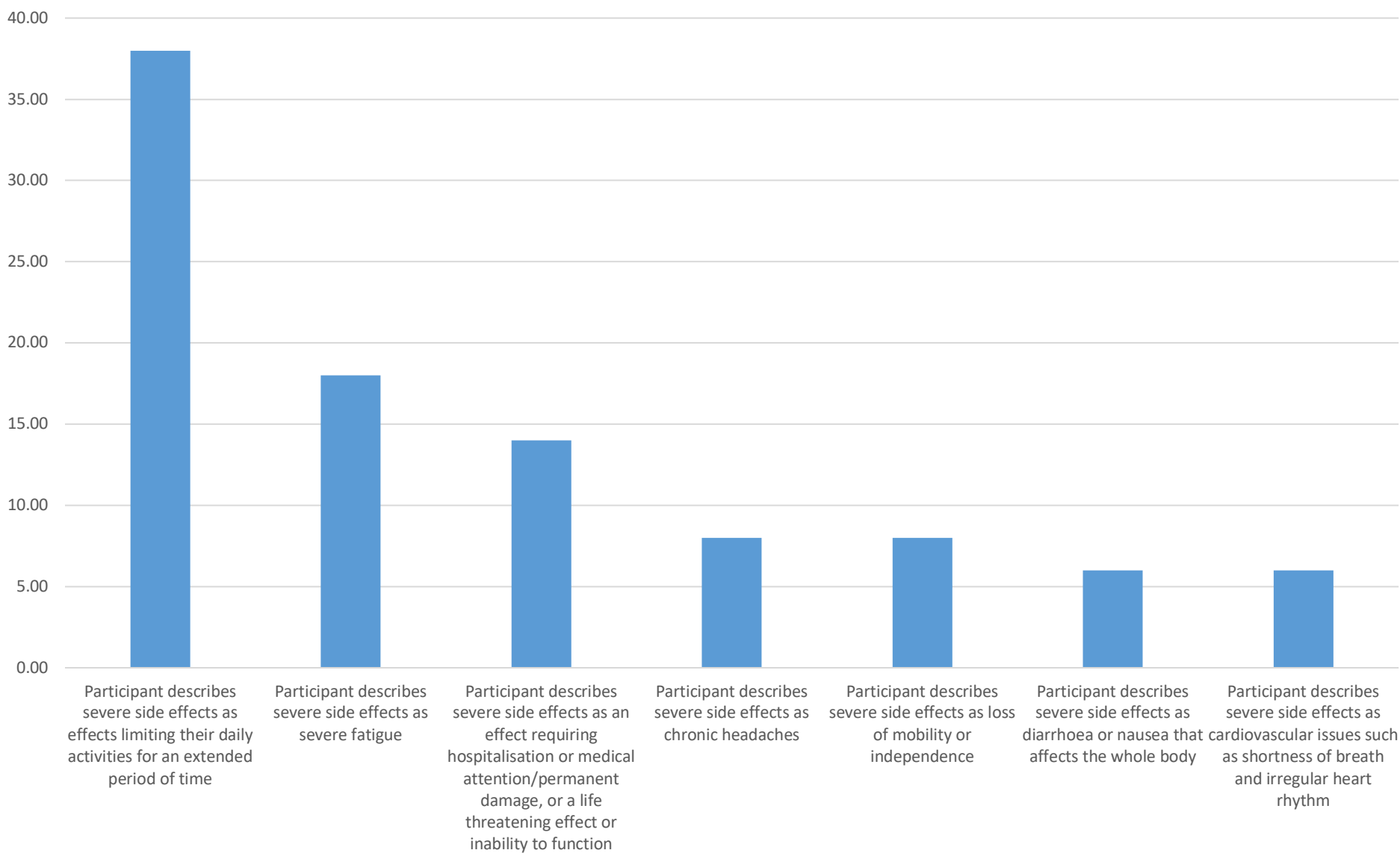


| Description of severe side effects  | All participants |       | Social functioning (High) |       | Social functioning (Low) |       | General health (High) |       | General health (Low) |       |
|---|------------------|-------|---------------------------|-------|--------------------------|-------|-----------------------|-------|----------------------|-------|
|   | n=50             | %     | n=20                      | %     | n=30                     | %     | n=22                  | %     | n=28                 | %     |
| Participant describes severe side effects as effects limiting their daily activities for an extended period of time   | 19               | 38.00 | 11                        | 55.00 | 8                        | 26.67 | 11                    | 50.00 | 8                    | 28.57 |
| Participant describes severe side effects as severe fatigue   | 9                | 18.00 | 5                         | 25.00 | 4                        | 13.33 | 5                     | 22.73 | 4                    | 14.29 |
| Participant describes severe side effects as an effect requiring hospitalisation or medical attention/permanent damage, or a life threatening effect or inability to function | 7                | 14.00 | 1                         | 5.00  | 6                        | 20.00 | 0                     | 0.00  | 7                    | 25.00 |
| Participant describes severe side effects as chronic headaches  | 4                | 8.00  | 2                         | 10.00 | 2                        | 6.67  | 0                     | 0.00  | 4                    | 14.29 |
| Participant describes severe side effects as loss of mobility or independence   | 4                | 8.00  | 1                         | 5.00  | 3                        | 10.00 | 2                     | 9.09  | 2                    | 7.14  |
| Participant describes severe side effects as diarrhoea or nausea that affects the whole body  | 3                | 6.00  | 1                         | 5.00  | 2                        | 6.67  | 1                     | 4.55  | 2                    | 7.14  |
| Participant describes severe side effects as cardiovascular issues such as shortness of breath and irregular heart rhythm   | 3                | 6.00  | 1                         | 5.00  | 2                        | 6.67  | 2                     | 9.09  | 1                    | 3.57  |



| Description of severe side effects  | All participants |       | Under 18 |       | 24-44 |       | 45-54 |       | 55-64 |       | 65-74+ |       |
|---|------------------|-------|----------|-------|-------|-------|-------|-------|-------|-------|--------|-------|
|   | n=50             | %     | n=6      | %     | n=14  | %     | n=9   | %     | n=11  | %     | n=10   | %     |
| Participant describes severe side effects as effects limiting their daily activities for an extended period of time   | 19               | 38.00 | 1        | 16.67 | 7     | 50.00 | 5     | 55.56 | 3     | 27.27 | 3      | 30.00 |
| Participant describes severe side effects as severe fatigue   | 9                | 18.00 | 1        | 16.67 | 2     | 14.29 | 1     | 11.11 | 4     | 36.36 | 1      | 10.00 |
| Participant describes severe side effects as an effect requiring hospitalisation or medical attention/permanent damage, or a life threatening effect or inability to function | 7                | 14.00 | 1        | 16.67 | 3     | 21.43 | 1     | 11.11 | 1     | 9.09  | 1      | 10.00 |
| Participant describes severe side effects as chronic headaches  | 4                | 8.00  | 0        | 0.00  | 1     | 7.14  | 1     | 11.11 | 1     | 9.09  | 1      | 10.00 |
| Participant describes severe side effects as loss of mobility or independence   | 4                | 8.00  | 1        | 16.67 | 1     | 7.14  | 0     | 0.00  | 1     | 9.09  | 1      | 10.00 |
| Participant describes severe side effects as diarrhoea or nausea that affects the whole body  | 3                | 6.00  | 0        | 0.00  | 1     | 7.14  | 1     | 11.11 | 0     | 0.00  | 1      | 10.00 |
| Participant describes severe side effects as cardiovascular issues such as shortness of breath and irregular heart rhythm   | 3                | 6.00  | 1        | 16.67 | 1     | 7.14  | 0     | 0.00  | 1     | 9.09  | 0      | 0.00  |





## Description of severe side effects (% of all participants)



| Use of complementary therapies   | All participants |       | Metropolitan |       | Rural |       | SEIFA (High) |       | SEIFA (Low) |       |
|--|------------------|-------|--------------|-------|-------|-------|--------------|-------|-------------|-------|
|  | n=50             | %     | n=30         | %     | n=20  | %     | n=27         | %     | n=23        | %     |
| Participant describes taking vitamin, mineral and various supplements  | 14               | 28.00 | 7            | 23.33 | 7     | 35.00 | 9            | 33.33 | 5           | 21.74 |
| Participant describes having a form of allied health e.g. physiotherapy (including massage and hydrotherapy), speech therapy, occupational therapy | 14               | 28.00 | 9            | 30.00 | 5     | 25.00 | 7            | 25.93 | 7           | 30.43 |
| Participant describes having a form of alternative medicine, e.g. osteopathy, acupuncture, chiropractor, Bowen therapy                             | 12               | 24.00 | 7            | 23.33 | 5     | 25.00 | 5            | 18.52 | 7           | 30.43 |
| Participant describes not trying any complementary medicines   | 11               | 22.00 | 8            | 26.67 | 3     | 15.00 | 7            | 25.93 | 4           | 17.39 |





| Use of complementary therapies   | All participants |       | High school or trade |       | University |       | Hearing impairment |       | Eye or visual impairment |       |
|--|------------------|-------|----------------------|-------|------------|-------|--------------------|-------|--------------------------|-------|
|  | n=50             | %     | n=26                 | %     | n=24       | %     | n=24               | %     | n=34                     | %     |
| Participant describes taking vitamin, mineral and various supplements  | 14               | 28.00 | 8                    | 30.77 | 6          | 25.00 | 5                  | 20.83 | 9                        | 26.47 |
| Participant describes having a form of allied health e.g. physiotherapy (including massage and hydrotherapy), speech therapy, occupational therapy | 14               | 28.00 | 6                    | 23.08 | 8          | 33.33 | 6                  | 25.00 | 12                       | 35.29 |
| Participant describes having a form of alternative medicine, e.g. osteopathy, acupuncture, chiropractor, Bowen therapy                             | 12               | 24.00 | 6                    | 23.08 | 6          | 25.00 | 6                  | 25.00 | 9                        | 26.47 |
| Participant describes not trying any complementary medicines   | 11               | 22.00 | 5                    | 19.23 | 6          | 25.00 | 6                  | 25.00 | 6                        | 17.65 |



| Use of complementary therapies   | All participants |       | Physical function (High) |       | Physical function (Low) |       | Emotional well-being (High) |       | Emotional well-being (Low) |       |
|--|------------------|-------|--------------------------|-------|-------------------------|-------|-----------------------------|-------|----------------------------|-------|
|  | n=50             | %     | n=22                     | %     | n=28                    | %     | n=26                        | %     | n=24                       | %     |
| Participant describes taking vitamin, mineral and various supplements  | 14               | 28.00 | 5                        | 22.73 | 9                       | 32.14 | 9                           | 34.62 | 5                          | 20.83 |
| Participant describes having a form of allied health e.g. physiotherapy (including massage and hydrotherapy), speech therapy, occupational therapy | 14               | 28.00 | 5                        | 22.73 | 9                       | 32.14 | 7                           | 26.92 | 7                          | 29.17 |
| Participant describes having a form of alternative medicine, e.g. osteopathy, acupuncture, chiropractor, Bowen therapy                             | 12               | 24.00 | 7                        | 31.82 | 5                       | 17.86 | 6                           | 23.08 | 6                          | 25.00 |
| Participant describes not trying any complementary medicines   | 11               | 22.00 | 5                        | 22.73 | 6                       | 21.43 | 5                           | 19.23 | 6                          | 25.00 |



| Use of complementary therapies   | All participants |       | Social functioning (High) |       | Social functioning (Low) |       | General health (High) |       | General health (Low) |       |
|--|------------------|-------|---------------------------|-------|--------------------------|-------|-----------------------|-------|----------------------|-------|
|  | n=50             | %     | n=20                      | %     | n=30                     | %     | n=22                  | %     | n=28                 | %     |
| Participant describes taking vitamin, mineral and various supplements  | 14               | 28.00 | 5                         | 25.00 | 9                        | 30.00 | 7                     | 31.82 | 7                    | 25.00 |
| Participant describes having a form of allied health e.g. physiotherapy (including massage and hydrotherapy), speech therapy, occupational therapy | 14               | 28.00 | 7                         | 35.00 | 7                        | 23.33 | 4                     | 18.18 | 10                   | 35.71 |
| Participant describes having a form of alternative medicine, e.g. osteopathy, acupuncture, chiropractor, Bowen therapy                             | 12               | 24.00 | 5                         | 25.00 | 7                        | 23.33 | 6                     | 27.27 | 6                    | 21.43 |
| Participant describes not trying any complementary medicines   | 11               | 22.00 | 4                         | 20.00 | 7                        | 23.33 | 6                     | 27.27 | 5                    | 17.86 |



| Use of complementary therapies   | All participants |       | Under 18 |       | 24-44 |       | 45-54 |       | 55-64 |       | 65-74+ |       |
|--|------------------|-------|----------|-------|-------|-------|-------|-------|-------|-------|--------|-------|
|  | n=50             | %     | n=6      | %     | n=14  | %     | n=9   | %     | n=11  | %     | n=10   | %     |
| Participant describes taking vitamin, mineral and various supplements  | 14               | 28.00 | 2        | 33.33 | 4     | 28.57 | 0     | 0.00  | 5     | 45.45 | 3      | 30.00 |
| Participant describes having a form of allied health e.g. physiotherapy (including massage and hydrotherapy), speech therapy, occupational therapy | 14               | 28.00 | 2        | 33.33 | 6     | 42.86 | 2     | 22.22 | 2     | 18.18 | 2      | 20.00 |
| Participant describes having a form of alternative medicine, e.g. osteopathy, acupuncture, chiropractor, Bowen therapy                             | 12               | 24.00 | 3        | 50.00 | 4     | 28.57 | 1     | 11.11 | 1     | 9.09  | 3      | 30.00 |
| Participant describes not trying any complementary medicines   | 11               | 22.00 | 1        | 16.67 | 1     | 7.14  | 4     | 44.44 | 2     | 18.18 | 3      | 30.00 |



30.00

25.00

20.00

15.00

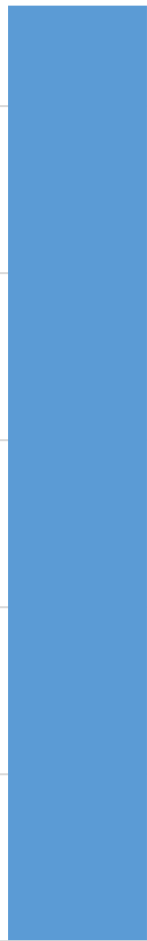
10.00

5.00

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Participant describes taking vitamin, mineral and various supplements



Participant describes having a form of allied health e.g. physiotherapy (including massage and hydrotherapy), speech therapy, occupational therapy



Participant describes having a form of alternative medicine, e.g. osteopathy, acupuncture, chiropractor, Bowen therapy



Participant describes not trying any complementary medicines



| Adherence to treatment   | All participants |       | Metropolitan |       | Rural |       | SEIFA (High) |       | SEIFA (Low) |       |
|--|------------------|-------|--------------|-------|-------|-------|--------------|-------|-------------|-------|
|  | n=50             | %     | n=30         | %     | n=20  | %     | n=27         | %     | n=23        | %     |
| Participant describes using treatment for a period of one to three months before deciding if its working   | 24               | 48.00 | 15           | 50.00 | 9     | 45.00 | 11           | 40.74 | 13          | 56.52 |
| Participant describes continuing a treatment indefinitely or as recommended by clinician/specialist  | 9                | 18.00 | 3            | 10.00 | 6     | 30.00 | 5            | 18.52 | 4           | 17.39 |
| Participant describes not trying new medications for mitochondrial disease and such not knowing how long they would continue a treatment           | 6                | 12.00 | 5            | 16.67 | 1     | 5.00  | 5            | 18.52 | 1           | 4.35  |
| Participant describes the time period varying depending on what the treatment is, however if it is causing severe discomfort then they would cease | 4                | 8.00  | 4            | 13.33 | 0     | 0.00  | 3            | 11.11 | 1           | 4.35  |
| Participant describes continuing a treatment indefinitely unless there is a severe reaction  | 2                | 4.00  | 1            | 3.33  | 1     | 5.00  | 2            | 7.41  | 0           | 0.00  |



| Adherence to treatment   | All participants |       | High school or trade |       | University |       | Hearing impairment |       | Eye or visual impairment |       |
|--|------------------|-------|----------------------|-------|------------|-------|--------------------|-------|--------------------------|-------|
|  | n=50             | %     | n=26                 | %     | n=24       | %     | n=24               | %     | n=34                     | %     |
| Participant describes using treatment for a period of one to three months before deciding if its working   | 24               | 48.00 | 13                   | 50.00 | 11         | 45.83 | 7                  | 29.17 | 18                       | 52.94 |
| Participant describes continuing a treatment indefinitely or as recommended by clinician/specialist  | 9                | 18.00 | 3                    | 11.54 | 6          | 25.00 | 7                  | 29.17 | 7                        | 20.59 |
| Participant describes not trying new medications for mitochondrial disease and such not knowing how long they would continue a treatment           | 6                | 12.00 | 3                    | 11.54 | 3          | 12.50 | 3                  | 12.50 | 4                        | 11.76 |
| Participant describes the time period varying depending on what the treatment is, however if it is causing severe discomfort then they would cease | 4                | 8.00  | 3                    | 11.54 | 1          | 4.17  | 2                  | 8.33  | 2                        | 5.88  |
| Participant describes continuing a treatment indefinitely unless there is a severe reaction  | 2                | 4.00  | 1                    | 3.85  | 1          | 4.17  | 2                  | 8.33  | 1                        | 2.94  |



| Adherence to treatment   | All participants |       | Physical function (High) |       | Physical function (Low) |       | Emotional well-being (High) |       | Emotional well-being (Low) |       |
|--|------------------|-------|--------------------------|-------|-------------------------|-------|-----------------------------|-------|----------------------------|-------|
|  | n=50             | %     | n=22                     | %     | n=28                    | %     | n=26                        | %     | n=24                       | %     |
| Participant describes using treatment for a period of one to three months before deciding if its working   | 24               | 48.00 | 10                       | 45.45 | 14                      | 50.00 | 15                          | 57.69 | 9                          | 37.50 |
| Participant describes continuing a treatment indefinitely or as recommended by clinician/specialist  | 9                | 18.00 | 6                        | 27.27 | 3                       | 10.71 | 6                           | 23.08 | 3                          | 12.50 |
| Participant describes not trying new medications for mitochondrial disease and such not knowing how long they would continue a treatment           | 6                | 12.00 | 2                        | 9.09  | 4                       | 14.29 | 3                           | 11.54 | 3                          | 12.50 |
| Participant describes the time period varying depending on what the treatment is, however if it is causing severe discomfort then they would cease | 4                | 8.00  | 2                        | 9.09  | 2                       | 7.14  | 1                           | 3.85  | 3                          | 12.50 |
| Participant describes continuing a treatment indefinitely unless there is a severe reaction  | 2                | 4.00  | 2                        | 9.09  | 0                       | 0.00  | 1                           | 3.85  | 1                          | 4.17  |



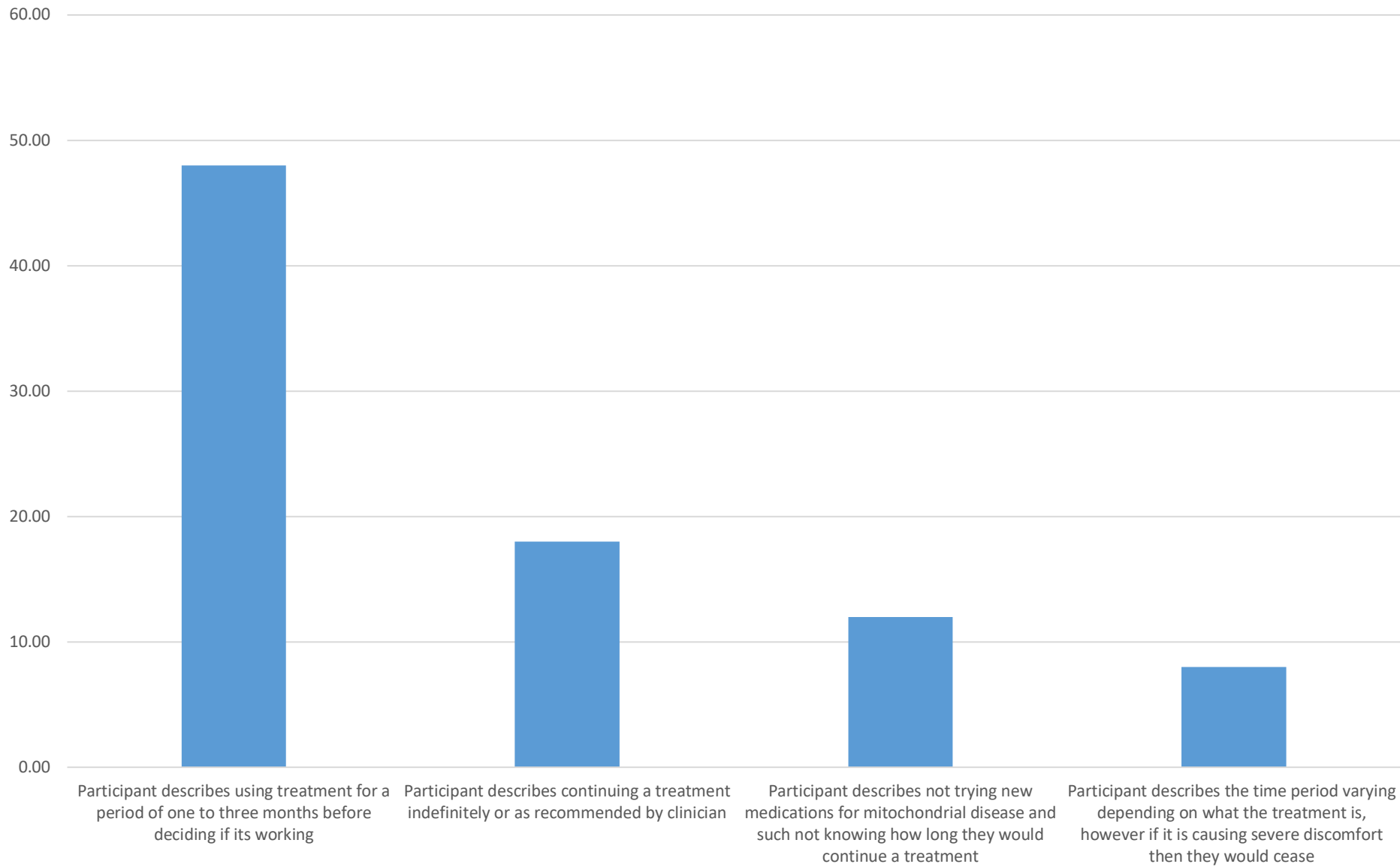


| Adherence to treatment   | All participants |       | Social functioning (High) |       | Social functioning (Low) |       | General health (High) |       | General health (Low) |       |
|--|------------------|-------|---------------------------|-------|--------------------------|-------|-----------------------|-------|----------------------|-------|
|  | n=50             | %     | n=20                      | %     | n=30                     | %     | n=22                  | %     | n=28                 | %     |
| Participant describes using treatment for a period of one to three months before deciding if its working   | 24               | 48.00 | 12                        | 60.00 | 12                       | 40.00 | 13                    | 59.09 | 11                   | 39.29 |
| Participant describes continuing a treatment indefinitely or as recommended by clinician/specialist  | 9                | 18.00 | 5                         | 25.00 | 4                        | 13.33 | 5                     | 22.73 | 4                    | 14.29 |
| Participant describes not trying new medications for mitochondrial disease and such not knowing how long they would continue a treatment           | 6                | 12.00 | 2                         | 10.00 | 4                        | 13.33 | 2                     | 9.09  | 4                    | 14.29 |
| Participant describes the time period varying depending on what the treatment is, however if it is causing severe discomfort then they would cease | 4                | 8.00  | 0                         | 0.00  | 4                        | 13.33 | 1                     | 4.55  | 3                    | 10.71 |
| Participant describes continuing a treatment indefinitely unless there is a severe reaction  | 2                | 4.00  | 2                         | 10.00 | 0                        | 0.00  | 1                     | 4.55  | 1                    | 3.57  |



| Adherence to treatment   | All participants |       | Under 18 |       | 24-44 |       | 45-54 |       | 55-64 |       | 65-74+ |       |
|--|------------------|-------|----------|-------|-------|-------|-------|-------|-------|-------|--------|-------|
|  | n=50             | %     | n=6      | %     | n=14  | %     | n=9   | %     | n=11  | %     | n=10   | %     |
| Participant describes using treatment for a period of one to three months before deciding if its working   | 24               | 48.00 | 3        | 50.00 | 7     | 50.00 | 4     | 44.44 | 5     | 45.45 | 5      | 50.00 |
| Participant describes continuing a treatment indefinitely or as recommended by clinician/specialist  | 9                | 18.00 | 1        | 16.67 | 4     | 28.57 | 2     | 22.22 | 1     | 9.09  | 1      | 10.00 |
| Participant describes not trying new medications for mitochondrial disease and such not knowing how long they would continue a treatment           | 6                | 12.00 | 0        | 0.00  | 1     | 7.14  | 1     | 11.11 | 3     | 27.27 | 1      | 10.00 |
| Participant describes the time period varying depending on what the treatment is, however if it is causing severe discomfort then they would cease | 4                | 8.00  | 2        | 33.33 | 1     | 7.14  | 0     | 0.00  | 0     | 0.00  | 1      | 10.00 |
| Participant describes continuing a treatment indefinitely unless there is a severe reaction  | 2                | 4.00  | 0        | 0.00  | 0     | 0.00  | 0     | 0.00  | 1     | 9.09  | 1      | 10.00 |





| What needs to change to feel like treatment is effective   | All participants |       | Metropolitan |       | Rural |       | SEIFA (High) |       | SEIFA (Low) |       |
|--|------------------|-------|--------------|-------|-------|-------|--------------|-------|-------------|-------|
|  | n=50             | %     | n=30         | %     | n=20  | %     | n=27         | %     | n=23        | %     |
| Participant describes needing to feel more energetic, and increase in physical ability, to know a treatment is working | 20               | 40.00 | 8            | 26.67 | 12    | 60.00 | 7            | 25.93 | 13          | 56.52 |
| Participant describes improved symptoms by clinical measurement (test result)  | 13               | 26.00 | 9            | 30.00 | 4     | 20.00 | 9            | 33.33 | 4           | 17.39 |
| Participant describes needing to generally feel better to know that a treatment is working                             | 9                | 18.00 | 7            | 23.33 | 2     | 10.00 | 6            | 22.22 | 3           | 13.04 |
| Participant describes needing to reduce pain to know a treatment is working  | 5                | 10.00 | 1            | 3.33  | 4     | 20.00 | 1            | 3.70  | 4           | 17.39 |
| Participant describes needing to improve their quality of life to know a treatment is working                          | 5                | 10.00 | 3            | 10.00 | 2     | 10.00 | 3            | 11.11 | 2           | 8.70  |



## What needs to change to feel like treatment is effective (Table a)

| What needs to change to feel like treatment is effective   | All participants |       | High school or trade |       | University |       | Hearing impairment |       | Eye or visual impairment |       |
|--|------------------|-------|----------------------|-------|------------|-------|--------------------|-------|--------------------------|-------|
|  | n=50             | %     | n=26                 | %     | n=24       | %     | n=24               | %     | n=34                     | %     |
| Participant describes needing to feel more energetic, and increase in physical ability, to know a treatment is working | 20               | 40.00 | 10                   | 38.46 | 10         | 41.67 | 8                  | 33.33 | 17                       | 50.00 |
| Participant describes improved symptoms by clinical measurement (test result)  | 13               | 26.00 | 5                    | 19.23 | 8          | 33.33 | 10                 | 41.67 | 6                        | 17.65 |
| Participant describes needing to generally feel better to know that a treatment is working                             | 9                | 18.00 | 5                    | 19.23 | 4          | 16.67 | 4                  | 16.67 | 7                        | 20.59 |
| Participant describes needing to reduce pain to know a treatment is working  | 5                | 10.00 | 3                    | 11.54 | 2          | 8.33  | 3                  | 12.50 | 2                        | 5.88  |
| Participant describes needing to improve their quality of life to know a treatment is working                          | 5                | 10.00 | 2                    | 7.69  | 3          | 12.50 | 3                  | 12.50 | 2                        | 5.88  |



## What needs to change to feel like treatment is effective (Table b)

| What needs to change to feel like treatment is effective   | All participants |       | Physical function (High) |       | Physical function (Low) |       | Emotional well-being (High) |       | Emotional well-being (Low) |       |
|--|------------------|-------|--------------------------|-------|-------------------------|-------|-----------------------------|-------|----------------------------|-------|
|  | n=50             | %     | n=22                     | %     | n=28                    | %     | n=26                        | %     | n=24                       | %     |
| Participant describes needing to feel more energetic, and increase in physical ability, to know a treatment is working | 20               | 40.00 | 7                        | 31.82 | 13                      | 46.43 | 12                          | 46.15 | 8                          | 33.33 |
| Participant describes improved symptoms by clinical measurement (test result)  | 13               | 26.00 | 7                        | 31.82 | 6                       | 21.43 | 9                           | 34.62 | 4                          | 16.67 |
| Participant describes needing to generally feel better to know that a treatment is working                             | 9                | 18.00 | 7                        | 31.82 | 2                       | 7.14  | 7                           | 26.92 | 2                          | 8.33  |
| Participant describes needing to reduce pain to know a treatment is working  | 5                | 10.00 | 3                        | 13.64 | 2                       | 7.14  | 1                           | 3.85  | 4                          | 16.67 |
| Participant describes needing to improve their quality of life to know a treatment is working                          | 5                | 10.00 | 0                        | 0.00  | 5                       | 17.86 | 2                           | 7.69  | 3                          | 12.50 |



## What needs to change to feel like treatment is effective (Table c)

| What needs to change to feel like treatment is effective   | All participants |       | Social functioning (High) |       | Social functioning (Low) |       | General health (High) |       | General health (Low) |       |
|--|------------------|-------|---------------------------|-------|--------------------------|-------|-----------------------|-------|----------------------|-------|
|  | n=50             | %     | n=20                      | %     | n=30                     | %     | n=22                  | %     | n=28                 | %     |
| Participant describes needing to feel more energetic, and increase in physical ability, to know a treatment is working | 20               | 40.00 | 10                        | 50.00 | 10                       | 33.33 | 7                     | 31.82 | 13                   | 46.43 |
| Participant describes improved symptoms by clinical measurement (test result)  | 13               | 26.00 | 6                         | 30.00 | 7                        | 23.33 | 6                     | 27.27 | 7                    | 25.00 |
| Participant describes needing to generally feel better to know that a treatment is working                             | 9                | 18.00 | 5                         | 25.00 | 4                        | 13.33 | 4                     | 18.18 | 5                    | 17.86 |
| Participant describes needing to reduce pain to know a treatment is working  | 5                | 10.00 | 1                         | 5.00  | 4                        | 13.33 | 2                     | 9.09  | 3                    | 10.71 |
| Participant describes needing to improve their quality of life to know a treatment is working                          | 5                | 10.00 | 0                         | 0.00  | 5                        | 16.67 | 1                     | 4.55  | 4                    | 14.29 |



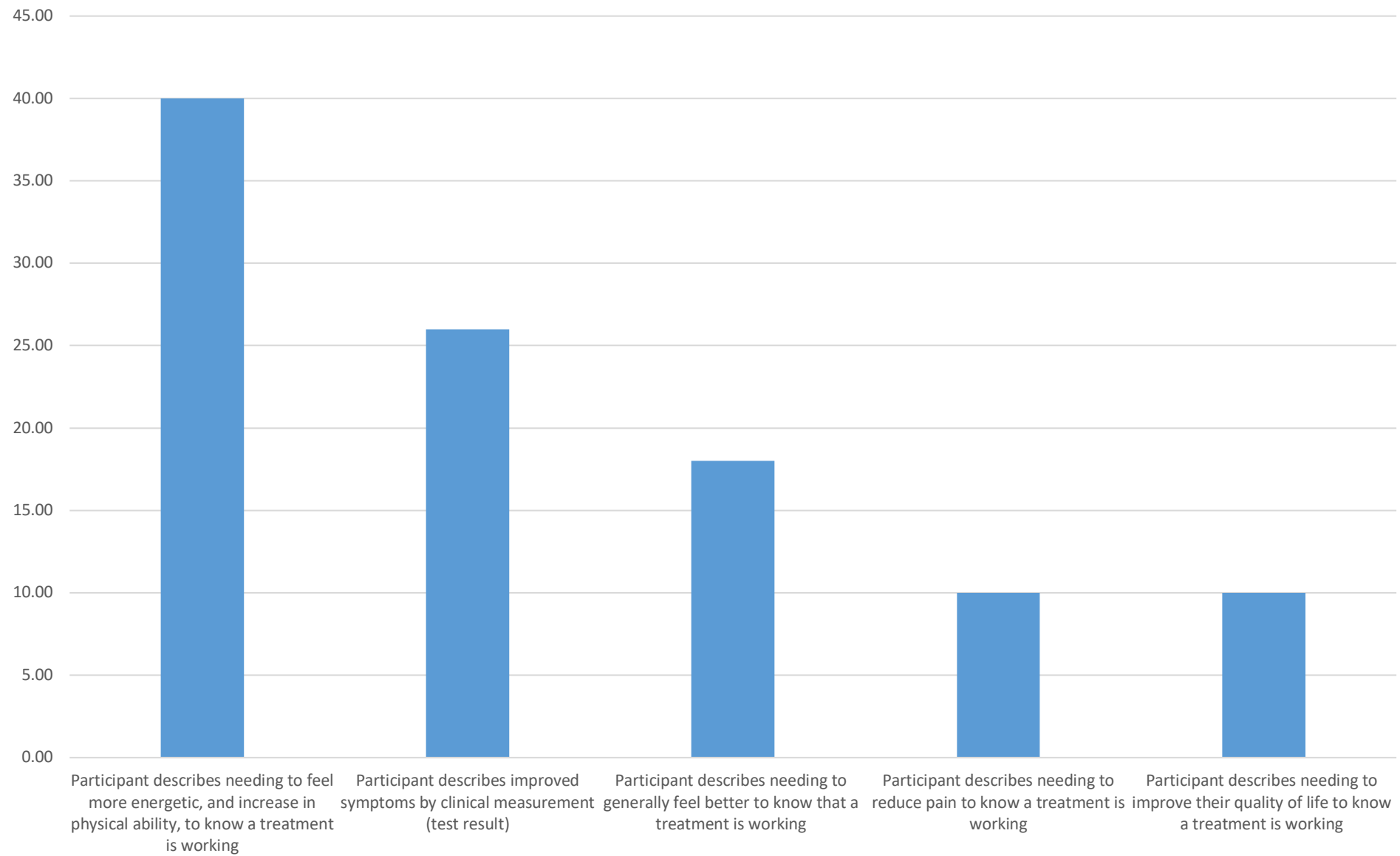
## What needs to change to feel like treatment is effective (Table d)

| What needs to change to feel like treatment is effective   | All participants |       | Under 18 |       | 24-44 |       | 45-54 |       | 55-64 |       | 65-74+ |       |
|--|------------------|-------|----------|-------|-------|-------|-------|-------|-------|-------|--------|-------|
|  | n=50             | %     | n=6      | %     | n=14  | %     | n=9   | %     | n=11  | %     | n=10   | %     |
| Participant describes needing to feel more energetic, and increase in physical ability, to know a treatment is working | 20               | 40.00 | 3        | 50.00 | 5     | 35.71 | 5     | 55.56 | 4     | 36.36 | 3      | 30.00 |
| Participant describes improved symptoms by clinical measurement (test result)  | 13               | 26.00 | 0        | 0.00  | 3     | 21.43 | 5     | 55.56 | 3     | 27.27 | 2      | 20.00 |
| Participant describes needing to generally feel better to know that a treatment is working                             | 9                | 18.00 | 2        | 33.33 | 4     | 28.57 | 2     | 22.22 | 1     | 9.09  | 0      | 0.00  |
| Participant describes needing to reduce pain to know a treatment is working  | 5                | 10.00 | 0        | 0.00  | 1     | 7.14  | 1     | 11.11 | 1     | 9.09  | 2      | 20.00 |
| Participant describes needing to improve their quality of life to know a treatment is working                          | 5                | 10.00 | 1        | 16.67 | 3     | 21.43 | 0     | 0.00  | 1     | 9.09  | 0      | 0.00  |



## What needs to change to feel like treatment is effective (Table e)







## SECTION 6: COMMUNICATION & INFORMATION

| Information accessed  | All participants |       | Metropolitan |       | Rural |       | SEIFA (High) |       | SEIFA (Low) |       |
|---|------------------|-------|--------------|-------|-------|-------|--------------|-------|-------------|-------|
|   | n=50             | %     | n=30         | %     | n=20  | %     | n=27         | %     | n=23        | %     |
| Participant describes accessing information from the Australian Mitochondrial Disease Foundation              | 32               | 64.00 | 17           | 56.67 | 15    | 75.00 | 16           | 59.26 | 16          | 69.57 |
| Participant describes accessing information from the internet (general searching e.g. google)                 | 25               | 50.00 | 12           | 40.00 | 13    | 65.00 | 10           | 37.04 | 15          | 65.22 |
| Participant describes accessing medical journals, peer reviewed papers  | 14               | 28.00 | 11           | 36.67 | 3     | 15.00 | 9            | 33.33 | 5           | 21.74 |
| Participant describes accessing information from their clinician  | 13               | 26.00 | 9            | 30.00 | 4     | 20.00 | 9            | 33.33 | 4           | 17.39 |
| Participant describes accessing information from online forums for mitochondrial disease (including Facebook) | 7                | 14.00 | 4            | 13.33 | 3     | 15.00 | 1            | 3.70  | 6           | 26.09 |
| Participant describes accessing information from mitochondrial foundations websites                           | 6                | 12.00 | 4            | 13.33 | 2     | 10.00 | 3            | 11.11 | 3           | 13.04 |



| Information accessed  | All participants |       | High school or trade |       | University |       | Hearing impairment |       | Eye or visual impairment |       |
|---|------------------|-------|----------------------|-------|------------|-------|--------------------|-------|--------------------------|-------|
|   | n=50             | %     | n=26                 | %     | n=24       | %     | n=24               | %     | n=34                     | %     |
| Participant describes accessing information from the Australian Mitochondrial Disease Foundation              | 32               | 64.00 | 20                   | 76.92 | 12         | 50.00 | 16                 | 66.67 | 24                       | 70.59 |
| Participant describes accessing information from the internet (general searching e.g. google)                 | 25               | 50.00 | 14                   | 53.85 | 11         | 45.83 | 13                 | 54.17 | 20                       | 58.82 |
| Participant describes accessing medical journals, peer reviewed papers  | 14               | 28.00 | 6                    | 23.08 | 8          | 33.33 | 6                  | 25.00 | 7                        | 20.59 |
| Participant describes accessing information from their clinician  | 13               | 26.00 | 6                    | 23.08 | 7          | 29.17 | 6                  | 25.00 | 7                        | 20.59 |
| Participant describes accessing information from online forums for mitochondrial disease (including Facebook) | 7                | 14.00 | 3                    | 11.54 | 4          | 16.67 | 3                  | 12.50 | 6                        | 17.65 |
| Participant describes accessing information from mitochondrial foundations websites                           | 6                | 12.00 | 3                    | 11.54 | 3          | 12.50 | 2                  | 8.33  | 5                        | 14.71 |



| Information accessed  | All participants |       | Physical function (High) |       | Physical function (Low) |       | Emotional well-being (High) |       | Emotional well-being (Low) |       |
|---|------------------|-------|--------------------------|-------|-------------------------|-------|-----------------------------|-------|----------------------------|-------|
|   | n=50             | %     | n=22                     | %     | n=28                    | %     | n=26                        | %     | n=24                       | %     |
| Participant describes accessing information from the Australian Mitochondrial Disease Foundation              | 32               | 64.00 | 11                       | 50.00 | 21                      | 75.00 | 14                          | 53.85 | 18                         | 75.00 |
| Participant describes accessing information from the internet (general searching e.g. google)                 | 25               | 50.00 | 15                       | 68.18 | 10                      | 35.71 | 12                          | 46.15 | 13                         | 54.17 |
| Participant describes accessing medical journals, peer reviewed papers  | 14               | 28.00 | 4                        | 18.18 | 10                      | 35.71 | 6                           | 23.08 | 8                          | 33.33 |
| Participant describes accessing information from their clinician  | 13               | 26.00 | 5                        | 22.73 | 8                       | 28.57 | 8                           | 30.77 | 5                          | 20.83 |
| Participant describes accessing information from online forums for mitochondrial disease (including Facebook) | 7                | 14.00 | 5                        | 22.73 | 2                       | 7.14  | 4                           | 15.38 | 3                          | 12.50 |
| Participant describes accessing information from mitochondrial foundations websites                           | 6                | 12.00 | 2                        | 9.09  | 4                       | 14.29 | 2                           | 7.69  | 4                          | 16.67 |

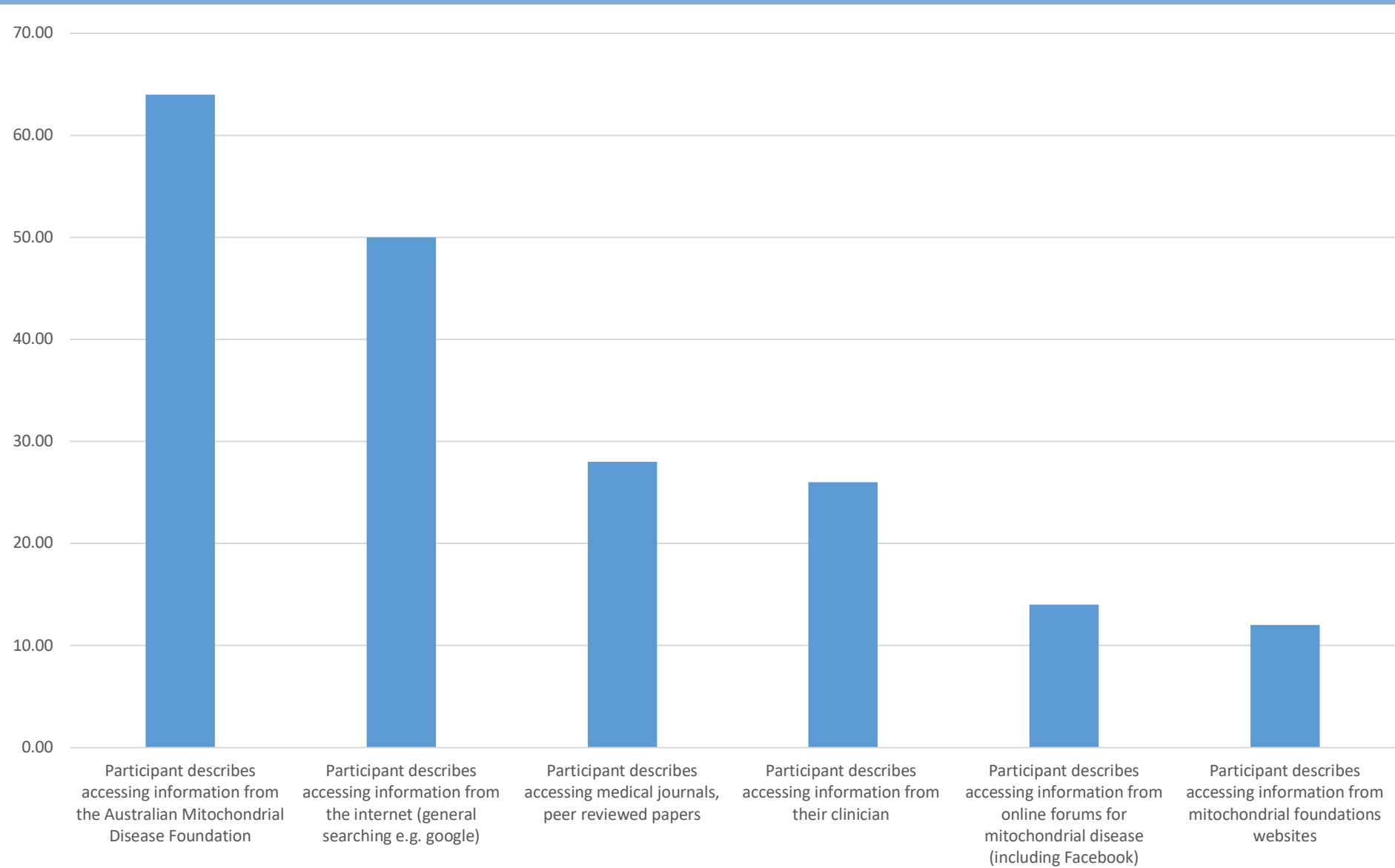


| Information accessed  | All participants |       | Social functioning (High) |       | Social functioning (Low) |       | General health (High) |       | General health (Low) |       |
|---|------------------|-------|---------------------------|-------|--------------------------|-------|-----------------------|-------|----------------------|-------|
|   | n=50             | %     | n=20                      | %     | n=30                     | %     | n=22                  | %     | n=28                 | %     |
| Participant describes accessing information from the Australian Mitochondrial Disease Foundation              | 32               | 64.00 | 12                        | 60.00 | 20                       | 66.67 | 11                    | 50.00 | 21                   | 75.00 |
| Participant describes accessing information from the internet (general searching e.g. google)                 | 25               | 50.00 | 11                        | 55.00 | 14                       | 46.67 | 13                    | 59.09 | 12                   | 42.86 |
| Participant describes accessing medical journals, peer reviewed papers  | 14               | 28.00 | 4                         | 20.00 | 10                       | 33.33 | 4                     | 18.18 | 10                   | 35.71 |
| Participant describes accessing information from their clinician  | 13               | 26.00 | 6                         | 30.00 | 7                        | 23.33 | 7                     | 31.82 | 6                    | 21.43 |
| Participant describes accessing information from online forums for mitochondrial disease (including Facebook) | 7                | 14.00 | 4                         | 20.00 | 3                        | 10.00 | 3                     | 13.64 | 4                    | 14.29 |
| Participant describes accessing information from mitochondrial foundations websites                           | 6                | 12.00 | 4                         | 20.00 | 2                        | 6.67  | 1                     | 4.55  | 5                    | 17.86 |



| Information accessed  | All participants |       | Under 18 |       | 24-44 |       | 45-54 |       | 55-64 |       | 65-74+ |       |
|---|------------------|-------|----------|-------|-------|-------|-------|-------|-------|-------|--------|-------|
|   | n=50             | %     | n=6      | %     | n=14  | %     | n=9   | %     | n=11  | %     | n=10   | %     |
| Participant describes accessing information from the Australian Mitochondrial Disease Foundation              | 32               | 64.00 | 5        | 83.33 | 5     | 35.71 | 7     | 77.78 | 6     | 54.55 | 9      | 90.00 |
| Participant describes accessing information from the internet (general searching e.g. google)                 | 25               | 50.00 | 1        | 16.67 | 8     | 57.14 | 5     | 55.56 | 8     | 72.73 | 3      | 30.00 |
| Participant describes accessing medical journals, peer reviewed papers  | 14               | 28.00 | 2        | 33.33 | 6     | 42.86 | 1     | 11.11 | 3     | 27.27 | 2      | 20.00 |
| Participant describes accessing information from their clinician  | 13               | 26.00 | 2        | 33.33 | 4     | 28.57 | 2     | 22.22 | 2     | 18.18 | 3      | 30.00 |
| Participant describes accessing information from online forums for mitochondrial disease (including Facebook) | 7                | 14.00 | 0        | 0.00  | 5     | 35.71 | 1     | 11.11 | 1     | 9.09  | 0      | 0.00  |
| Participant describes accessing information from mitochondrial foundations websites                           | 6                | 12.00 | 0        | 0.00  | 1     | 7.14  | 2     | 22.22 | 1     | 9.09  | 2      | 20.00 |







| Information that has been helpful   | All participants |       | Metropolitan |       | Rural |       | SEIFA (High) |       | SEIFA (Low) |       |
|---|------------------|-------|--------------|-------|-------|-------|--------------|-------|-------------|-------|
|   | n=50             | %     | n=30         | %     | n=20  | %     | n=27         | %     | n=23        | %     |
| Participant describes the AMDF as being helpful   | 9                | 18.00 | 5            | 16.67 | 4     | 20.00 | 4            | 14.81 | 5           | 21.74 |
| Participant describes no information being specifically helpful                           | 8                | 16.00 | 4            | 13.33 | 4     | 20.00 | 3            | 11.11 | 5           | 21.74 |
| Participant describes current research papers as being helpful                            | 7                | 14.00 | 5            | 16.67 | 2     | 10.00 | 5            | 18.52 | 2           | 8.70  |
| Participant describes communicating with others with mitochondrial disease as most useful | 7                | 14.00 | 4            | 13.33 | 3     | 15.00 | 3            | 11.11 | 4           | 17.39 |
| Participant describes information form clinical team as being helpful                     | 5                | 10.00 | 4            | 13.33 | 1     | 5.00  | 4            | 14.81 | 1           | 4.35  |



| Information that has been helpful   | All participants |       | High school or trade |       | University |       | Hearing impairment |       | Eye or visual impairment |       |
|---|------------------|-------|----------------------|-------|------------|-------|--------------------|-------|--------------------------|-------|
|   | n=50             | %     | n=26                 | %     | n=24       | %     | n=24               | %     | n=34                     | %     |
| Participant describes the AMDF as being helpful   | 9                | 18.00 | 3                    | 11.54 | 6          | 25.00 | 5                  | 20.83 | 7                        | 20.59 |
| Participant describes no information being specifically helpful                           | 8                | 16.00 | 6                    | 23.08 | 2          | 8.33  | 4                  | 16.67 | 5                        | 14.71 |
| Participant describes current research papers as being helpful                            | 7                | 14.00 | 3                    | 11.54 | 4          | 16.67 | 2                  | 8.33  | 5                        | 14.71 |
| Participant describes communicating with others with mitochondrial disease as most useful | 7                | 14.00 | 4                    | 15.38 | 3          | 12.50 | 2                  | 8.33  | 5                        | 14.71 |
| Participant describes information form clinical team as being helpful                     | 5                | 10.00 | 2                    | 7.69  | 3          | 12.50 | 2                  | 8.33  | 2                        | 5.88  |



| Information that has been helpful   | All participants |       | Physical function (High) |       | Physical function (Low) |       | Emotional well-being (High) |       | Emotional well-being (Low) |       |
|---|------------------|-------|--------------------------|-------|-------------------------|-------|-----------------------------|-------|----------------------------|-------|
|   | n=50             | %     | n=22                     | %     | n=28                    | %     | n=26                        | %     | n=24                       | %     |
| Participant describes the AMDF as being helpful   | 9                | 18.00 | 5                        | 22.73 | 4                       | 14.29 | 5                           | 19.23 | 4                          | 16.67 |
| Participant describes no information being specifically helpful                           | 8                | 16.00 | 4                        | 18.18 | 4                       | 14.29 | 3                           | 11.54 | 5                          | 20.83 |
| Participant describes current research papers as being helpful                            | 7                | 14.00 | 3                        | 13.64 | 4                       | 14.29 | 6                           | 23.08 | 1                          | 4.17  |
| Participant describes communicating with others with mitochondrial disease as most useful | 7                | 14.00 | 3                        | 13.64 | 4                       | 14.29 | 4                           | 15.38 | 3                          | 12.50 |
| Participant describes information from clinical team as being helpful                     | 5                | 10.00 | 4                        | 18.18 | 1                       | 3.57  | 3                           | 11.54 | 2                          | 8.33  |

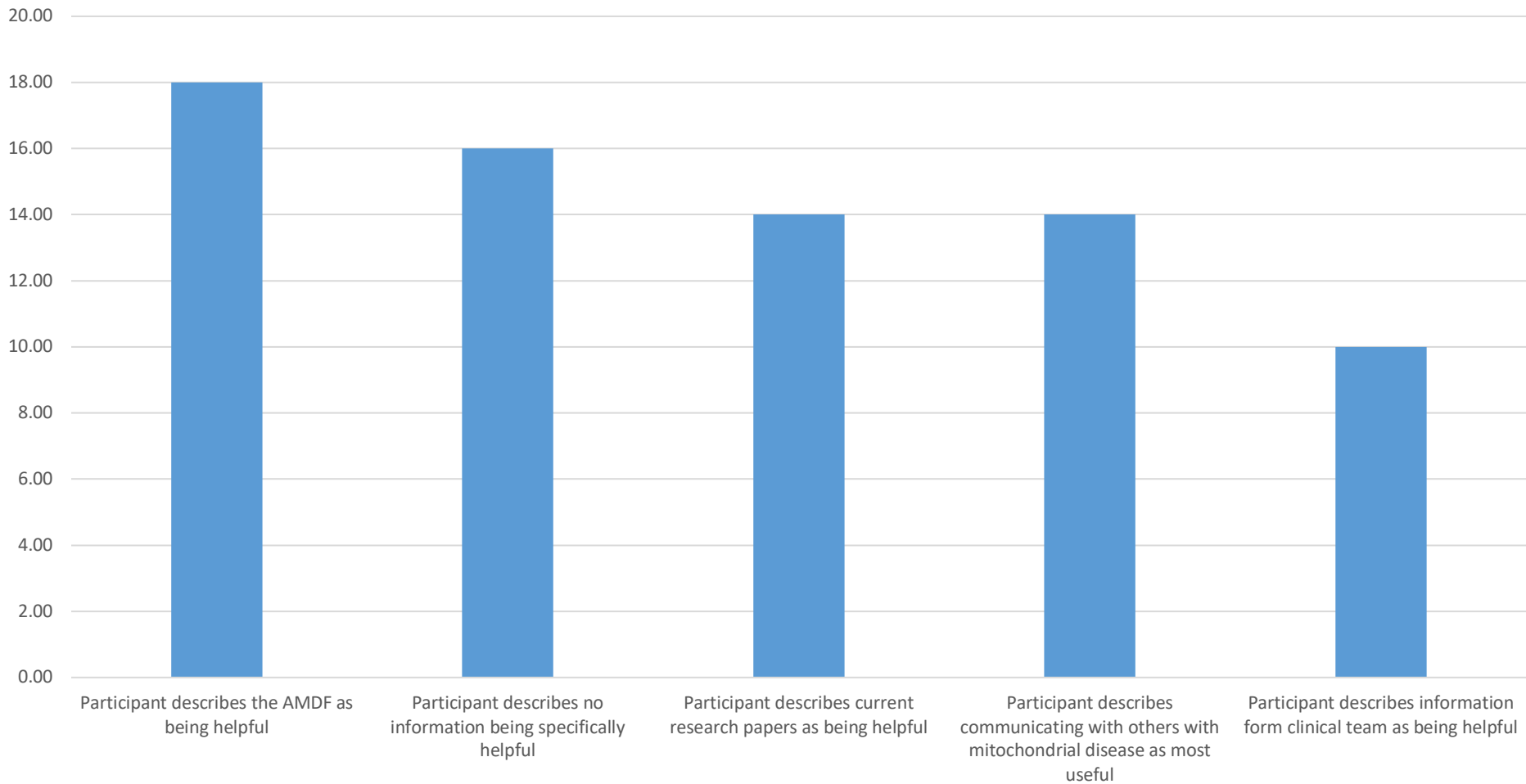


| Information that has been helpful   | All participants |       | Social functioning (High) |       | Social functioning (Low) |       | General health (High) |       | General health (Low) |       |
|---|------------------|-------|---------------------------|-------|--------------------------|-------|-----------------------|-------|----------------------|-------|
|   | n=50             | %     | n=20                      | %     | n=30                     | %     | n=22                  | %     | n=28                 | %     |
| Participant describes the AMDF as being helpful   | 9                | 18.00 | 5                         | 25.00 | 4                        | 13.33 | 4                     | 18.18 | 5                    | 17.86 |
| Participant describes no information being specifically helpful                           | 8                | 16.00 | 3                         | 15.00 | 5                        | 16.67 | 4                     | 18.18 | 4                    | 14.29 |
| Participant describes current research papers as being helpful                            | 7                | 14.00 | 3                         | 15.00 | 4                        | 13.33 | 3                     | 13.64 | 4                    | 14.29 |
| Participant describes communicating with others with mitochondrial disease as most useful | 7                | 14.00 | 3                         | 15.00 | 4                        | 13.33 | 2                     | 9.09  | 5                    | 17.86 |
| Participant describes information from clinical team as being helpful                     | 5                | 10.00 | 3                         | 15.00 | 2                        | 6.67  | 4                     | 18.18 | 1                    | 3.57  |



| Information that has been helpful   | All participants |       | Under 18 |       | 24-44 |       | 45-54 |       | 55-64 |       | 65-74+ |       |
|---|------------------|-------|----------|-------|-------|-------|-------|-------|-------|-------|--------|-------|
|   | n=50             | %     | n=6      | %     | n=14  | %     | n=9   | %     | n=11  | %     | n=10   | %     |
| Participant describes the AMDF as being helpful   | 9                | 18.00 | 0        | 0.00  | 5     | 35.71 | 1     | 11.11 | 2     | 18.18 | 1      | 10.00 |
| Participant describes no information being specifically helpful                           | 8                | 16.00 | 1        | 16.67 | 1     | 7.14  | 2     | 22.22 | 2     | 18.18 | 2      | 20.00 |
| Participant describes current research papers as being helpful                            | 7                | 14.00 | 1        | 16.67 | 3     | 21.43 | 2     | 22.22 | 1     | 9.09  | 0      | 0.00  |
| Participant describes communicating with others with mitochondrial disease as most useful | 7                | 14.00 | 2        | 33.33 | 2     | 14.29 | 1     | 11.11 | 2     | 18.18 | 0      | 0.00  |
| Participant describes information from clinical team as being helpful                     | 5                | 10.00 | 1        | 16.67 | 0     | 0.00  | 1     | 11.11 | 1     | 9.09  | 2      | 20.00 |





| Information that has not been helpful  | All participants |       | Metropolitan |       | Rural |       | SEIFA (High) |       | SEIFA (Low) |       |
|--|------------------|-------|--------------|-------|-------|-------|--------------|-------|-------------|-------|
|  | n=50             | %     | n=30         | %     | n=20  | %     | n=27         | %     | n=23        | %     |
| Participant describes no information as being unhelpful  | 22               | 44.00 | 13           | 43.33 | 9     | 45.00 | 10           | 37.04 | 12          | 52.17 |
| Participant describes the stories about other patients as unhelpful  | 3                | 6.00  | 1            | 3.33  | 2     | 10.00 | 2            | 7.41  | 1           | 4.35  |
| Participant describes the lack of concise and comprehensive information as unhelpful                       | 3                | 6.00  | 1            | 3.33  | 2     | 10.00 | 1            | 3.70  | 2           | 8.70  |
| Participant describes not knowing if information is helpful or unhelpful                                   | 2                | 4.00  | 2            | 6.67  | 0     | 0.00  | 2            | 7.41  | 0           | 0.00  |
| Participant describes information that is too general (not specific to their type of disease) as unhelpful | 2                | 4.00  | 1            | 3.33  | 1     | 5.00  | 1            | 3.70  | 1           | 4.35  |
| Participant describes information that is too scientific as unhelpful                                      | 2                | 4.00  | 0            | 0.00  | 2     | 10.00 | 1            | 3.70  | 1           | 4.35  |
| Participant describes health professionals that do not take a holistic approach as unhelpful               | 2                | 4.00  | 2            | 6.67  | 0     | 0.00  | 1            | 3.70  | 1           | 4.35  |



| Information that has not been helpful  | All participants |       | High school or trade |       | University |       | Hearing impairment |       | Eye or visual impairment |       |
|--|------------------|-------|----------------------|-------|------------|-------|--------------------|-------|--------------------------|-------|
|  | n=50             | %     | n=26                 | %     | n=24       | %     | n=24               | %     | n=34                     | %     |
| Participant describes no information as being unhelpful  | 22               | 44.00 | 14                   | 53.85 | 8          | 33.33 | 10                 | 41.67 | 16                       | 47.06 |
| Participant describes the stories about other patients as unhelpful  | 3                | 6.00  | 2                    | 7.69  | 1          | 4.17  | 2                  | 8.33  | 1                        | 2.94  |
| Participant describes the lack of concise and comprehensive information as unhelpful                       | 3                | 6.00  | 0                    | 0.00  | 3          | 12.50 | 2                  | 8.33  | 3                        | 8.82  |
| Participant describes not knowing if information is helpful or unhelpful                                   | 2                | 4.00  | 2                    | 7.69  | 0          | 0.00  | 1                  | 4.17  | 2                        | 5.88  |
| Participant describes information that is too general (not specific to their type of disease) as unhelpful | 2                | 4.00  | 0                    | 0.00  | 2          | 8.33  | 2                  | 8.33  | 0                        | 0.00  |
| Participant describes information that is too scientific as unhelpful                                      | 2                | 4.00  | 1                    | 3.85  | 1          | 4.17  | 2                  | 8.33  | 2                        | 5.88  |
| Participant describes health professionals that do not take a holistic approach as unhelpful               | 2                | 4.00  | 0                    | 0.00  | 2          | 8.33  | 2                  | 8.33  | 0                        | 0.00  |





| Information that has not been helpful  | All participants |       | Physical function (High) |       | Physical function (Low) |       | Emotional well-being (High) |       | Emotional well-being (Low) |       |
|--|------------------|-------|--------------------------|-------|-------------------------|-------|-----------------------------|-------|----------------------------|-------|
|  | n=50             | %     | n=22                     | %     | n=28                    | %     | n=26                        | %     | n=24                       | %     |
| Participant describes no information as being unhelpful  | 22               | 44.00 | 10                       | 45.45 | 12                      | 42.86 | 12                          | 46.15 | 10                         | 41.67 |
| Participant describes the stories about other patients as unhelpful  | 3                | 6.00  | 1                        | 4.55  | 2                       | 7.14  | 3                           | 11.54 | 0                          | 0.00  |
| Participant describes the lack of concise and comprehensive information as unhelpful                       | 3                | 6.00  | 1                        | 4.55  | 2                       | 7.14  | 1                           | 3.85  | 2                          | 8.33  |
| Participant describes not knowing if information is helpful or unhelpful                                   | 2                | 4.00  | 1                        | 4.55  | 1                       | 3.57  | 1                           | 3.85  | 1                          | 4.17  |
| Participant describes information that is too general (not specific to their type of disease) as unhelpful | 2                | 4.00  | 2                        | 9.09  | 0                       | 0.00  | 1                           | 3.85  | 1                          | 4.17  |
| Participant describes information that is too scientific as unhelpful                                      | 2                | 4.00  | 1                        | 4.55  | 1                       | 3.57  | 1                           | 3.85  | 1                          | 4.17  |
| Participant describes health professionals that do not take a holistic approach as unhelpful               | 2                | 4.00  | 0                        | 0.00  | 2                       | 7.14  | 1                           | 3.85  | 1                          | 4.17  |

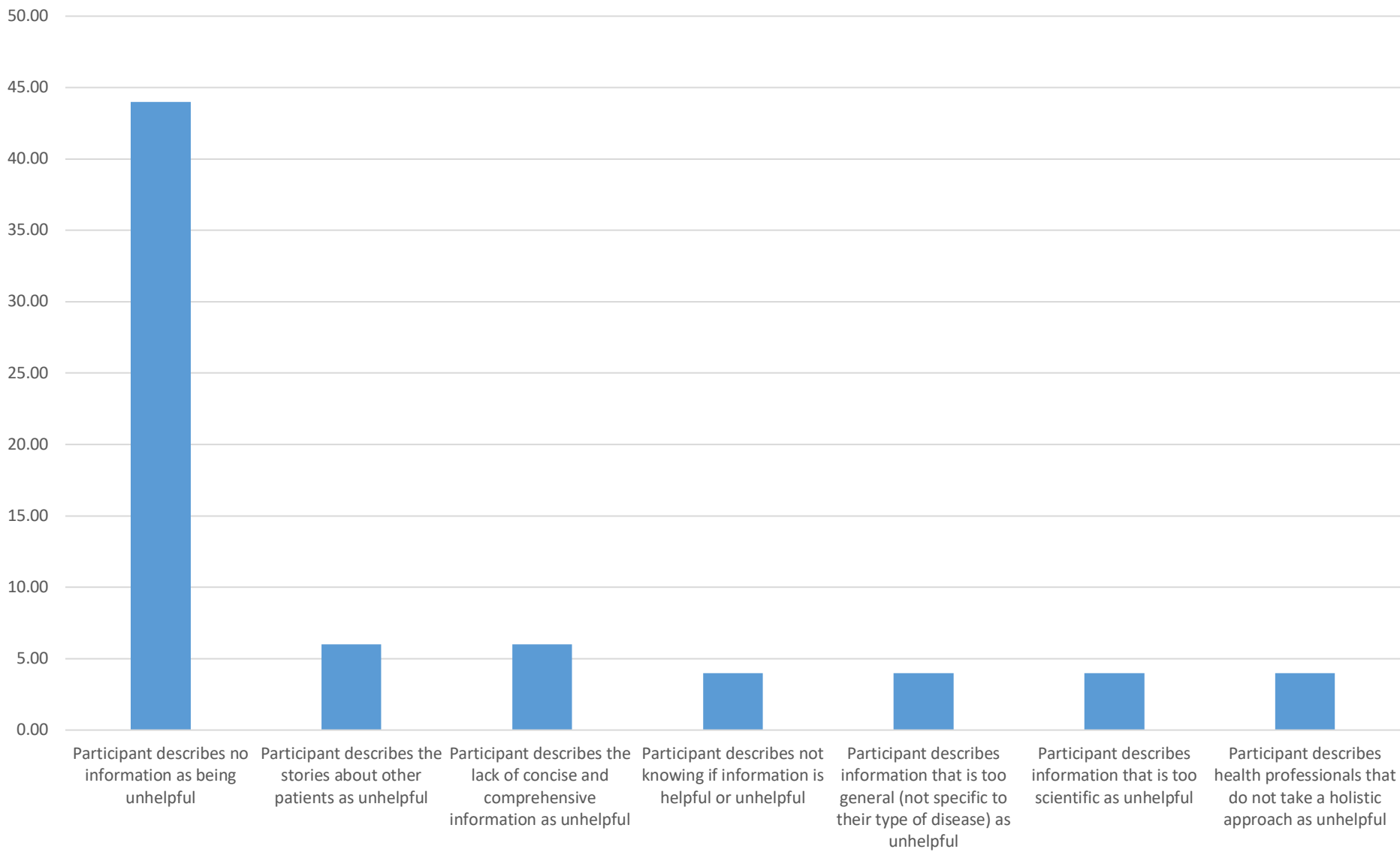


| Information that has not been helpful  | All participants |       | Social functioning (High) |       | Social functioning (Low) |       | General health (High) |       | General health (Low) |       |
|--|------------------|-------|---------------------------|-------|--------------------------|-------|-----------------------|-------|----------------------|-------|
|  | n=50             | %     | n=20                      | %     | n=30                     | %     | n=22                  | %     | n=28                 | %     |
| Participant describes no information as being unhelpful  | 22               | 44.00 | 8                         | 40.00 | 14                       | 46.67 | 10                    | 45.45 | 12                   | 42.86 |
| Participant describes the stories about other patients as unhelpful  | 3                | 6.00  | 1                         | 5.00  | 2                        | 6.67  | 2                     | 9.09  | 1                    | 3.57  |
| Participant describes the lack of concise and comprehensive information as unhelpful                       | 3                | 6.00  | 2                         | 10.00 | 1                        | 3.33  | 1                     | 4.55  | 2                    | 7.14  |
| Participant describes not knowing if information is helpful or unhelpful                                   | 2                | 4.00  | 1                         | 5.00  | 1                        | 3.33  | 1                     | 4.55  | 1                    | 3.57  |
| Participant describes information that is too general (not specific to their type of disease) as unhelpful | 2                | 4.00  | 0                         | 0.00  | 2                        | 6.67  | 1                     | 4.55  | 1                    | 3.57  |
| Participant describes information that is too scientific as unhelpful                                      | 2                | 4.00  | 1                         | 5.00  | 1                        | 3.33  | 0                     | 0.00  | 2                    | 7.14  |
| Participant describes health professionals that do not take a holistic approach as unhelpful               | 2                | 4.00  | 0                         | 0.00  | 2                        | 6.67  | 0                     | 0.00  | 2                    | 7.14  |



| Information that has not been helpful  | All participants |       | Under 18 |       | 24-44 |       | 45-54 |       | 55-64 |       | 65-74+ |       |
|--|------------------|-------|----------|-------|-------|-------|-------|-------|-------|-------|--------|-------|
|  | n=50             | %     | n=6      | %     | n=14  | %     | n=9   | %     | n=11  | %     | n=10   | %     |
| Participant describes no information as being unhelpful  | 22               | 44.00 | 4        | 66.67 | 5     | 35.71 | 6     | 66.67 | 2     | 18.18 | 5      | 50.00 |
| Participant describes the stories about other patients as unhelpful  | 3                | 6.00  | 1        | 16.67 | 0     | 0.00  | 0     | 0.00  | 1     | 9.09  | 1      | 10.00 |
| Participant describes the lack of concise and comprehensive information as unhelpful                       | 3                | 6.00  | 0        | 0.00  | 2     | 14.29 | 0     | 0.00  | 0     | 0.00  | 1      | 10.00 |
| Participant describes not knowing if information is helpful or unhelpful                                   | 2                | 4.00  | 0        | 0.00  | 1     | 7.14  | 1     | 11.11 | 0     | 0.00  | 0      | 0.00  |
| Participant describes information that is too general (not specific to their type of disease) as unhelpful | 2                | 4.00  | 0        | 0.00  | 1     | 7.14  | 0     | 0.00  | 1     | 9.09  | 0      | 0.00  |
| Participant describes information that is too scientific as unhelpful                                      | 2                | 4.00  | 0        | 0.00  | 0     | 0.00  | 0     | 0.00  | 2     | 18.18 | 0      | 0.00  |
| Participant describes health professionals that do not take a holistic approach as unhelpful               | 2                | 4.00  | 0        | 0.00  | 2     | 14.29 | 0     | 0.00  | 0     | 0.00  | 0      | 0.00  |





| Information preferences   | All participants |       | Metropolitan |       | Rural |       | SEIFA (High) |       | SEIFA (Low) |       |
|---|------------------|-------|--------------|-------|-------|-------|--------------|-------|-------------|-------|
|   | n=50             | %     | n=30         | %     | n=20  | %     | n=27         | %     | n=23        | %     |
| Participant describes preferring to talk to someone   | 20               | 40.00 | 12           | 40.00 | 8     | 40.00 | 12           | 44.44 | 8           | 34.78 |
| Participant describes preferring to talk to someone (face-to-face)                                  | 5                | 10.00 | 2            | 6.67  | 3     | 15.00 | 2            | 7.41  | 3           | 13.04 |
| Participant describes preferring information online   | 21               | 42.00 | 13           | 43.33 | 9     | 45.00 | 10           | 37.04 | 12          | 52.17 |
| Participant describes preferring information in a written format like a booklet                     | 7                | 14.00 | 5            | 16.67 | 2     | 10.00 | 4            | 14.81 | 3           | 13.04 |
| Participant describes not having a preferred information format and/or various modes are acceptable | 6                | 12.00 | 5            | 16.67 | 1     | 5.00  | 6            | 22.22 | 0           | 0.00  |
| Participant describes preferring information from their specialist                                  | 5                | 10.00 | 4            | 13.33 | 1     | 5.00  | 2            | 7.41  | 3           | 13.04 |



| Information preferences   | All participants |       | High school or trade |       | University |       | Hearing impairment |       | Eye or visual impairment |       |
|---|------------------|-------|----------------------|-------|------------|-------|--------------------|-------|--------------------------|-------|
|   | n=50             | %     | n=26                 | %     | n=24       | %     | n=24               | %     | n=34                     | %     |
| Participant describes preferring to talk to someone   | 20               | 40.00 | 11                   | 42.31 | 9          | 37.50 | 13                 | 54.17 | 11                       | 32.35 |
| Participant describes preferring to talk to someone (face-to-face)                                  | 5                | 10.00 | 2                    | 7.69  | 3          | 12.50 | 2                  | 8.33  | 3                        | 8.82  |
| Participant describes preferring information online   | 21               | 42.00 | 12                   | 46.15 | 10         | 41.67 | 7                  | 29.17 | 16                       | 47.06 |
| Participant describes preferring information in a written format like a booklet                     | 7                | 14.00 | 2                    | 7.69  | 5          | 20.83 | 6                  | 25.00 | 3                        | 8.82  |
| Participant describes not having a preferred information format and/or various modes are acceptable | 6                | 12.00 | 4                    | 15.38 | 2          | 8.33  | 4                  | 16.67 | 3                        | 8.82  |
| Participant describes preferring information from their specialist                                  | 5                | 10.00 | 4                    | 15.38 | 1          | 4.17  | 1                  | 4.17  | 5                        | 14.71 |



| Information preferences   | All participants |       | Physical function (High) |       | Physical function (Low) |       | Emotional well-being (High) |       | Emotional well-being (Low) |       |
|---|------------------|-------|--------------------------|-------|-------------------------|-------|-----------------------------|-------|----------------------------|-------|
|   | n=50             | %     | n=22                     | %     | n=28                    | %     | n=26                        | %     | n=24                       | %     |
| Participant describes preferring to talk to someone   | 20               | 40.00 | 11                       | 50.00 | 9                       | 32.14 | 12                          | 46.15 | 8                          | 33.33 |
| Participant describes preferring to talk to someone (face-to-face)                                  | 5                | 10.00 | 2                        | 9.09  | 3                       | 10.71 | 2                           | 7.69  | 3                          | 12.50 |
| Participant describes preferring information online   | 21               | 42.00 | 7                        | 31.82 | 15                      | 53.57 | 12                          | 46.15 | 10                         | 41.67 |
| Participant describes preferring information in a written format like a booklet                     | 7                | 14.00 | 3                        | 13.64 | 4                       | 14.29 | 5                           | 19.23 | 2                          | 8.33  |
| Participant describes not having a preferred information format and/or various modes are acceptable | 6                | 12.00 | 3                        | 13.64 | 3                       | 10.71 | 3                           | 11.54 | 3                          | 12.50 |
| Participant describes preferring information from their specialist                                  | 5                | 10.00 | 2                        | 9.09  | 3                       | 10.71 | 3                           | 11.54 | 2                          | 8.33  |



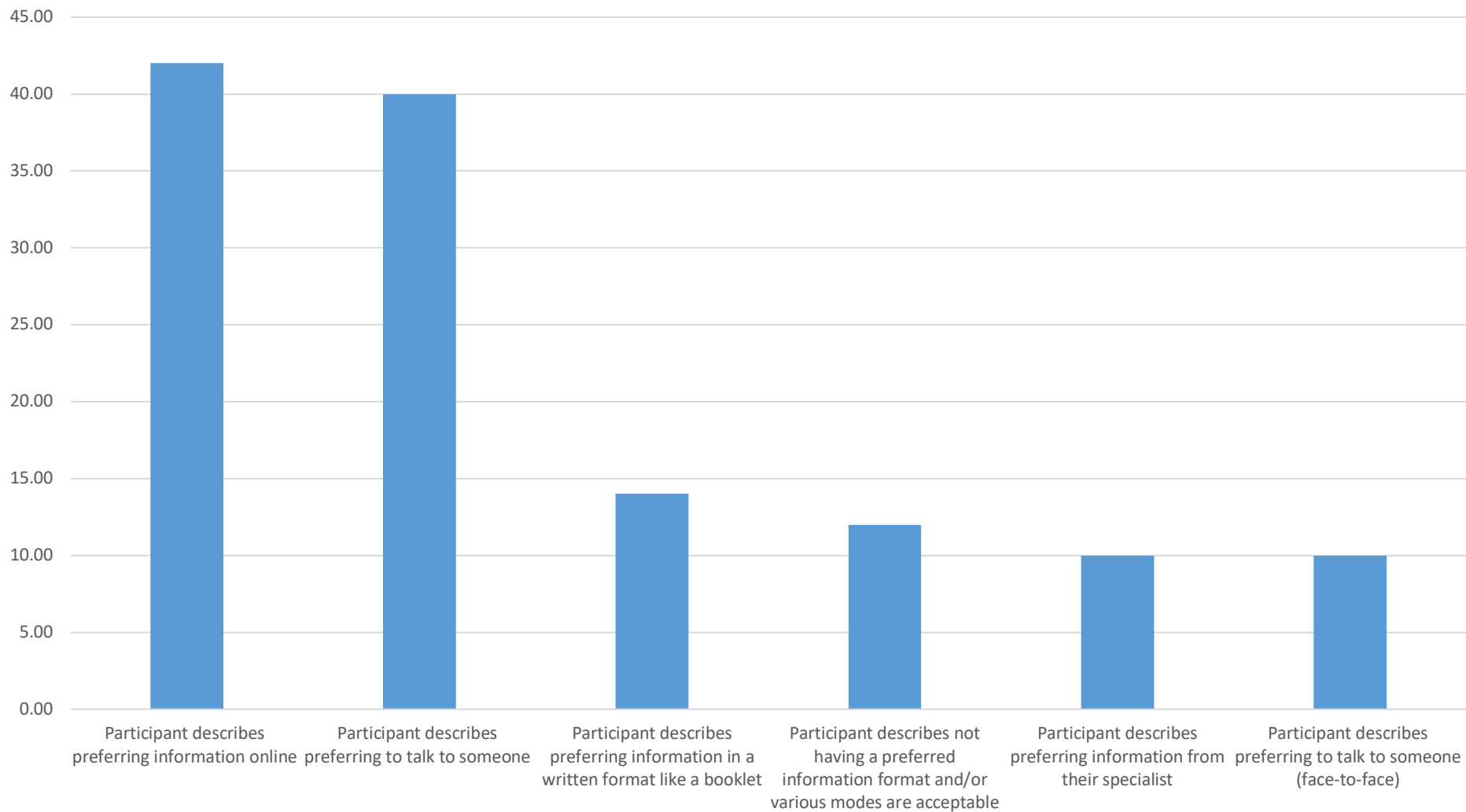
| Information preferences   | All participants |       | Social functioning (High) |       | Social functioning (Low) |       | General health (High) |       | General health (Low) |       |
|---|------------------|-------|---------------------------|-------|--------------------------|-------|-----------------------|-------|----------------------|-------|
|   | n=50             | %     | n=20                      | %     | n=30                     | %     | n=22                  | %     | n=28                 | %     |
| Participant describes preferring to talk to someone   | 20               | 40.00 | 6                         | 30.00 | 14                       | 46.67 | 10                    | 45.45 | 10                   | 35.71 |
| Participant describes preferring to talk to someone (face-to-face)                                  | 5                | 10.00 | 2                         | 10.00 | 3                        | 10.00 | 3                     | 13.64 | 2                    | 7.14  |
| Participant describes preferring information online   | 21               | 42.00 | 9                         | 45.00 | 13                       | 43.33 | 7                     | 31.82 | 15                   | 53.57 |
| Participant describes preferring information in a written format like a booklet                     | 7                | 14.00 | 2                         | 10.00 | 5                        | 16.67 | 5                     | 22.73 | 2                    | 7.14  |
| Participant describes not having a preferred information format and/or various modes are acceptable | 6                | 12.00 | 3                         | 15.00 | 3                        | 10.00 | 3                     | 13.64 | 3                    | 10.71 |
| Participant describes preferring information from their specialist                                  | 5                | 10.00 | 2                         | 10.00 | 3                        | 10.00 | 2                     | 9.09  | 3                    | 10.71 |





| Information preferences   | All participants |       | Under 18 |       | 24-44 |       | 45-54 |       | 55-64 |       | 65-74+ |       |
|---|------------------|-------|----------|-------|-------|-------|-------|-------|-------|-------|--------|-------|
|   | n=50             | %     | n=6      | %     | n=14  | %     | n=9   | %     | n=11  | %     | n=10   | %     |
| Participant describes preferring to talk to someone   | 20               | 40.00 | 2        | 33.33 | 5     | 35.71 | 4     | 44.44 | 4     | 36.36 | 5      | 50.00 |
| Participant describes preferring to talk to someone (face-to-face)                                  | 5                | 10.00 | 0        | 0.00  | 0     | 0.00  | 2     | 22.22 | 1     | 9.09  | 2      | 20.00 |
| Participant describes preferring information online   | 21               | 42.00 | 4        | 66.67 | 9     | 64.29 | 2     | 22.22 | 4     | 36.36 | 3      | 30.00 |
| Participant describes preferring information in a written format like a booklet                     | 7                | 14.00 | 1        | 16.67 | 2     | 14.29 | 0     | 0.00  | 2     | 18.18 | 2      | 20.00 |
| Participant describes not having a preferred information format and/or various modes are acceptable | 6                | 12.00 | 0        | 0.00  | 1     | 7.14  | 1     | 11.11 | 2     | 18.18 | 2      | 20.00 |
| Participant describes preferring information from their specialist                                  | 5                | 10.00 | 1        | 16.67 | 1     | 7.14  | 1     | 11.11 | 1     | 9.09  | 1      | 10.00 |





| Timing of information  | All participants |       | Metropolitan |       | Rural |       | SEIFA (High) |       | SEIFA (Low) |       |
|--|------------------|-------|--------------|-------|-------|-------|--------------|-------|-------------|-------|
|  | n=50             | %     | n=30         | %     | n=20  | %     | n=27         | %     | n=23        | %     |
| Participant describes being most receptive when they were first diagnosed (beginning)  | 18               | 36.00 | 13           | 43.33 | 5     | 25.00 | 11           | 40.74 | 7           | 30.43 |
| Participant describes there not being a specific time when they were most receptive - an ongoing process                                     | 10               | 20.00 | 5            | 16.67 | 5     | 25.00 | 7            | 25.93 | 3           | 13.04 |
| Participant describes there not being a specific time when they were most receptive - depends on their emotional state and level of interest | 6                | 12.00 | 3            | 10.00 | 3     | 15.00 | 2            | 7.41  | 4           | 17.39 |
| Participant describes not being receptive during diagnosis but being more receptive post diagnosis   | 3                | 6.00  | 1            | 3.33  | 2     | 10.00 | 1            | 3.70  | 2           | 8.70  |
| Participant describes being always receptive to receiving information  | 2                | 4.00  | 1            | 3.33  | 1     | 5.00  | 1            | 3.70  | 1           | 4.35  |
| Participant describes being most receptive a year(s) after diagnosis   | 2                | 4.00  | 1            | 3.33  | 1     | 5.00  | 0            | 0.00  | 2           | 8.70  |
| Participant describes being more receptive now once learning more about the disease, compared to the beginning                               | 2                | 4.00  | 1            | 3.33  | 1     | 5.00  | 1            | 3.70  | 1           | 4.35  |



| Timing of information  | All participants |       | High school or trade |       | University |       | Hearing impairment |       | Eye or visual impairment |       |
|--|------------------|-------|----------------------|-------|------------|-------|--------------------|-------|--------------------------|-------|
|  | n=50             | %     | n=26                 | %     | n=24       | %     | n=24               | %     | n=34                     | %     |
| Participant describes being most receptive when they were first diagnosed (beginning)  | 18               | 36.00 | 11                   | 42.31 | 7          | 29.17 | 7                  | 29.17 | 13                       | 38.24 |
| Participant describes there not being a specific time when they were most receptive - an ongoing process                                     | 10               | 20.00 | 6                    | 23.08 | 4          | 16.67 | 5                  | 20.83 | 7                        | 20.59 |
| Participant describes there not being a specific time when they were most receptive - depends on their emotional state and level of interest | 6                | 12.00 | 2                    | 7.69  | 4          | 16.67 | 5                  | 20.83 | 5                        | 14.71 |
| Participant describes not being receptive during diagnosis but being more receptive post diagnosis   | 3                | 6.00  | 3                    | 11.54 | 0          | 0.00  | 1                  | 4.17  | 3                        | 8.82  |
| Participant describes being always receptive to receiving information  | 2                | 4.00  | 1                    | 3.85  | 1          | 4.17  | 1                  | 4.17  | 1                        | 2.94  |
| Participant describes being most receptive a year(s) after diagnosis   | 2                | 4.00  | 0                    | 0.00  | 2          | 8.33  | 1                  | 4.17  | 1                        | 2.94  |
| Participant describes being more receptive now once learning more about the disease, compared to the beginning                               | 2                | 4.00  | 1                    | 3.85  | 1          | 4.17  | 1                  | 4.17  | 2                        | 5.88  |



| Timing of information  | All participants |       | Physical function (High) |       | Physical function (Low) |       | Emotional well-being (High) |       | Emotional well-being (Low) |       |
|--|------------------|-------|--------------------------|-------|-------------------------|-------|-----------------------------|-------|----------------------------|-------|
|  | n=50             | %     | n=22                     | %     | n=28                    | %     | n=26                        | %     | n=24                       | %     |
| Participant describes being most receptive when they were first diagnosed (beginning)  | 18               | 36.00 | 8                        | 36.36 | 10                      | 35.71 | 10                          | 38.46 | 8                          | 33.33 |
| Participant describes there not being a specific time when they were most receptive - an ongoing process                                     | 10               | 20.00 | 3                        | 13.64 | 7                       | 25.00 | 7                           | 26.92 | 3                          | 12.50 |
| Participant describes there not being a specific time when they were most receptive - depends on their emotional state and level of interest | 6                | 12.00 | 3                        | 13.64 | 3                       | 10.71 | 3                           | 11.54 | 3                          | 12.50 |
| Participant describes not being receptive during diagnosis but being more receptive post diagnosis   | 3                | 6.00  | 1                        | 4.55  | 2                       | 7.14  | 1                           | 3.85  | 2                          | 8.33  |
| Participant describes being always receptive to receiving information  | 2                | 4.00  | 0                        | 0.00  | 2                       | 7.14  | 0                           | 0.00  | 2                          | 8.33  |
| Participant describes being most receptive a year(s) after diagnosis   | 2                | 4.00  | 1                        | 4.55  | 1                       | 3.57  | 1                           | 3.85  | 1                          | 4.17  |
| Participant describes being more receptive now once learning more about the disease, compared to the beginning                               | 2                | 4.00  | 1                        | 4.55  | 1                       | 3.57  | 2                           | 7.69  | 0                          | 0.00  |

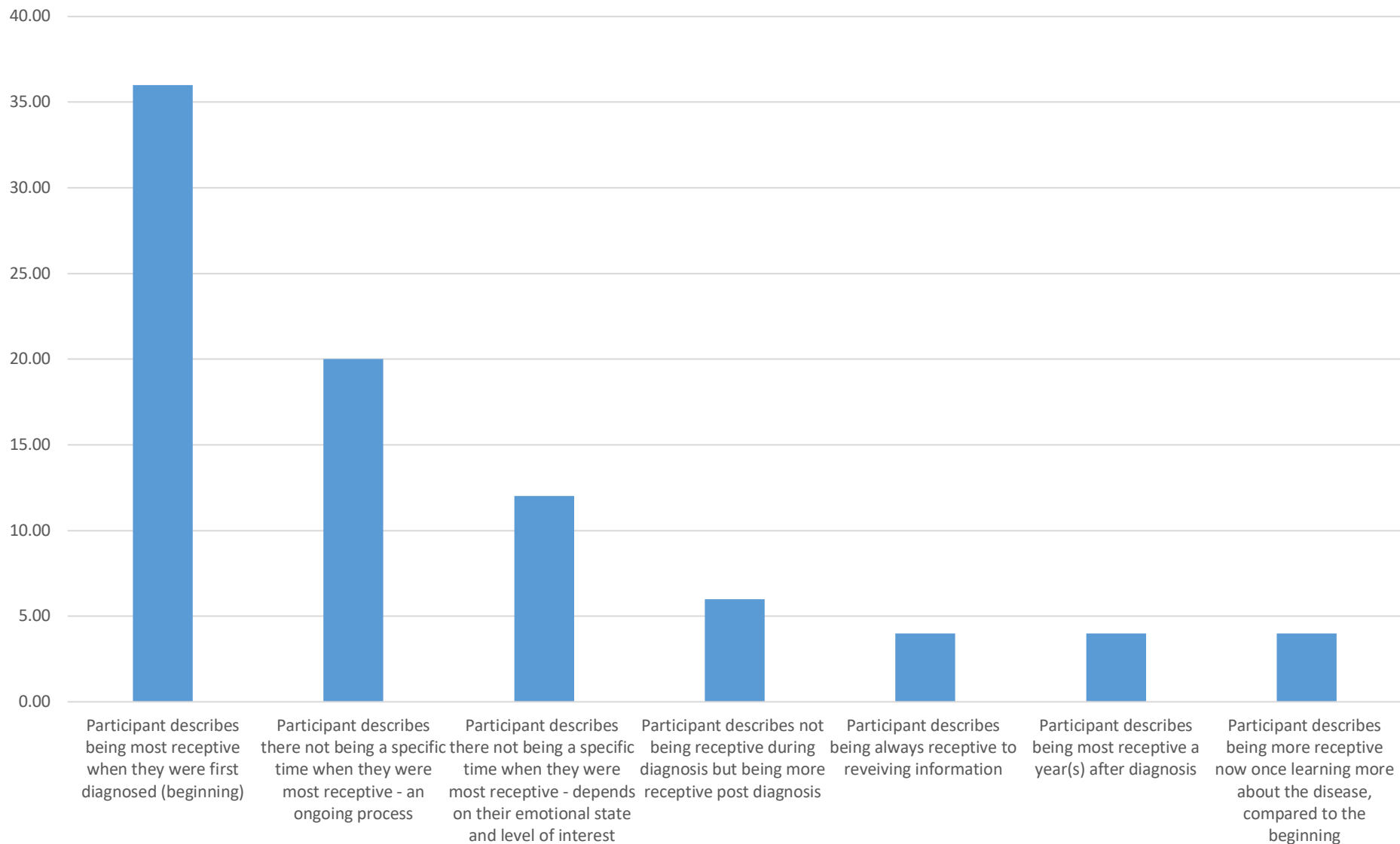


| Timing of information  | All participants |       | Social functioning (High) |       | Social functioning (Low) |       | General health (High) |       | General health (Low) |       |
|--|------------------|-------|---------------------------|-------|--------------------------|-------|-----------------------|-------|----------------------|-------|
|  | n=50             | %     | n=20                      | %     | n=30                     | %     | n=22                  | %     | n=28                 | %     |
| Participant describes being most receptive when they were first diagnosed (beginning)  | 18               | 36.00 | 5                         | 25.00 | 13                       | 43.33 | 5                     | 22.73 | 13                   | 46.43 |
| Participant describes there not being a specific time when they were most receptive - an ongoing process                                     | 10               | 20.00 | 6                         | 30.00 | 4                        | 13.33 | 5                     | 22.73 | 5                    | 17.86 |
| Participant describes there not being a specific time when they were most receptive - depends on their emotional state and level of interest | 6                | 12.00 | 3                         | 15.00 | 3                        | 10.00 | 3                     | 13.64 | 3                    | 10.71 |
| Participant describes not being receptive during diagnosis but being more receptive post diagnosis   | 3                | 6.00  | 1                         | 5.00  | 2                        | 6.67  | 1                     | 4.55  | 2                    | 7.14  |
| Participant describes being always receptive to receiving information  | 2                | 4.00  | 0                         | 0.00  | 2                        | 6.67  | 1                     | 4.55  | 1                    | 3.57  |
| Participant describes being most receptive a year(s) after diagnosis   | 2                | 4.00  | 1                         | 5.00  | 1                        | 3.33  | 1                     | 4.55  | 1                    | 3.57  |
| Participant describes being more receptive now once learning more about the disease, compared to the beginning                               | 2                | 4.00  | 1                         | 5.00  | 1                        | 3.33  | 1                     | 4.55  | 1                    | 3.57  |



| Timing of information  | All participants |       | Under 18 |       | 24-44 |       | 45-54 |       | 55-64 |       | 65-74+ |       |
|--|------------------|-------|----------|-------|-------|-------|-------|-------|-------|-------|--------|-------|
|  | n=50             | %     | n=6      | %     | n=14  | %     | n=9   | %     | n=11  | %     | n=10   | %     |
| Participant describes being most receptive when they were first diagnosed (beginning)  | 18               | 36.00 | 2        | 33.33 | 5     | 35.71 | 5     | 55.56 | 4     | 36.36 | 2      | 20.00 |
| Participant describes there not being a specific time when they were most receptive - an ongoing process                                     | 10               | 20.00 | 2        | 33.33 | 2     | 14.29 | 0     | 0.00  | 3     | 27.27 | 3      | 30.00 |
| Participant describes there not being a specific time when they were most receptive - depends on their emotional state and level of interest | 6                | 12.00 | 0        | 0.00  | 3     | 21.43 | 1     | 11.11 | 1     | 9.09  | 1      | 10.00 |
| Participant describes not being receptive during diagnosis but being more receptive post diagnosis   | 3                | 6.00  | 0        | 0.00  | 0     | 0.00  | 1     | 11.11 | 1     | 9.09  | 1      | 10.00 |
| Participant describes being always receptive to receiving information  | 2                | 4.00  | 1        | 16.67 | 0     | 0.00  | 0     | 0.00  | 0     | 0.00  | 1      | 10.00 |
| Participant describes being most receptive a year(s) after diagnosis   | 2                | 4.00  | 0        | 0.00  | 1     | 7.14  | 1     | 11.11 | 0     | 0.00  | 0      | 0.00  |
| Participant describes being more receptive now once learning more about the disease, compared to the beginning                               | 2                | 4.00  | 0        | 0.00  | 1     | 7.14  | 0     | 0.00  | 1     | 9.09  | 0      | 0.00  |







| Health professional communication  | All participants |       | Metropolitan |       | Rural |       | SEIFA (High) |       | SEIFA (Low) |       |
|--|------------------|-------|--------------|-------|-------|-------|--------------|-------|-------------|-------|
|  | n=50             | %     | n=30         | %     | n=20  | %     | n=27         | %     | n=23        | %     |
| Participant describes most healthcare professionals not knowing about mitochondrial disease                              | 11               | 22.00 | 5            | 16.67 | 6     | 30.00 | 5            | 18.52 | 6           | 26.09 |
| Participant describes being satisfied with health professional communication   | 10               | 20.00 | 5            | 16.67 | 5     | 25.00 | 2            | 7.41  | 8           | 34.78 |
| Participant describes excellent communication with their specialists   | 7                | 14.00 | 4            | 13.33 | 3     | 15.00 | 4            | 14.81 | 3           | 13.04 |
| Participant describes having minimal communication with healthcare professionals   | 6                | 12.00 | 5            | 16.67 | 2     | 10.00 | 5            | 18.52 | 2           | 8.70  |
| Participant describes mostly good experiences, however there is a general lack of understanding of mitochondrial disease | 6                | 12.00 | 5            | 16.67 | 1     | 5.00  | 5            | 18.52 | 1           | 4.35  |
| Participant describes a few poor experiences with general practitioners  | 4                | 8.00  | 3            | 10.00 | 1     | 5.00  | 3            | 11.11 | 1           | 4.35  |
| Participant describes feeling as though time with specialists is too short (rushed)                                      | 4                | 8.00  | 3            | 10.00 | 1     | 5.00  | 3            | 11.11 | 1           | 4.35  |



| Health professional communication  | All participants |       | High school or trade |       | University |       | Hearing impairment |       | Eye or visual impairment |       |
|--|------------------|-------|----------------------|-------|------------|-------|--------------------|-------|--------------------------|-------|
|  | n=50             | %     | n=26                 | %     | n=24       | %     | n=24               | %     | n=34                     | %     |
| Participant describes most healthcare professionals not knowing about mitochondrial disease                              | 11               | 22.00 | 7                    | 26.92 | 4          | 16.67 | 7                  | 29.17 | 10                       | 29.41 |
| Participant describes being satisfied with health professional communication   | 10               | 20.00 | 5                    | 19.23 | 5          | 20.83 | 4                  | 16.67 | 8                        | 23.53 |
| Participant describes excellent communication with their specialists   | 7                | 14.00 | 4                    | 15.38 | 3          | 12.50 | 3                  | 12.50 | 4                        | 11.76 |
| Participant describes having minimal communication with healthcare professionals   | 6                | 12.00 | 5                    | 19.23 | 2          | 8.33  | 2                  | 8.33  | 4                        | 11.76 |
| Participant describes mostly good experiences, however there is a general lack of understanding of mitochondrial disease | 6                | 12.00 | 3                    | 11.54 | 3          | 12.50 | 4                  | 16.67 | 2                        | 5.88  |
| Participant describes a few poor experiences with general practitioners  | 4                | 8.00  | 2                    | 7.69  | 2          | 8.33  | 2                  | 8.33  | 3                        | 8.82  |
| Participant describes feeling as though time with specialists is too short (rushed)                                      | 4                | 8.00  | 2                    | 7.69  | 2          | 8.33  | 2                  | 8.33  | 3                        | 8.82  |



| Health professional communication  | All participants |       | Physical function (High) |       | Physical function (Low) |       | Emotional well-being (High) |       | Emotional well-being (Low) |       |
|--|------------------|-------|--------------------------|-------|-------------------------|-------|-----------------------------|-------|----------------------------|-------|
|  | n=50             | %     | n=22                     | %     | n=28                    | %     | n=26                        | %     | n=24                       | %     |
| Participant describes most healthcare professionals not knowing about mitochondrial disease                              | 11               | 22.00 | 2                        | 9.09  | 9                       | 32.14 | 5                           | 19.23 | 6                          | 25.00 |
| Participant describes being satisfied with health professional communication   | 10               | 20.00 | 5                        | 22.73 | 5                       | 17.86 | 4                           | 15.38 | 6                          | 25.00 |
| Participant describes excellent communication with their specialists   | 7                | 14.00 | 3                        | 13.64 | 4                       | 14.29 | 6                           | 23.08 | 1                          | 4.17  |
| Participant describes having minimal communication with healthcare professionals   | 6                | 12.00 | 3                        | 13.64 | 4                       | 14.29 | 2                           | 7.69  | 5                          | 20.83 |
| Participant describes mostly good experiences, however there is a general lack of understanding of mitochondrial disease | 6                | 12.00 | 2                        | 9.09  | 4                       | 14.29 | 4                           | 15.38 | 2                          | 8.33  |
| Participant describes a few poor experiences with general practitioners  | 4                | 8.00  | 3                        | 13.64 | 1                       | 3.57  | 4                           | 15.38 | 0                          | 0.00  |
| Participant describes feeling as though time with specialists is too short (rushed)                                      | 4                | 8.00  | 3                        | 13.64 | 1                       | 3.57  | 2                           | 7.69  | 2                          | 8.33  |

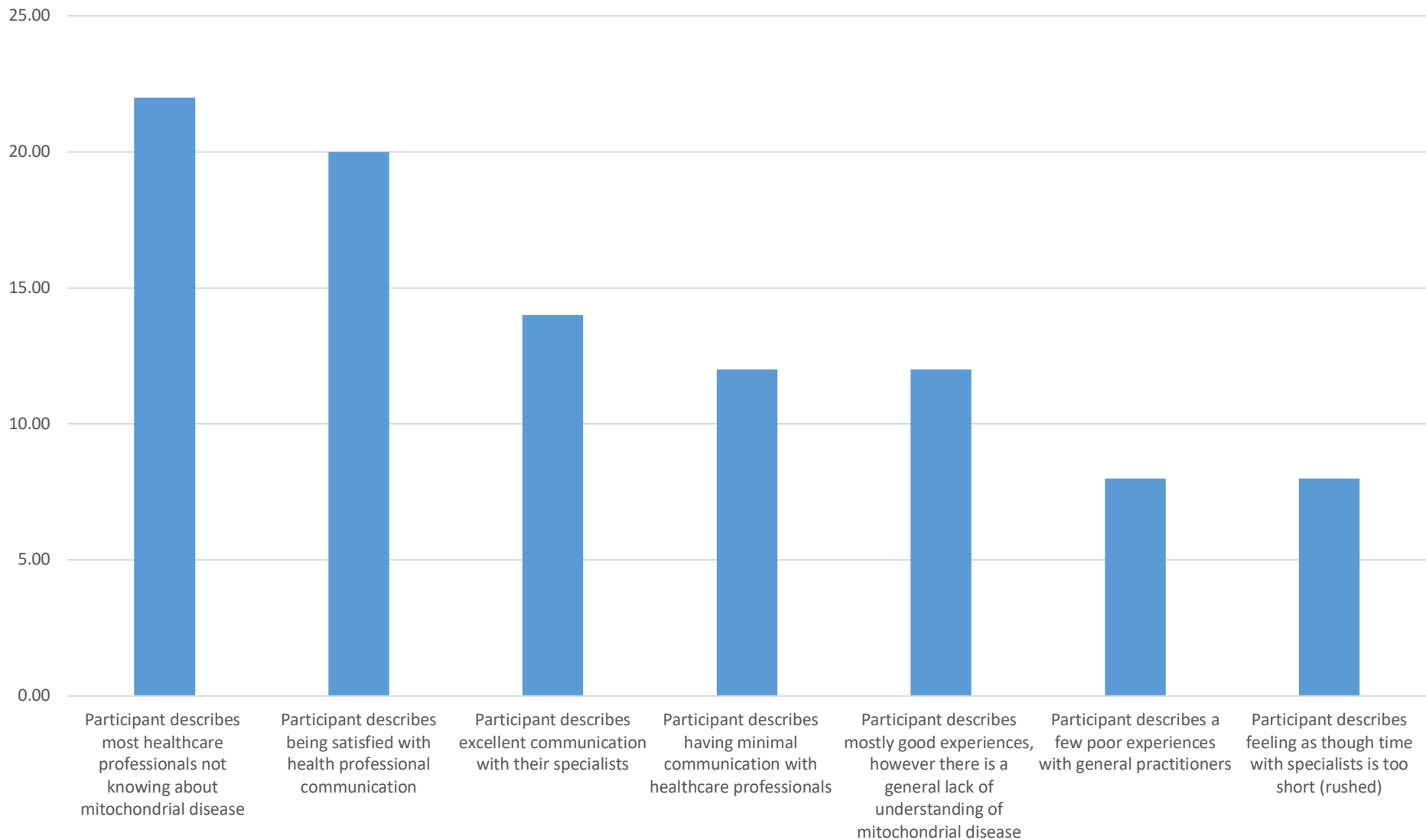


| Health professional communication  | All participants |       | Social functioning (High) |       | Social functioning (Low) |       | General health (High) |       | General health (Low) |       |
|--|------------------|-------|---------------------------|-------|--------------------------|-------|-----------------------|-------|----------------------|-------|
|  | n=50             | %     | n=20                      | %     | n=30                     | %     | n=22                  | %     | n=28                 | %     |
| Participant describes most healthcare professionals not knowing about mitochondrial disease                              | 11               | 22.00 | 4                         | 20.00 | 7                        | 23.33 | 1                     | 4.55  | 10                   | 35.71 |
| Participant describes being satisfied with health professional communication   | 10               | 20.00 | 3                         | 15.00 | 7                        | 23.33 | 3                     | 13.64 | 7                    | 25.00 |
| Participant describes excellent communication with their specialists   | 7                | 14.00 | 5                         | 25.00 | 2                        | 6.67  | 5                     | 22.73 | 2                    | 7.14  |
| Participant describes having minimal communication with healthcare professionals   | 6                | 12.00 | 4                         | 20.00 | 3                        | 10.00 | 3                     | 13.64 | 4                    | 14.29 |
| Participant describes mostly good experiences, however there is a general lack of understanding of mitochondrial disease | 6                | 12.00 | 1                         | 5.00  | 5                        | 16.67 | 2                     | 9.09  | 4                    | 14.29 |
| Participant describes a few poor experiences with general practitioners  | 4                | 8.00  | 2                         | 10.00 | 2                        | 6.67  | 3                     | 13.64 | 1                    | 3.57  |
| Participant describes feeling as though time with specialists is too short (rushed)                                      | 4                | 8.00  | 1                         | 5.00  | 3                        | 10.00 | 3                     | 13.64 | 1                    | 3.57  |



| Health professional communication  | All participants |       | Under 18 |       | 24-44 |       | 45-54 |       | 55-64 |       | 65-74+ |       |
|--|------------------|-------|----------|-------|-------|-------|-------|-------|-------|-------|--------|-------|
|  | n=50             | %     | n=6      | %     | n=14  | %     | n=9   | %     | n=11  | %     | n=10   | %     |
| Participant describes most healthcare professionals not knowing about mitochondrial disease                              | 11               | 22.00 | 1        | 16.67 | 3     | 21.43 | 1     | 11.11 | 2     | 18.18 | 4      | 40.00 |
| Participant describes being satisfied with health professional communication   | 10               | 20.00 | 0        | 0.00  | 3     | 21.43 | 3     | 33.33 | 2     | 18.18 | 2      | 20.00 |
| Participant describes excellent communication with their specialists   | 7                | 14.00 | 1        | 16.67 | 1     | 7.14  | 1     | 11.11 | 1     | 9.09  | 3      | 30.00 |
| Participant describes having minimal communication with healthcare professionals   | 6                | 12.00 | 1        | 16.67 | 1     | 7.14  | 3     | 33.33 | 2     | 18.18 | 0      | 0.00  |
| Participant describes mostly good experiences, however there is a general lack of understanding of mitochondrial disease | 6                | 12.00 | 1        | 16.67 | 3     | 21.43 | 1     | 11.11 | 0     | 0.00  | 1      | 10.00 |
| Participant describes a few poor experiences with general practitioners  | 4                | 8.00  | 0        | 0.00  | 2     | 14.29 | 0     | 0.00  | 2     | 18.18 | 0      | 0.00  |
| Participant describes feeling as though time with specialists is too short (rushed)                                      | 4                | 8.00  | 0        | 0.00  | 1     | 7.14  | 0     | 0.00  | 2     | 18.18 | 1      | 10.00 |







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# SECTION 7: CARE & SUPPORT

| Care and support received   | All participants |       | Metropolitan |       | Rural |       | SEIFA (High) |       | SEIFA (Low) |       |
|---|------------------|-------|--------------|-------|-------|-------|--------------|-------|-------------|-------|
|   | n=50             | %     | n=30         | %     | n=20  | %     | n=27         | %     | n=23        | %     |
| Participant describes support and care in the form of domestic and home care support from government services and NDIS                  | 14               | 28.00 | 8            | 26.67 | 6     | 30.00 | 8            | 29.63 | 6           | 26.09 |
| Participant describes not receiving any care and support  | 9                | 18.00 | 7            | 23.33 | 2     | 10.00 | 6            | 22.22 | 3           | 13.04 |
| Participant describes not receiving significant support and care from the clinical setting  | 9                | 18.00 | 4            | 13.33 | 5     | 25.00 | 4            | 14.81 | 5           | 21.74 |
| Participant describes support and care from family friends (general)  | 7                | 14.00 | 4            | 13.33 | 3     | 15.00 | 3            | 11.11 | 4           | 17.39 |
| Participant describes support and care in the form of community health services (Neurological service)                                  | 6                | 12.00 | 4            | 13.33 | 2     | 10.00 | 3            | 11.11 | 3           | 13.04 |
| Participant describes receiving additional care and support for allied health services  | 6                | 12.00 | 5            | 16.67 | 2     | 10.00 | 4            | 14.81 | 3           | 13.04 |
| Participant describes support and care in the form of family or friends to help with transport(to appointments and everyday activities) | 5                | 10.00 | 4            | 13.33 | 1     | 5.00  | 3            | 11.11 | 2           | 8.70  |
| Participant describes support and care in the form of help with visual impairment (Vision Australia)                                    | 5                | 10.00 | 2            | 6.67  | 3     | 15.00 | 2            | 7.41  | 3           | 13.04 |
| Participant describes satisfaction with accessing support and assistance from the AMDF  | 5                | 10.00 | 3            | 10.00 | 2     | 10.00 | 4            | 14.81 | 1           | 4.35  |
| Participant describes support and care in the form of connecting with other patients and sharing their experience                       | 4                | 8.00  | 3            | 10.00 | 1     | 5.00  | 2            | 7.41  | 2           | 8.70  |
| Participant describes support and care in the form of family and friends helping with domestic help                                     | 4                | 8.00  | 2            | 6.67  | 3     | 15.00 | 2            | 7.41  | 3           | 13.04 |





| Care and support received   | All participants |       | High school or trade |       | University |       | Hearing impairment |       | Eye or visual impairment |       |
|---|------------------|-------|----------------------|-------|------------|-------|--------------------|-------|--------------------------|-------|
|   | n=50             | %     | n=26                 | %     | n=24       | %     | n=24               | %     | n=34                     | %     |
| Participant describes support and care in the form of domestic and home care support from government services and NDIS                  | 14               | 28.00 | 7                    | 26.92 | 7          | 29.17 | 7                  | 29.17 | 9                        | 26.47 |
| Participant describes not receiving any care and support  | 9                | 18.00 | 7                    | 26.92 | 2          | 8.33  | 3                  | 12.50 | 9                        | 26.47 |
| Participant describes not receiving significant support and care from the clinical setting  | 9                | 18.00 | 5                    | 19.23 | 4          | 16.67 | 6                  | 25.00 | 7                        | 20.59 |
| Participant describes support and care from family friends (general)  | 7                | 14.00 | 3                    | 11.54 | 4          | 16.67 | 3                  | 12.50 | 5                        | 14.71 |
| Participant describes support and care in the form of community health services (Neurological service)                                  | 6                | 12.00 | 3                    | 11.54 | 3          | 12.50 | 4                  | 16.67 | 4                        | 11.76 |
| Participant describes receiving additional care and support for allied health services  | 6                | 12.00 | 3                    | 11.54 | 4          | 16.67 | 3                  | 12.50 | 4                        | 11.76 |
| Participant describes support and care in the form of family or friends to help with transport(to appointments and everyday activities) | 5                | 10.00 | 1                    | 3.85  | 4          | 16.67 | 3                  | 12.50 | 2                        | 5.88  |
| Participant describes support and care in the form of help with visual impairment (Vision Australia)                                    | 5                | 10.00 | 2                    | 7.69  | 3          | 12.50 | 3                  | 12.50 | 3                        | 8.82  |
| Participant describes satisfaction with accessing support and assistance from the AMDF  | 5                | 10.00 | 2                    | 7.69  | 3          | 12.50 | 4                  | 16.67 | 4                        | 11.76 |
| Participant describes support and care in the form of connecting with other patients and sharing their experience                       | 4                | 8.00  | 2                    | 7.69  | 2          | 8.33  | 1                  | 4.17  | 4                        | 11.76 |
| Participant describes support and care in the form of family and friends helping with domestic help                                     | 4                | 8.00  | 3                    | 11.54 | 2          | 8.33  | 2                  | 8.33  | 2                        | 5.88  |



| Care and support received   | All participants |       | Physical function (High) |       | Physical function (Low) |       | Emotional well-being (High) |       | Emotional well-being (Low) |       |
|---|------------------|-------|--------------------------|-------|-------------------------|-------|-----------------------------|-------|----------------------------|-------|
|   | n=50             | %     | n=22                     | %     | n=28                    | %     | n=26                        | %     | n=24                       | %     |
| Participant describes support and care in the form of domestic and home care support from government services and NDIS                  | 14               | 28.00 | 4                        | 18.18 | 10                      | 35.71 | 7                           | 26.92 | 7                          | 29.17 |
| Participant describes not receiving any care and support  | 9                | 18.00 | 6                        | 27.27 | 3                       | 10.71 | 4                           | 15.38 | 5                          | 20.83 |
| Participant describes not receiving significant support and care from the clinical setting  | 9                | 18.00 | 6                        | 27.27 | 3                       | 10.71 | 5                           | 19.23 | 4                          | 16.67 |
| Participant describes support and care from family friends (general)  | 7                | 14.00 | 4                        | 18.18 | 3                       | 10.71 | 2                           | 7.69  | 5                          | 20.83 |
| Participant describes support and care in the form of community health services (Neurological service)                                  | 6                | 12.00 | 3                        | 13.64 | 3                       | 10.71 | 3                           | 11.54 | 3                          | 12.50 |
| Participant describes receiving additional care and support for allied health services  | 6                | 12.00 | 2                        | 9.09  | 5                       | 17.86 | 4                           | 15.38 | 3                          | 12.50 |
| Participant describes support and care in the form of family or friends to help with transport(to appointments and everyday activities) | 5                | 10.00 | 1                        | 4.55  | 4                       | 14.29 | 2                           | 7.69  | 3                          | 12.50 |
| Participant describes support and care in the form of help with visual impairment (Vision Australia)                                    | 5                | 10.00 | 2                        | 9.09  | 3                       | 10.71 | 3                           | 11.54 | 2                          | 8.33  |
| Participant describes satisfaction with accessing support and assistance from the AMDF  | 5                | 10.00 | 4                        | 18.18 | 1                       | 3.57  | 2                           | 7.69  | 3                          | 12.50 |
| Participant describes support and care in the form of connecting with other patients and sharing their experience                       | 4                | 8.00  | 2                        | 9.09  | 2                       | 7.14  | 4                           | 15.38 | 0                          | 0.00  |
| Participant describes support and care in the form of family and friends helping with domestic help                                     | 4                | 8.00  | 2                        | 9.09  | 3                       | 10.71 | 1                           | 3.85  | 4                          | 16.67 |

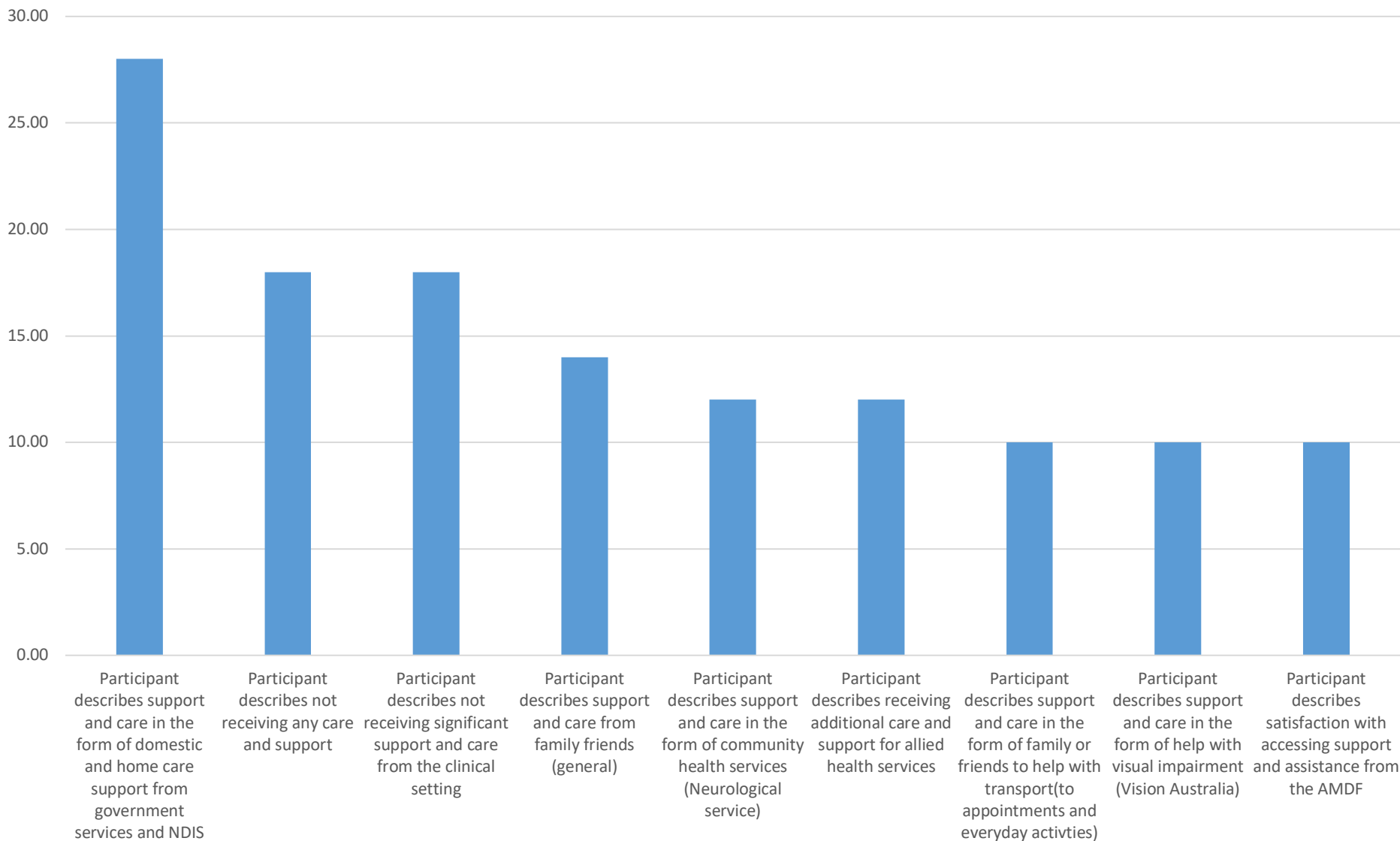


| Care and support received   | All participants |       | Social functioning (High) |       | Social functioning (Low) |       | General health (High) |       | General health (Low) |       |
|---|------------------|-------|---------------------------|-------|--------------------------|-------|-----------------------|-------|----------------------|-------|
|   | n=50             | %     | n=20                      | %     | n=30                     | %     | n=22                  | %     | n=28                 | %     |
| Participant describes support and care in the form of domestic and home care support from government services and NDIS                  | 14               | 28.00 | 5                         | 25.00 | 9                        | 30.00 | 5                     | 22.73 | 9                    | 32.14 |
| Participant describes not receiving any care and support  | 9                | 18.00 | 6                         | 30.00 | 3                        | 10.00 | 3                     | 13.64 | 6                    | 21.43 |
| Participant describes not receiving significant support and care from the clinical setting  | 9                | 18.00 | 3                         | 15.00 | 6                        | 20.00 | 6                     | 27.27 | 3                    | 10.71 |
| Participant describes support and care from family friends (general)  | 7                | 14.00 | 2                         | 10.00 | 5                        | 16.67 | 3                     | 13.64 | 4                    | 14.29 |
| Participant describes support and care in the form of community health services (Neurological service)                                  | 6                | 12.00 | 1                         | 5.00  | 5                        | 16.67 | 3                     | 13.64 | 3                    | 10.71 |
| Participant describes receiving additional care and support for allied health services  | 6                | 12.00 | 3                         | 15.00 | 4                        | 13.33 | 3                     | 13.64 | 4                    | 14.29 |
| Participant describes support and care in the form of family or friends to help with transport(to appointments and everyday activities) | 5                | 10.00 | 0                         | 0.00  | 5                        | 16.67 | 3                     | 13.64 | 2                    | 7.14  |
| Participant describes support and care in the form of help with visual impairment (Vision Australia)                                    | 5                | 10.00 | 1                         | 5.00  | 4                        | 13.33 | 1                     | 4.55  | 4                    | 14.29 |
| Participant describes satisfaction with accessing support and assistance from the AMDF  | 5                | 10.00 | 4                         | 20.00 | 1                        | 3.33  | 2                     | 9.09  | 3                    | 10.71 |
| Participant describes support and care in the form of connecting with other patients and sharing their experience                       | 4                | 8.00  | 3                         | 15.00 | 1                        | 3.33  | 2                     | 9.09  | 2                    | 7.14  |
| Participant describes support and care in the form of family and friends helping with domestic help                                     | 4                | 8.00  | 2                         | 10.00 | 3                        | 10.00 | 2                     | 9.09  | 3                    | 10.71 |



| Care and support received   | All participants |       | Under 18 |       | 24-44 |       | 45-54 |       | 55-64 |       | 65-74+ |       |
|---|------------------|-------|----------|-------|-------|-------|-------|-------|-------|-------|--------|-------|
|   | n=50             | %     | n=6      | %     | n=14  | %     | n=9   | %     | n=11  | %     | n=10   | %     |
| Participant describes support and care in the form of domestic and home care support from government services and NDIS                  | 14               | 28.00 | 0        | 0.00  | 2     | 14.29 | 3     | 33.33 | 4     | 36.36 | 5      | 50.00 |
| Participant describes not receiving any care and support  | 9                | 18.00 | 0        | 0.00  | 3     | 21.43 | 2     | 22.22 | 3     | 27.27 | 1      | 10.00 |
| Participant describes not receiving significant support and care from the clinical setting  | 9                | 18.00 | 1        | 16.67 | 2     | 14.29 | 3     | 33.33 | 1     | 9.09  | 2      | 20.00 |
| Participant describes support and care from family friends (general)  | 7                | 14.00 | 1        | 16.67 | 1     | 7.14  | 1     | 11.11 | 2     | 18.18 | 2      | 20.00 |
| Participant describes support and care in the form of community health services (Neurological service)                                  | 6                | 12.00 | 2        | 33.33 | 1     | 7.14  | 1     | 11.11 | 1     | 9.09  | 1      | 10.00 |
| Participant describes receiving additional care and support for allied health services  | 6                | 12.00 | 3        | 50.00 | 2     | 14.29 | 0     | 0.00  | 1     | 9.09  | 1      | 10.00 |
| Participant describes support and care in the form of family or friends to help with transport(to appointments and everyday activities) | 5                | 10.00 | 0        | 0.00  | 2     | 14.29 | 0     | 0.00  | 1     | 9.09  | 2      | 20.00 |
| Participant describes support and care in the form of help with visual impairment (Vision Australia)                                    | 5                | 10.00 | 0        | 0.00  | 1     | 7.14  | 3     | 33.33 | 1     | 9.09  | 0      | 0.00  |
| Participant describes satisfaction with accessing support and assistance from the AMDF  | 5                | 10.00 | 0        | 0.00  | 2     | 14.29 | 1     | 11.11 | 1     | 9.09  | 1      | 10.00 |
| Participant describes support and care in the form of connecting with other patients and sharing their experience                       | 4                | 8.00  | 1        | 16.67 | 1     | 7.14  | 2     | 22.22 | 0     | 0.00  | 0      | 0.00  |
| Participant describes support and care in the form of family and friends helping with domestic help                                     | 4                | 8.00  | 1        | 16.67 | 1     | 7.14  | 1     | 11.11 | 1     | 9.09  | 1      | 10.00 |







The International Centre for Community-Driven Research

# SECTION 8: QUALITY OF LIFE

| Impact on quality of life  | All participants |       | Metropolitan |       | Rural |       | SEIFA (High) |       | SEIFA (Low) |       |
|--|------------------|-------|--------------|-------|-------|-------|--------------|-------|-------------|-------|
|  | n=50             | %     | n=30         | %     | n=20  | %     | n=27         | %     | n=23        | %     |
| Participant describes poor mental health of patient as a consequence of the disease                                    | 19               | 38.00 | 11           | 36.67 | 8     | 40.00 | 10           | 37.04 | 9           | 39.13 |
| Participant describes a significant impact on family relationships and family dynamics                                 | 16               | 32.00 | 10           | 33.33 | 7     | 35.00 | 10           | 37.04 | 7           | 30.43 |
| Participant describes withdrawing from activities with family and friends due to physical limitations                  | 16               | 32.00 | 10           | 33.33 | 6     | 30.00 | 8            | 29.63 | 8           | 34.78 |
| Participant describes accessing mental health services to maintain high QOL  | 13               | 26.00 | 6            | 20.00 | 7     | 35.00 | 6            | 22.22 | 7           | 30.43 |
| Participant describes having some days where physical limitations can be frustrating                                   | 12               | 24.00 | 9            | 30.00 | 4     | 20.00 | 6            | 22.22 | 7           | 30.43 |
| Participant describes the limitations of freedom to travel   | 8                | 16.00 | 8            | 26.67 | 1     | 5.00  | 6            | 22.22 | 3           | 13.04 |
| Participant describes poor mental health of family or friends as carers as a consequence of the disease                | 8                | 16.00 | 4            | 13.33 | 4     | 20.00 | 4            | 14.81 | 4           | 17.39 |
| Participant describes pleasure with maintaining hobbies and activities to overcome feelings of sadness or depression   | 7                | 14.00 | 2            | 6.67  | 5     | 25.00 | 4            | 14.81 | 3           | 13.04 |
| Participant describes inability to participate in workforce to their level of expectation due to Mitochondrial disease | 7                | 14.00 | 4            | 13.33 | 4     | 20.00 | 2            | 7.41  | 6           | 26.09 |
| Participant describes little or no impact for family or friends in relation to quality of life                         | 6                | 12.00 | 5            | 16.67 | 1     | 5.00  | 3            | 11.11 | 3           | 13.04 |
| Participant describes no real affect on quality of life of patient   | 5                | 10.00 | 2            | 6.67  | 3     | 15.00 | 3            | 11.11 | 2           | 8.70  |
| Participant describes feelings of sadness and/or frustration with experiencing episodes of illness or injury           | 5                | 10.00 | 3            | 10.00 | 2     | 10.00 | 3            | 11.11 | 2           | 8.70  |



| Impact on quality of life  | All participants |       | High school or trade |       | University |       | Hearing impairment |       | Eye or visual impairment |       |
|--|------------------|-------|----------------------|-------|------------|-------|--------------------|-------|--------------------------|-------|
|  | n=50             | %     | n=26                 | %     | n=24       | %     | n=24               | %     | n=34                     | %     |
| Participant describes poor mental health of patient as a consequence of the disease                                    | 19               | 38.00 | 8                    | 30.77 | 11         | 45.83 | 11                 | 45.83 | 13                       | 38.24 |
| Participant describes a significant impact on family relationships and family dynamics                                 | 16               | 32.00 | 10                   | 38.46 | 7          | 29.17 | 8                  | 33.33 | 10                       | 29.41 |
| Participant describes withdrawing from activities with family and friends due to physical limitations                  | 16               | 32.00 | 10                   | 38.46 | 6          | 25.00 | 8                  | 33.33 | 14                       | 41.18 |
| Participant describes accessing mental health services to maintain high QOL  | 13               | 26.00 | 5                    | 19.23 | 8          | 33.33 | 7                  | 29.17 | 7                        | 20.59 |
| Participant describes having some days where physical limitations can be frustrating                                   | 12               | 24.00 | 9                    | 34.62 | 4          | 16.67 | 7                  | 29.17 | 10                       | 29.41 |
| Participant describes the limitations of freedom to travel   | 8                | 16.00 | 5                    | 19.23 | 4          | 16.67 | 4                  | 16.67 | 6                        | 17.65 |
| Participant describes poor mental health of family or friends as carers as a consequence of the disease                | 8                | 16.00 | 4                    | 15.38 | 4          | 16.67 | 5                  | 20.83 | 6                        | 17.65 |
| Participant describes pleasure with maintaining hobbies and activities to overcome feelings of sadness or depression   | 7                | 14.00 | 5                    | 19.23 | 2          | 8.33  | 4                  | 16.67 | 5                        | 14.71 |
| Participant describes inability to participate in workforce to their level of expectation due to Mitochondrial disease | 7                | 14.00 | 2                    | 7.69  | 6          | 25.00 | 4                  | 16.67 | 5                        | 14.71 |
| Participant describes little or no impact for family or friends in relation to quality of life                         | 6                | 12.00 | 3                    | 11.54 | 3          | 12.50 | 1                  | 4.17  | 5                        | 14.71 |
| Participant describes no real affect on quality of life of patient   | 5                | 10.00 | 4                    | 15.38 | 1          | 4.17  | 2                  | 8.33  | 4                        | 11.76 |
| Participant describes feelings of sadness and/or frustration with experiencing episodes of illness or injury           | 5                | 10.00 | 2                    | 7.69  | 3          | 12.50 | 1                  | 4.17  | 3                        | 8.82  |





| Impact on quality of life  | All participants |       | Physical function (High) |       | Physical function (Low) |       | Emotional well-being (High) |       | Emotional well-being (Low) |       |
|--|------------------|-------|--------------------------|-------|-------------------------|-------|-----------------------------|-------|----------------------------|-------|
|  | n=50             | %     | n=22                     | %     | n=28                    | %     | n=26                        | %     | n=24                       | %     |
| Participant describes poor mental health of patient as a consequence of the disease                                    | 19               | 38.00 | 6                        | 27.27 | 13                      | 46.43 | 11                          | 42.31 | 8                          | 33.33 |
| Participant describes a significant impact on family relationships and family dynamics                                 | 16               | 32.00 | 6                        | 27.27 | 11                      | 39.29 | 7                           | 26.92 | 10                         | 41.67 |
| Participant describes withdrawing from activities with family and friends due to physical limitations                  | 16               | 32.00 | 7                        | 31.82 | 9                       | 32.14 | 10                          | 38.46 | 6                          | 25.00 |
| Participant describes accessing mental health services to maintain high QOL  | 13               | 26.00 | 5                        | 22.73 | 8                       | 28.57 | 4                           | 15.38 | 9                          | 37.50 |
| Participant describes having some days where physical limitations can be frustrating                                   | 12               | 24.00 | 8                        | 36.36 | 5                       | 17.86 | 6                           | 23.08 | 7                          | 29.17 |
| Participant describes the limitations of freedom to travel   | 8                | 16.00 | 6                        | 27.27 | 3                       | 10.71 | 6                           | 23.08 | 3                          | 12.50 |
| Participant describes poor mental health of family or friends as carers as a consequence of the disease                | 8                | 16.00 | 4                        | 18.18 | 4                       | 14.29 | 4                           | 15.38 | 4                          | 16.67 |
| Participant describes pleasure with maintaining hobbies and activities to overcome feelings of sadness or depression   | 7                | 14.00 | 1                        | 4.55  | 6                       | 21.43 | 5                           | 19.23 | 2                          | 8.33  |
| Participant describes inability to participate in workforce to their level of expectation due to Mitochondrial disease | 7                | 14.00 | 4                        | 18.18 | 4                       | 14.29 | 3                           | 11.54 | 5                          | 20.83 |
| Participant describes little or no impact for family or friends in relation to quality of life                         | 6                | 12.00 | 5                        | 22.73 | 1                       | 3.57  | 4                           | 15.38 | 2                          | 8.33  |
| Participant describes no real affect on quality of life of patient   | 5                | 10.00 | 3                        | 13.64 | 2                       | 7.14  | 4                           | 15.38 | 1                          | 4.17  |
| Participant describes feelings of sadness and/or frustration with experiencing episodes of illness or injury           | 5                | 10.00 | 1                        | 4.55  | 4                       | 14.29 | 1                           | 3.85  | 4                          | 16.67 |

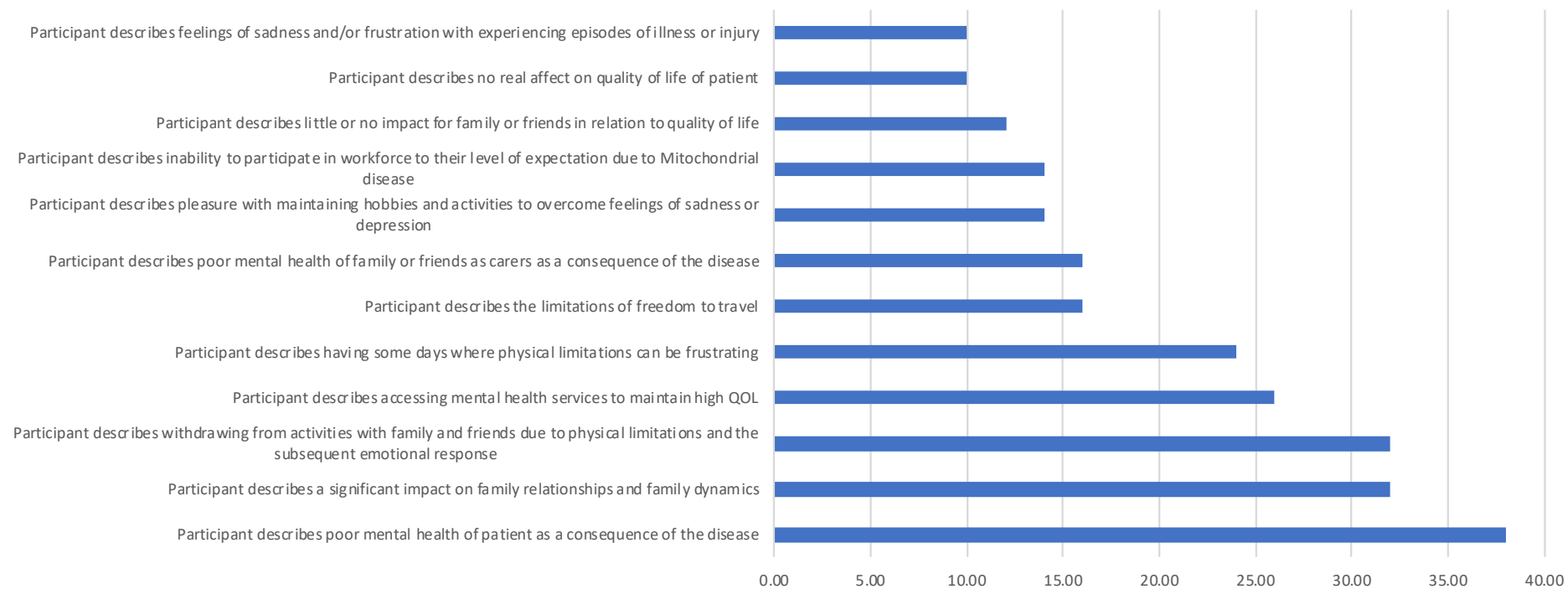


| Impact on quality of life  | All participants |       | Social functioning (High) |       | Social functioning (Low) |       | General health (High) |       | General health (Low) |       |
|--|------------------|-------|---------------------------|-------|--------------------------|-------|-----------------------|-------|----------------------|-------|
|  | n=50             | %     | n=20                      | %     | n=30                     | %     | n=22                  | %     | n=28                 | %     |
| Participant describes poor mental health of patient as a consequence of the disease                                    | 19               | 38.00 | 5                         | 25.00 | 14                       | 46.67 | 7                     | 31.82 | 12                   | 42.86 |
| Participant describes a significant impact on family relationships and family dynamics                                 | 16               | 32.00 | 6                         | 30.00 | 11                       | 36.67 | 8                     | 36.36 | 9                    | 32.14 |
| Participant describes withdrawing from activities with family and friends due to physical limitations                  | 16               | 32.00 | 5                         | 25.00 | 11                       | 36.67 | 7                     | 31.82 | 9                    | 32.14 |
| Participant describes accessing mental health services to maintain high QOL  | 13               | 26.00 | 4                         | 20.00 | 9                        | 30.00 | 3                     | 13.64 | 10                   | 35.71 |
| Participant describes having some days where physical limitations can be frustrating                                   | 12               | 24.00 | 6                         | 30.00 | 7                        | 23.33 | 6                     | 27.27 | 7                    | 25.00 |
| Participant describes the limitations of freedom to travel   | 8                | 16.00 | 5                         | 25.00 | 4                        | 13.33 | 5                     | 22.73 | 4                    | 14.29 |
| Participant describes poor mental health of family or friends as carers as a consequence of the disease                | 8                | 16.00 | 3                         | 15.00 | 5                        | 16.67 | 5                     | 22.73 | 3                    | 10.71 |
| Participant describes pleasure with maintaining hobbies and activities to overcome feelings of sadness or depression   | 7                | 14.00 | 3                         | 15.00 | 4                        | 13.33 | 3                     | 13.64 | 4                    | 14.29 |
| Participant describes inability to participate in workforce to their level of expectation due to Mitochondrial disease | 7                | 14.00 | 3                         | 15.00 | 5                        | 16.67 | 3                     | 13.64 | 5                    | 17.86 |
| Participant describes little or no impact for family or friends in relation to quality of life                         | 6                | 12.00 | 3                         | 15.00 | 3                        | 10.00 | 4                     | 18.18 | 2                    | 7.14  |
| Participant describes no real affect on quality of life of patient   | 5                | 10.00 | 3                         | 15.00 | 2                        | 6.67  | 3                     | 13.64 | 2                    | 7.14  |
| Participant describes feelings of sadness and/or frustration with experiencing episodes of illness or injury           | 5                | 10.00 | 0                         | 0.00  | 5                        | 16.67 | 2                     | 9.09  | 3                    | 10.71 |



| Impact on quality of life  | All participants |       | Under 18 |       | 24-44 |       | 45-54 |       | 55-64 |       | 65-74+ |       |
|--|------------------|-------|----------|-------|-------|-------|-------|-------|-------|-------|--------|-------|
|  | n=50             | %     | n=6      | %     | n=14  | %     | n=9   | %     | n=11  | %     | n=10   | %     |
| Participant describes poor mental health of patient as a consequence of the disease                                    | 19               | 38.00 | 2        | 33.33 | 9     | 64.29 | 1     | 11.11 | 4     | 36.36 | 3      | 30.00 |
| Participant describes a significant impact on family relationships and family dynamics                                 | 16               | 32.00 | 3        | 50.00 | 3     | 21.43 | 2     | 22.22 | 5     | 45.45 | 4      | 40.00 |
| Participant describes withdrawing from activities with family and friends due to physical limitations                  | 16               | 32.00 | 2        | 33.33 | 2     | 14.29 | 2     | 22.22 | 7     | 63.64 | 3      | 30.00 |
| Participant describes accessing mental health services to maintain high QOL  | 13               | 26.00 | 2        | 33.33 | 2     | 14.29 | 3     | 33.33 | 4     | 36.36 | 2      | 20.00 |
| Participant describes having some days where physical limitations can be frustrating                                   | 12               | 24.00 | 2        | 33.33 | 3     | 21.43 | 5     | 55.56 | 1     | 9.09  | 2      | 20.00 |
| Participant describes the limitations of freedom to travel   | 8                | 16.00 | 2        | 33.33 | 3     | 21.43 | 2     | 22.22 | 2     | 18.18 | 0      | 0.00  |
| Participant describes poor mental health of family or friends as carers as a consequence of the disease                | 8                | 16.00 | 2        | 33.33 | 2     | 14.29 | 1     | 11.11 | 2     | 18.18 | 1      | 10.00 |
| Participant describes pleasure with maintaining hobbies and activities to overcome feelings of sadness or depression   | 7                | 14.00 | 1        | 16.67 | 1     | 7.14  | 2     | 22.22 | 2     | 18.18 | 1      | 10.00 |
| Participant describes inability to participate in workforce to their level of expectation due to Mitochondrial disease | 7                | 14.00 | 1        | 16.67 | 3     | 21.43 | 0     | 0.00  | 4     | 36.36 | 0      | 0.00  |
| Participant describes little or no impact for family or friends in relation to quality of life                         | 6                | 12.00 | 0        | 0.00  | 2     | 14.29 | 1     | 11.11 | 1     | 9.09  | 2      | 20.00 |
| Participant describes no real affect on quality of life of patient   | 5                | 10.00 | 1        | 16.67 | 2     | 14.29 | 0     | 0.00  | 1     | 9.09  | 1      | 10.00 |
| Participant describes feelings of sadness and/or frustration with experiencing episodes of illness or injury           | 5                | 10.00 | 1        | 16.67 | 1     | 7.14  | 1     | 11.11 | 1     | 9.09  | 1      | 10.00 |





| Regular activities to maintain health  | All participants |       | Metropolitan |       | Rural |       | SEIFA (High) |       | SEIFA (Low) |       |
|--|------------------|-------|--------------|-------|-------|-------|--------------|-------|-------------|-------|
|  | n=50             | %     | n=30         | %     | n=20  | %     | n=27         | %     | n=23        | %     |
| Participants reports ensuring they have adequate rest to minimise fatigue  | 21               | 42.00 | 13           | 43.33 | 9     | 45.00 | 9            | 33.33 | 13          | 56.52 |
| Participant reports having regular exercise to increase energy levels  | 15               | 30.00 | 10           | 33.33 | 5     | 25.00 | 10           | 37.04 | 5           | 21.74 |
| Participant describes eating a healthy and/or modified diet  | 10               | 20.00 | 6            | 20.00 | 4     | 20.00 | 6            | 22.22 | 4           | 17.39 |
| Participant describes taking prescribed medication on a daily basis  | 7                | 14.00 | 3            | 10.00 | 4     | 20.00 | 3            | 11.11 | 4           | 17.39 |
| Participant describes taking supplements on a daily basis  | 6                | 12.00 | 4            | 13.33 | 2     | 10.00 | 5            | 18.52 | 1           | 4.35  |
| Participant reports maintaining hobbies and activities in support of good mental health  | 6                | 12.00 | 5            | 16.67 | 1     | 5.00  | 3            | 11.11 | 3           | 13.04 |
| Participants reports no modification to behaviour or diet- just takes each day as it comes   | 5                | 10.00 | 2            | 6.67  | 3     | 15.00 | 2            | 7.41  | 3           | 13.04 |
| Participant reports requiring home care or family providing care 24/7  | 5                | 10.00 | 4            | 13.33 | 1     | 5.00  | 3            | 11.11 | 2           | 8.70  |
| Participant recommends minimising daily activities or using the spoon theory to accomplish all necessary requirements of a daily or weekly basis | 5                | 10.00 | 3            | 10.00 | 2     | 10.00 | 3            | 11.11 | 2           | 8.70  |
| Participant reports that monitoring health to ensure continuous good health  | 5                | 10.00 | 2            | 6.67  | 3     | 15.00 | 2            | 7.41  | 3           | 13.04 |
| Participant reports maintaining a positive frame of mind   | 4                | 8.00  | 4            | 13.33 | 0     | 0.00  | 2            | 7.41  | 2           | 8.70  |



| Regular activities to maintain health  | All participants |       | High school or trade |       | University |       | Hearing impairment |       | Eye or visual impairment |       |
|--|------------------|-------|----------------------|-------|------------|-------|--------------------|-------|--------------------------|-------|
|  | n=50             | %     | n=26                 | %     | n=24       | %     | n=24               | %     | n=34                     | %     |
| Participants reports ensuring they have adequate rest to minimise fatigue  | 21               | 42.00 | 12                   | 46.15 | 10         | 41.67 | 10                 | 41.67 | 14                       | 41.18 |
| Participant reports having regular exercise to increase energy levels  | 15               | 30.00 | 6                    | 23.08 | 9          | 37.50 | 9                  | 37.50 | 9                        | 26.47 |
| Participant describes eating a healthy and/or modified diet  | 10               | 20.00 | 4                    | 15.38 | 6          | 25.00 | 4                  | 16.67 | 7                        | 20.59 |
| Participant describes taking prescribed medication on a daily basis  | 7                | 14.00 | 2                    | 7.69  | 5          | 20.83 | 5                  | 20.83 | 5                        | 14.71 |
| Participant describes taking supplements on a daily basis  | 6                | 12.00 | 4                    | 15.38 | 2          | 8.33  | 4                  | 16.67 | 4                        | 11.76 |
| Participant reports maintaining hobbies and activities in support of good mental health  | 6                | 12.00 | 4                    | 15.38 | 2          | 8.33  | 3                  | 12.50 | 4                        | 11.76 |
| Participants reports no modification to behaviour or diet- just takes each day as it comes   | 5                | 10.00 | 5                    | 19.23 | 0          | 0.00  | 0                  | 0.00  | 5                        | 14.71 |
| Participant reports requiring home care or family providing care 24/7  | 5                | 10.00 | 2                    | 7.69  | 3          | 12.50 | 2                  | 8.33  | 4                        | 11.76 |
| Participant recommends minimising daily activities or using the spoon theory to accomplish all necessary requirements of a daily or weekly basis | 5                | 10.00 | 0                    | 0.00  | 5          | 20.83 | 3                  | 12.50 | 4                        | 11.76 |
| Participant reports that monitoring health to ensure continuous good health  | 5                | 10.00 | 2                    | 7.69  | 3          | 12.50 | 3                  | 12.50 | 4                        | 11.76 |
| Participant reports maintaining a positive frame of mind   | 4                | 8.00  | 2                    | 7.69  | 2          | 8.33  | 3                  | 12.50 | 3                        | 8.82  |



| Regular activities to maintain health  | All participants |       | Physical function (High) |       | Physical function (Low) |       | Emotional well-being (High) |       | Emotional well-being (Low) |       |
|--|------------------|-------|--------------------------|-------|-------------------------|-------|-----------------------------|-------|----------------------------|-------|
|  | n=50             | %     | n=22                     | %     | n=28                    | %     | n=26                        | %     | n=24                       | %     |
| Participants reports ensuring they have adequate rest to minimise fatigue  | 21               | 42.00 | 10                       | 45.45 | 12                      | 42.86 | 11                          | 42.31 | 11                         | 45.83 |
| Participant reports having regular exercise to increase energy levels  | 15               | 30.00 | 11                       | 50.00 | 4                       | 14.29 | 10                          | 38.46 | 5                          | 20.83 |
| Participant describes eating a healthy and/or modified diet  | 10               | 20.00 | 6                        | 27.27 | 4                       | 14.29 | 5                           | 19.23 | 5                          | 20.83 |
| Participant describes taking prescribed medication on a daily basis  | 7                | 14.00 | 2                        | 9.09  | 5                       | 17.86 | 3                           | 11.54 | 4                          | 16.67 |
| Participant describes taking supplements on a daily basis  | 6                | 12.00 | 4                        | 18.18 | 2                       | 7.14  | 4                           | 15.38 | 2                          | 8.33  |
| Participant reports maintaining hobbies and activities in support of good mental health  | 6                | 12.00 | 2                        | 9.09  | 4                       | 14.29 | 4                           | 15.38 | 2                          | 8.33  |
| Participants reports no modification to behaviour or diet- just takes each day as it comes   | 5                | 10.00 | 0                        | 0.00  | 5                       | 17.86 | 0                           | 0.00  | 5                          | 20.83 |
| Participant reports requiring home care or family providing care 24/7  | 5                | 10.00 | 2                        | 9.09  | 3                       | 10.71 | 1                           | 3.85  | 4                          | 16.67 |
| Participant recommends minimising daily activities or using the spoon theory to accomplish all necessary requirements of a daily or weekly basis | 5                | 10.00 | 1                        | 4.55  | 4                       | 14.29 | 4                           | 15.38 | 1                          | 4.17  |
| Participant reports that monitoring health to ensure continuous good health  | 5                | 10.00 | 1                        | 4.55  | 4                       | 14.29 | 3                           | 11.54 | 2                          | 8.33  |
| Participant reports maintaining a positive frame of mind   | 4                | 8.00  | 3                        | 13.64 | 1                       | 3.57  | 2                           | 7.69  | 2                          | 8.33  |



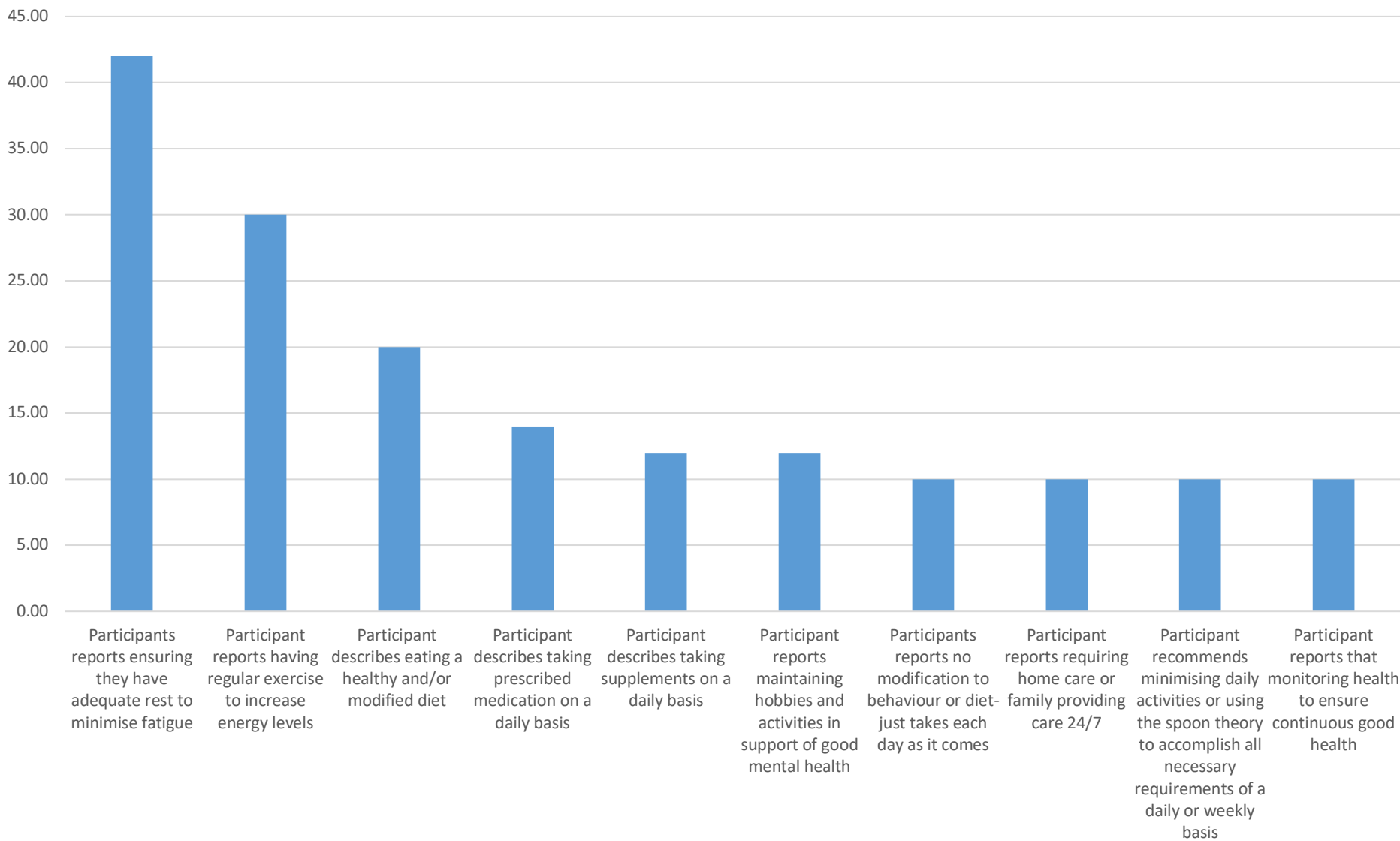
| Regular activities to maintain health  | All participants |       | Social functioning (High) |       | Social functioning (Low) |       | General health (High) |       | General health (Low) |       |
|--|------------------|-------|---------------------------|-------|--------------------------|-------|-----------------------|-------|----------------------|-------|
|  | n=50             | %     | n=20                      | %     | n=30                     | %     | n=22                  | %     | n=28                 | %     |
| Participants reports ensuring they have adequate rest to minimise fatigue  | 21               | 42.00 | 12                        | 60.00 | 10                       | 33.33 | 6                     | 27.27 | 16                   | 57.14 |
| Participant reports having regular exercise to increase energy levels  | 15               | 30.00 | 6                         | 30.00 | 9                        | 30.00 | 10                    | 45.45 | 5                    | 17.86 |
| Participant describes eating a healthy and/or modified diet  | 10               | 20.00 | 5                         | 25.00 | 5                        | 16.67 | 4                     | 18.18 | 6                    | 21.43 |
| Participant describes taking prescribed medication on a daily basis  | 7                | 14.00 | 1                         | 5.00  | 6                        | 20.00 | 1                     | 4.55  | 6                    | 21.43 |
| Participant describes taking supplements on a daily basis  | 6                | 12.00 | 3                         | 15.00 | 3                        | 10.00 | 2                     | 9.09  | 4                    | 14.29 |
| Participant reports maintaining hobbies and activities in support of good mental health  | 6                | 12.00 | 2                         | 10.00 | 4                        | 13.33 | 2                     | 9.09  | 4                    | 14.29 |
| Participants reports no modification to behaviour or diet- just takes each day as it comes   | 5                | 10.00 | 0                         | 0.00  | 5                        | 16.67 | 0                     | 0.00  | 5                    | 17.86 |
| Participant reports requiring home care or family providing care 24/7  | 5                | 10.00 | 1                         | 5.00  | 4                        | 13.33 | 2                     | 9.09  | 3                    | 10.71 |
| Participant recommends minimising daily activities or using the spoon theory to accomplish all necessary requirements of a daily or weekly basis | 5                | 10.00 | 2                         | 10.00 | 3                        | 10.00 | 1                     | 4.55  | 4                    | 14.29 |
| Participant reports that monitoring health to ensure continuous good health  | 5                | 10.00 | 1                         | 5.00  | 4                        | 13.33 | 2                     | 9.09  | 3                    | 10.71 |
| Participant reports maintaining a positive frame of mind   | 4                | 8.00  | 2                         | 10.00 | 2                        | 6.67  | 1                     | 4.55  | 3                    | 10.71 |





| Regular activities to maintain health  | All participants |       | Under 18 |       | 24-44 |       | 45-54 |       | 55-64 |       | 65-74+ |       |
|--|------------------|-------|----------|-------|-------|-------|-------|-------|-------|-------|--------|-------|
|  | n=50             | %     | n=6      | %     | n=14  | %     | n=9   | %     | n=11  | %     | n=10   | %     |
| Participants reports ensuring they have adequate rest to minimise fatigue  | 21               | 42.00 | 3        | 50.00 | 8     | 57.14 | 3     | 33.33 | 3     | 27.27 | 5      | 50.00 |
| Participant reports completing regular exercise  | 15               | 30.00 | 2        | 33.33 | 5     | 35.71 | 1     | 11.11 | 4     | 36.36 | 3      | 30.00 |
| Participant reports having regular exercise to increase energy levels  | 10               | 20.00 | 0        | 0.00  | 4     | 28.57 | 3     | 33.33 | 2     | 18.18 | 1      | 10.00 |
| Participant describes eating a healthy and/or modified diet  | 7                | 14.00 | 1        | 16.67 | 3     | 21.43 | 2     | 22.22 | 1     | 9.09  | 0      | 0.00  |
| Participant describes taking prescribed medication on a daily basis  | 6                | 12.00 | 1        | 16.67 | 2     | 14.29 | 1     | 11.11 | 1     | 9.09  | 1      | 10.00 |
| Participant describes taking supplements on a daily basis  | 6                | 12.00 | 1        | 16.67 | 2     | 14.29 | 1     | 11.11 | 1     | 9.09  | 1      | 10.00 |
| Participant reports maintaining hobbies and activities in support of good mental health  | 5                | 10.00 | 0        | 0.00  | 1     | 7.14  | 0     | 0.00  | 3     | 27.27 | 1      | 10.00 |
| Participants reports no modification to behaviour or diet- just takes each day as it comes   | 5                | 10.00 | 0        | 0.00  | 3     | 21.43 | 1     | 11.11 | 1     | 9.09  | 0      | 0.00  |
| Participant reports requiring home care or family providing care 24/7  | 5                | 10.00 | 0        | 0.00  | 1     | 7.14  | 1     | 11.11 | 3     | 27.27 | 0      | 0.00  |
| Participant recommends minimising daily activities or using the spoon theory to accomplish all necessary requirements of a daily or weekly basis | 5                | 10.00 | 2        | 33.33 | 3     | 21.43 | 0     | 0.00  | 0     | 0.00  | 0      | 0.00  |
| Participant reports that monitoring health to ensure continuous good health  | 4                | 8.00  | 0        | 0.00  | 1     | 7.14  | 2     | 22.22 | 1     | 9.09  | 0      | 0.00  |





| Impact on relationships  | All participants |       | Metropolitan |       | Rural |       | SEIFA (High) |       | SEIFA (Low) |       |
|--|------------------|-------|--------------|-------|-------|-------|--------------|-------|-------------|-------|
|  | n=50             | %     | n=30         | %     | n=20  | %     | n=27         | %     | n=23        | %     |
| Participant describes a negative impact on personal relationships due to people withdrawing from relationships or not being able to understand | 14               | 28.00 | 7            | 23.33 | 7     | 35.00 | 4            | 14.81 | 10          | 43.48 |
| Participant describes a negative impact on personal relationships due to social isolation  | 11               | 22.00 | 10           | 33.33 | 2     | 10.00 | 7            | 25.93 | 5           | 21.74 |
| Participant describes a negative impact on personal relationships due to not being able to do all activities with family and friends           | 10               | 20.00 | 5            | 16.67 | 5     | 25.00 | 3            | 11.11 | 7           | 30.43 |
| Participant describes no impact on personal relationships (No specific reason)   | 8                | 16.00 | 6            | 20.00 | 2     | 10.00 | 6            | 22.22 | 2           | 8.70  |
| Participant describes a positive impact of strengthening relationships   | 6                | 12.00 | 3            | 10.00 | 3     | 15.00 | 4            | 14.81 | 2           | 8.70  |
| Participant describes impact on personal relationships (No specific reason)  | 5                | 10.00 | 4            | 13.33 | 1     | 5.00  | 3            | 11.11 | 2           | 8.70  |
| Participant describes a negative impact of personal relationships due to communication problems (associated with hearing loss)                 | 5                | 10.00 | 3            | 10.00 | 2     | 10.00 | 2            | 7.41  | 3           | 13.04 |



| Impact on relationships  | All participants |       | High school or trade |       | University |       | Hearing impairment |       | Eye or visual impairment |       |
|--|------------------|-------|----------------------|-------|------------|-------|--------------------|-------|--------------------------|-------|
|  | n=50             | %     | n=26                 | %     | n=24       | %     | n=24               | %     | n=34                     | %     |
| Participant describes a negative impact on personal relationships due to people withdrawing from relationships or not being able to understand | 14               | 28.00 | 8                    | 30.77 | 6          | 25.00 | 8                  | 33.33 | 11                       | 32.35 |
| Participant describes a negative impact on personal relationships due to social isolation  | 11               | 22.00 | 6                    | 23.08 | 6          | 25.00 | 3                  | 12.50 | 8                        | 23.53 |
| Participant describes a negative impact on personal relationships due to not being able to do all activities with family and friends           | 10               | 20.00 | 5                    | 19.23 | 5          | 20.83 | 5                  | 20.83 | 8                        | 23.53 |
| Participant describes no impact on personal relationships (No specific reason)   | 8                | 16.00 | 6                    | 23.08 | 2          | 8.33  | 3                  | 12.50 | 5                        | 14.71 |
| Participant describes a positive impact of strengthening relationships   | 6                | 12.00 | 5                    | 19.23 | 1          | 4.17  | 3                  | 12.50 | 5                        | 14.71 |
| Participant describes impact on personal relationships (No specific reason)  | 5                | 10.00 | 2                    | 7.69  | 3          | 12.50 | 1                  | 4.17  | 1                        | 2.94  |
| Participant describes a negative impact of personal relationships due to communication problems (associated with hearing loss)                 | 5                | 10.00 | 4                    | 15.38 | 1          | 4.17  | 3                  | 12.50 | 5                        | 14.71 |



| Impact on relationships  | All participants |       | Physical function (High) |       | Physical function (Low) |       | Emotional well-being (High) |       | Emotional well-being (Low) |       |
|--|------------------|-------|--------------------------|-------|-------------------------|-------|-----------------------------|-------|----------------------------|-------|
|  | n=50             | %     | n=22                     | %     | n=28                    | %     | n=26                        | %     | n=24                       | %     |
| Participant describes a negative impact on personal relationships due to people withdrawing from relationships or not being able to understand | 14               | 28.00 | 7                        | 31.82 | 7                       | 25.00 | 5                           | 19.23 | 9                          | 37.50 |
| Participant describes a negative impact on personal relationships due to social isolation  | 11               | 22.00 | 4                        | 18.18 | 8                       | 28.57 | 4                           | 15.38 | 8                          | 33.33 |
| Participant describes a negative impact on personal relationships due to not being able to do all activities with family and friends           | 10               | 20.00 | 4                        | 18.18 | 6                       | 21.43 | 5                           | 19.23 | 5                          | 20.83 |
| Participant describes no impact on personal relationships (No specific reason)   | 8                | 16.00 | 6                        | 27.27 | 2                       | 7.14  | 6                           | 23.08 | 2                          | 8.33  |
| Participant describes a positive impact of strengthening relationships   | 6                | 12.00 | 2                        | 9.09  | 4                       | 14.29 | 2                           | 7.69  | 4                          | 16.67 |
| Participant describes impact on personal relationships (No specific reason)  | 5                | 10.00 | 2                        | 9.09  | 3                       | 10.71 | 4                           | 15.38 | 1                          | 4.17  |
| Participant describes a negative impact of personal relationships due to communication problems (associated with hearing loss)                 | 5                | 10.00 | 3                        | 13.64 | 2                       | 7.14  | 2                           | 7.69  | 3                          | 12.50 |

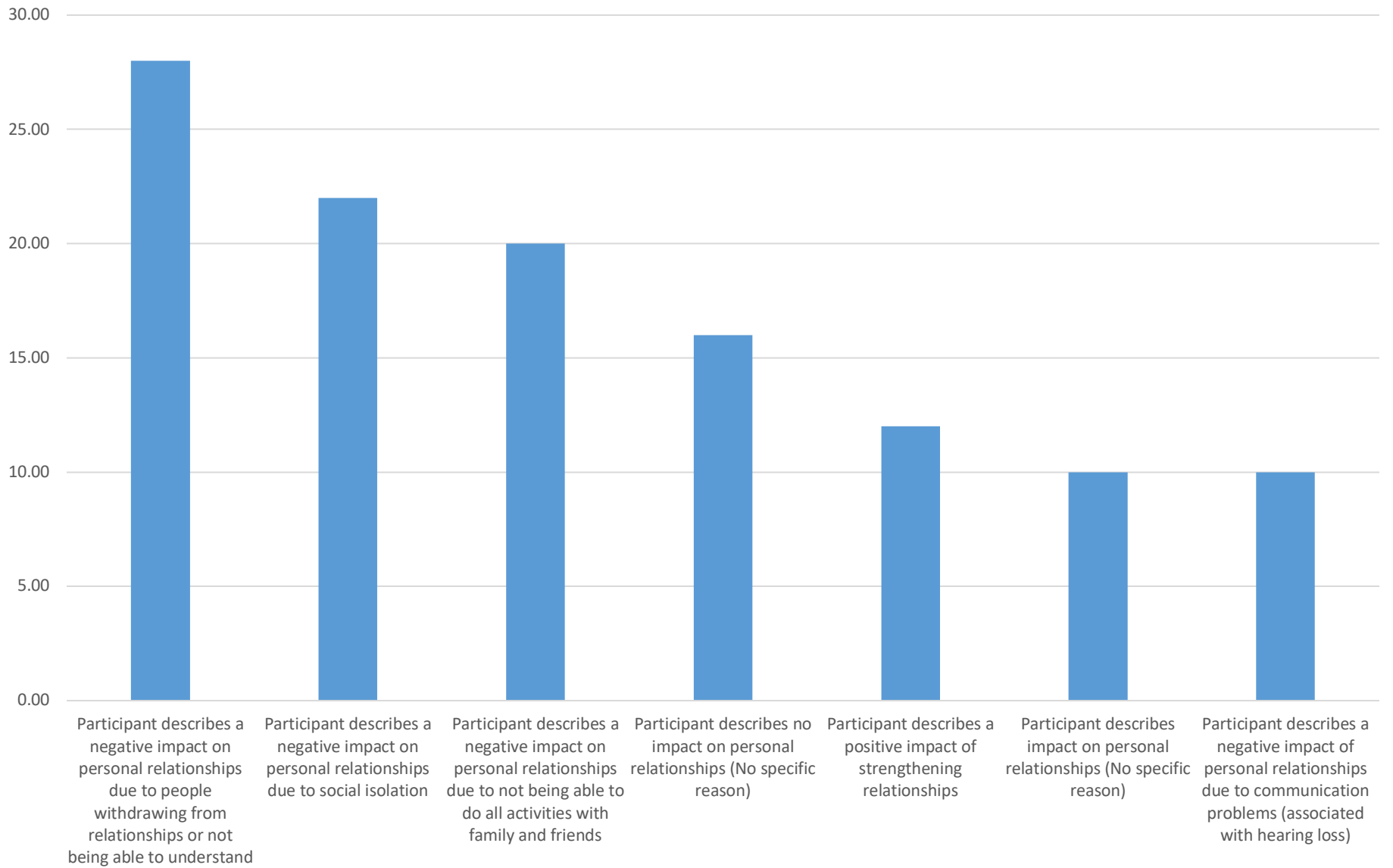


| Impact on relationships  | All participants |       | Social functioning (High) |       | Social functioning (Low) |       | General health (High) |       | General health (Low) |       |
|--|------------------|-------|---------------------------|-------|--------------------------|-------|-----------------------|-------|----------------------|-------|
|  | n=50             | %     | n=20                      | %     | n=30                     | %     | n=22                  | %     | n=28                 | %     |
| Participant describes a negative impact on personal relationships due to people withdrawing from relationships or not being able to understand | 14               | 28.00 | 2                         | 10.00 | 12                       | 40.00 | 5                     | 22.73 | 9                    | 32.14 |
| Participant describes a negative impact on personal relationships due to social isolation  | 11               | 22.00 | 3                         | 15.00 | 9                        | 30.00 | 4                     | 18.18 | 8                    | 28.57 |
| Participant describes a negative impact on personal relationships due to not being able to do all activities with family and friends           | 10               | 20.00 | 5                         | 25.00 | 5                        | 16.67 | 4                     | 18.18 | 6                    | 21.43 |
| Participant describes no impact on personal relationships (No specific reason)   | 8                | 16.00 | 7                         | 35.00 | 1                        | 3.33  | 5                     | 22.73 | 3                    | 10.71 |
| Participant describes a positive impact of strengthening relationships   | 6                | 12.00 | 2                         | 10.00 | 4                        | 13.33 | 0                     | 0.00  | 6                    | 21.43 |
| Participant describes impact on personal relationships (No specific reason)  | 5                | 10.00 | 4                         | 20.00 | 1                        | 3.33  | 3                     | 13.64 | 2                    | 7.14  |
| Participant describes a negative impact of personal relationships due to communication problems (associated with hearing loss)                 | 5                | 10.00 | 2                         | 10.00 | 3                        | 10.00 | 3                     | 13.64 | 2                    | 7.14  |



| Impact on relationships  | All participants |       | Under 18 |       | 24-44 |       | 45-54 |       | 55-64 |       | 65-74+ |       |
|--|------------------|-------|----------|-------|-------|-------|-------|-------|-------|-------|--------|-------|
|  | n=50             | %     | n=6      | %     | n=14  | %     | n=9   | %     | n=11  | %     | n=10   | %     |
| Participant describes a negative impact on personal relationships due to people withdrawing from relationships or not being able to understand | 14               | 28.00 | 1        | 16.67 | 5     | 35.71 | 2     | 22.22 | 4     | 36.36 | 2      | 20.00 |
| Participant describes a negative impact on personal relationships due to social isolation  | 11               | 22.00 | 3        | 50.00 | 4     | 28.57 | 0     | 0.00  | 3     | 27.27 | 2      | 20.00 |
| Participant describes a negative impact on personal relationships due to not being able to do all activities with family and friends           | 10               | 20.00 | 1        | 16.67 | 3     | 21.43 | 3     | 33.33 | 1     | 9.09  | 2      | 20.00 |
| Participant describes no impact on personal relationships (No specific reason)   | 8                | 16.00 | 0        | 0.00  | 2     | 14.29 | 2     | 22.22 | 1     | 9.09  | 3      | 30.00 |
| Participant describes a positive impact of strengthening relationships   | 6                | 12.00 | 1        | 16.67 | 3     | 21.43 | 0     | 0.00  | 2     | 18.18 | 0      | 0.00  |
| Participant describes impact on personal relationships (No specific reason)  | 5                | 10.00 | 1        | 16.67 | 1     | 7.14  | 2     | 22.22 | 0     | 0.00  | 1      | 10.00 |
| Participant describes a negative impact of personal relationships due to communication problems (associated with hearing loss)                 | 5                | 10.00 | 0        | 0.00  | 2     | 14.29 | 1     | 11.11 | 0     | 0.00  | 2      | 20.00 |







| Burden on family   | All participants |       | Metropolitan |       | Rural |       | SEIFA (High) |       | SEIFA (Low) |       |
|--|------------------|-------|--------------|-------|-------|-------|--------------|-------|-------------|-------|
|  | n=50             | %     | n=30         | %     | n=20  | %     | n=27         | %     | n=23        | %     |
| Participant describes there being an additional burden (No additional information)   | 13               | 26.00 | 7            | 23.33 | 6     | 30.00 | 8            | 29.63 | 5           | 21.74 |
| Participant describes there being an additional burden (Transport and driving due to vision impairment)  | 8                | 16.00 | 3            | 10.00 | 5     | 25.00 | 3            | 11.11 | 5           | 21.74 |
| Participant describes there not being an additional burden, that it is just part of their life as they know it.                                    | 7                | 14.00 | 3            | 10.00 | 4     | 20.00 | 3            | 11.11 | 4           | 17.39 |
| Participant describes there being an additional burden (Family required to take time to provide care or support)                                   | 5                | 10.00 | 3            | 10.00 | 2     | 10.00 | 2            | 7.41  | 3           | 13.04 |
| Participant describes there not being an additional burden, however it is something that they are concerned about for the future                   | 4                | 8.00  | 2            | 6.67  | 2     | 10.00 | 2            | 7.41  | 2           | 8.70  |
| Participant describes there not being an additional burden (No additional information)   | 4                | 8.00  | 4            | 13.33 | 0     | 0.00  | 2            | 7.41  | 2           | 8.70  |
| Participant describes there being an additional burden (Additional support to be able to participate in events/activities with family and friends) | 4                | 8.00  | 3            | 10.00 | 2     | 10.00 | 4            | 14.81 | 1           | 4.35  |



| Burden on family   | All participants |       | High school or trade |       | University |       | Hearing impairment |       | Eye or visual impairment |       |
|--|------------------|-------|----------------------|-------|------------|-------|--------------------|-------|--------------------------|-------|
|  | n=50             | %     | n=26                 | %     | n=24       | %     | n=24               | %     | n=34                     | %     |
| Participant describes there being an additional burden (No additional information)   | 13               | 26.00 | 4                    | 15.38 | 9          | 37.50 | 6                  | 25.00 | 7                        | 20.59 |
| Participant describes there being an additional burden (Transport and driving due to vision impairment)  | 8                | 16.00 | 5                    | 19.23 | 3          | 12.50 | 4                  | 16.67 | 7                        | 20.59 |
| Participant describes there not being an additional burden, that it is just part of their life as they know it.                                    | 7                | 14.00 | 3                    | 11.54 | 4          | 16.67 | 4                  | 16.67 | 6                        | 17.65 |
| Participant describes there being an additional burden (Family required to take time to provide care or support)                                   | 5                | 10.00 | 4                    | 15.38 | 1          | 4.17  | 4                  | 16.67 | 3                        | 8.82  |
| Participant describes there not being an additional burden, however it is something that they are concerned about for the future                   | 4                | 8.00  | 4                    | 15.38 | 0          | 0.00  | 2                  | 8.33  | 3                        | 8.82  |
| Participant describes there not being an additional burden (No additional information)   | 4                | 8.00  | 3                    | 11.54 | 1          | 4.17  | 1                  | 4.17  | 3                        | 8.82  |
| Participant describes there being an additional burden (Additional support to be able to participate in events/activities with family and friends) | 4                | 8.00  | 3                    | 11.54 | 2          | 8.33  | 2                  | 8.33  | 4                        | 11.76 |



| Burden on family   | All participants |       | Physical function (High) |       | Physical function (Low) |       | Emotional well-being (High) |       | Emotional well-being (Low) |       |
|--|------------------|-------|--------------------------|-------|-------------------------|-------|-----------------------------|-------|----------------------------|-------|
|  | n=50             | %     | n=22                     | %     | n=28                    | %     | n=26                        | %     | n=24                       | %     |
| Participant describes there being an additional burden (No additional information)   | 13               | 26.00 | 2                        | 9.09  | 11                      | 39.29 | 5                           | 19.23 | 8                          | 33.33 |
| Participant describes there being an additional burden (Transport and driving due to vision impairment)  | 8                | 16.00 | 4                        | 18.18 | 4                       | 14.29 | 6                           | 23.08 | 2                          | 8.33  |
| Participant describes there not being an additional burden, that it is just part of their life as they know it.                                    | 7                | 14.00 | 4                        | 18.18 | 3                       | 10.71 | 2                           | 7.69  | 5                          | 20.83 |
| Participant describes there being an additional burden (Family required to take time to provide care or support)                                   | 5                | 10.00 | 2                        | 9.09  | 3                       | 10.71 | 1                           | 3.85  | 4                          | 16.67 |
| Participant describes there not being an additional burden, however it is something that they are concerned about for the future                   | 4                | 8.00  | 2                        | 9.09  | 2                       | 7.14  | 3                           | 11.54 | 1                          | 4.17  |
| Participant describes there not being an additional burden (No additional information)   | 4                | 8.00  | 3                        | 13.64 | 1                       | 3.57  | 3                           | 11.54 | 1                          | 4.17  |
| Participant describes there being an additional burden (Additional support to be able to participate in events/activities with family and friends) | 4                | 8.00  | 1                        | 4.55  | 4                       | 14.29 | 4                           | 15.38 | 1                          | 4.17  |

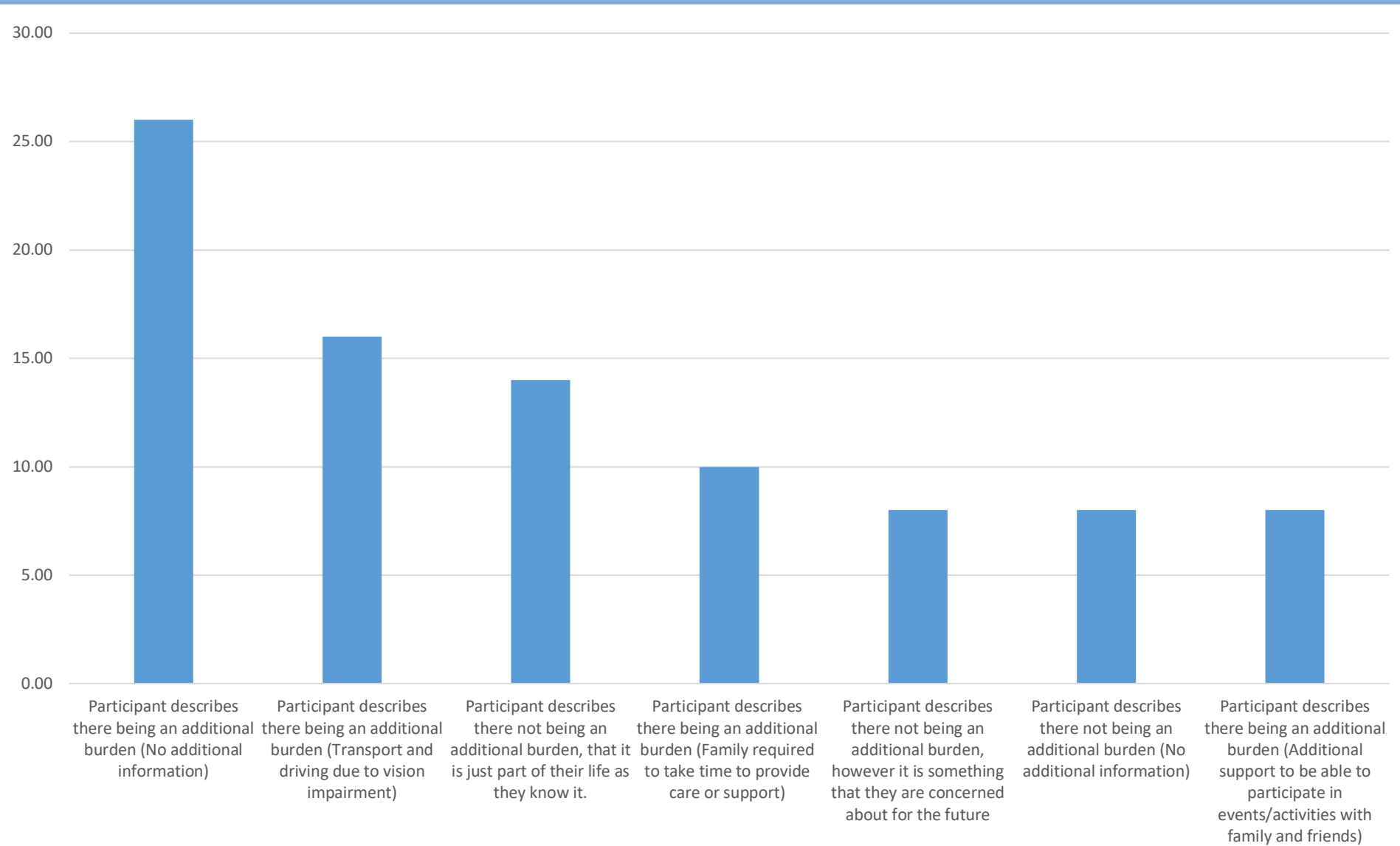


| Burden on family   | All participants |       | Social functioning (High) |       | Social functioning (Low) |       | General health (High) |       | General health (Low) |       |
|--|------------------|-------|---------------------------|-------|--------------------------|-------|-----------------------|-------|----------------------|-------|
|  | n=50             | %     | n=20                      | %     | n=30                     | %     | n=22                  | %     | n=28                 | %     |
| Participant describes there being an additional burden (No additional information)   | 13               | 26.00 | 3                         | 15.00 | 10                       | 33.33 | 6                     | 27.27 | 7                    | 25.00 |
| Participant describes there being an additional burden (Transport and driving due to vision impairment)  | 8                | 16.00 | 3                         | 15.00 | 5                        | 16.67 | 4                     | 18.18 | 4                    | 14.29 |
| Participant describes there not being an additional burden, that it is just part of their life as they know it.                                    | 7                | 14.00 | 3                         | 15.00 | 4                        | 13.33 | 3                     | 13.64 | 4                    | 14.29 |
| Participant describes there being an additional burden (Family required to take time to provide care or support)                                   | 5                | 10.00 | 1                         | 5.00  | 4                        | 13.33 | 0                     | 0.00  | 5                    | 17.86 |
| Participant describes there not being an additional burden, however it is something that they are concerned about for the future                   | 4                | 8.00  | 3                         | 15.00 | 1                        | 3.33  | 3                     | 13.64 | 1                    | 3.57  |
| Participant describes there not being an additional burden (No additional information)   | 4                | 8.00  | 3                         | 15.00 | 1                        | 3.33  | 2                     | 9.09  | 2                    | 7.14  |
| Participant describes there being an additional burden (Additional support to be able to participate in events/activities with family and friends) | 4                | 8.00  | 4                         | 20.00 | 1                        | 3.33  | 2                     | 9.09  | 3                    | 10.71 |



| Burden on family   | All participants |       | Under 18 |       | 24-44 |       | 45-54 |       | 55-64 |       | 65-74+ |       |
|--|------------------|-------|----------|-------|-------|-------|-------|-------|-------|-------|--------|-------|
|  | n=50             | %     | n=6      | %     | n=14  | %     | n=9   | %     | n=11  | %     | n=10   | %     |
| Participant describes there being an additional burden (No additional information)   | 13               | 26.00 | 3        | 50.00 | 2     | 14.29 | 1     | 11.11 | 4     | 36.36 | 3      | 30.00 |
| Participant describes there being an additional burden (Transport and driving due to vision impairment)  | 8                | 16.00 | 0        | 0.00  | 1     | 7.14  | 4     | 44.44 | 2     | 18.18 | 1      | 10.00 |
| Participant describes there not being an additional burden, that it is just part of their life as they know it.                                    | 7                | 14.00 | 1        | 16.67 | 4     | 28.57 | 0     | 0.00  | 2     | 18.18 | 0      | 0.00  |
| Participant describes there being an additional burden (Family required to take time to provide care or support)                                   | 5                | 10.00 | 0        | 0.00  | 3     | 21.43 | 0     | 0.00  | 1     | 9.09  | 1      | 10.00 |
| Participant describes there not being an additional burden, however it is something that they are concerned about for the future                   | 4                | 8.00  | 0        | 0.00  | 1     | 7.14  | 1     | 11.11 | 0     | 0.00  | 2      | 20.00 |
| Participant describes there not being an additional burden (No additional information)   | 4                | 8.00  | 0        | 0.00  | 2     | 14.29 | 0     | 0.00  | 0     | 0.00  | 2      | 20.00 |
| Participant describes there being an additional burden (Additional support to be able to participate in events/activities with family and friends) | 4                | 8.00  | 1        | 16.67 | 1     | 7.14  | 2     | 22.22 | 0     | 0.00  | 1      | 10.00 |







## SECTION 9: EXPECTATIONS & MESSAGES TO DECISION-MAKERS

| Expectations of future treatments   | All participants |       | Metropolitan |       | Rural |       | SEIFA (High) |       | SEIFA (Low) |       |
|---|------------------|-------|--------------|-------|-------|-------|--------------|-------|-------------|-------|
|   | n=50             | %     | n=30         | %     | n=20  | %     | n=27         | %     | n=23        | %     |
| Participant describes cost as a consideration in access to treatments   | 18               | 36.00 | 11           | 36.67 | 8     | 40.00 | 7            | 25.93 | 12          | 52.17 |
| Participant describes the need for effective treatments for mitochondrial disease (may also note that there are no or limited treatments available) | 16               | 32.00 | 14           | 46.67 | 3     | 15.00 | 9            | 33.33 | 8           | 34.78 |
| Participant describes the need for clinical trials in mitochondrial disease   | 7                | 14.00 | 4            | 13.33 | 3     | 15.00 | 4            | 14.81 | 3           | 13.04 |
| Participant describes the need for treatments that reduce muscle fatigue/improve muscle strength  | 6                | 12.00 | 4            | 13.33 | 2     | 10.00 | 3            | 11.11 | 3           | 13.04 |
| Participant describes not being sure because they haven't had any treatments to compare to  | 5                | 10.00 | 2            | 6.67  | 3     | 15.00 | 4            | 14.81 | 1           | 4.35  |
| Participant describes 'a cure' but also acknowledging this is not likely (for example, participant laughs when saying this)                         | 5                | 10.00 | 2            | 6.67  | 3     | 15.00 | 2            | 7.41  | 3           | 13.04 |
| Participant describes the need for treatments to reduce general exhaustion caused by mitochondrial disease  | 5                | 10.00 | 3            | 10.00 | 2     | 10.00 | 2            | 7.41  | 3           | 13.04 |
| Participant describes the need to evaluate the effectiveness of the use of vitamins and supplements to treat symptoms                               | 5                | 10.00 | 5            | 16.67 | 0     | 0.00  | 4            | 14.81 | 1           | 4.35  |





| Expectations of future treatments   | All participants |       | High school or trade |       | University |       | Hearing impairment |       | Eye or visual impairment |       |
|---|------------------|-------|----------------------|-------|------------|-------|--------------------|-------|--------------------------|-------|
|   | n=50             | %     | n=26                 | %     | n=24       | %     | n=24               | %     | n=34                     | %     |
| Participant describes cost as a consideration in access to treatments   | 18               | 36.00 | 11                   | 42.31 | 8          | 33.33 | 9                  | 37.50 | 13                       | 38.24 |
| Participant describes the need for effective treatments for mitochondrial disease (may also note that there are no or limited treatments available) | 16               | 32.00 | 7                    | 26.92 | 10         | 41.67 | 9                  | 37.50 | 9                        | 26.47 |
| Participant describes the need for clinical trials in mitochondrial disease   | 7                | 14.00 | 5                    | 19.23 | 2          | 8.33  | 3                  | 12.50 | 4                        | 11.76 |
| Participant describes the need for treatments that reduce muscle fatigue/improve muscle strength  | 6                | 12.00 | 3                    | 11.54 | 3          | 12.50 | 2                  | 8.33  | 5                        | 14.71 |
| Participant describes not being sure because they haven't had any treatments to compare to  | 5                | 10.00 | 3                    | 11.54 | 2          | 8.33  | 1                  | 4.17  | 4                        | 11.76 |
| Participant describes 'a cure' but also acknowledging this is not likely (for example, participant laughs when saying this)                         | 5                | 10.00 | 4                    | 15.38 | 1          | 4.17  | 2                  | 8.33  | 4                        | 11.76 |
| Participant describes the need for treatments to reduce general exhaustion caused by mitochondrial disease  | 5                | 10.00 | 3                    | 11.54 | 2          | 8.33  | 2                  | 8.33  | 5                        | 14.71 |
| Participant describes the need to evaluate the effectiveness of the use of vitamins and supplements to treat symptoms                               | 5                | 10.00 | 2                    | 7.69  | 3          | 12.50 | 2                  | 8.33  | 2                        | 5.88  |



| Expectations of future treatments   | All participants |       | Physical function (High) |       | Physical function (Low) |       | Emotional well-being (High) |       | Emotional well-being (Low) |       |
|---|------------------|-------|--------------------------|-------|-------------------------|-------|-----------------------------|-------|----------------------------|-------|
|   | n=50             | %     | n=22                     | %     | n=28                    | %     | n=26                        | %     | n=24                       | %     |
| Participant describes cost as a consideration in access to treatments   | 18               | 36.00 | 10                       | 45.45 | 9                       | 32.14 | 10                          | 38.46 | 9                          | 37.50 |
| Participant describes the need for effective treatments for mitochondrial disease (may also note that there are no or limited treatments available) | 16               | 32.00 | 9                        | 40.91 | 8                       | 28.57 | 6                           | 23.08 | 11                         | 45.83 |
| Participant describes the need for clinical trials in mitochondrial disease   | 7                | 14.00 | 4                        | 18.18 | 3                       | 10.71 | 5                           | 19.23 | 2                          | 8.33  |
| Participant describes the need for treatments that reduce muscle fatigue/improve muscle strength  | 6                | 12.00 | 3                        | 13.64 | 3                       | 10.71 | 4                           | 15.38 | 2                          | 8.33  |
| Participant describes not being sure because they haven't had any treatments to compare to  | 5                | 10.00 | 1                        | 4.55  | 4                       | 14.29 | 1                           | 3.85  | 4                          | 16.67 |
| Participant describes 'a cure' but also acknowledging this is not likely (for example, participant laughs when saying this)                         | 5                | 10.00 | 2                        | 9.09  | 3                       | 10.71 | 3                           | 11.54 | 2                          | 8.33  |
| Participant describes the need for treatments to reduce general exhaustion caused by mitochondrial disease  | 5                | 10.00 | 3                        | 13.64 | 2                       | 7.14  | 3                           | 11.54 | 2                          | 8.33  |
| Participant describes the need to evaluate the effectiveness of the use of vitamins and supplements to treat symptoms                               | 5                | 10.00 | 2                        | 9.09  | 3                       | 10.71 | 3                           | 11.54 | 2                          | 8.33  |

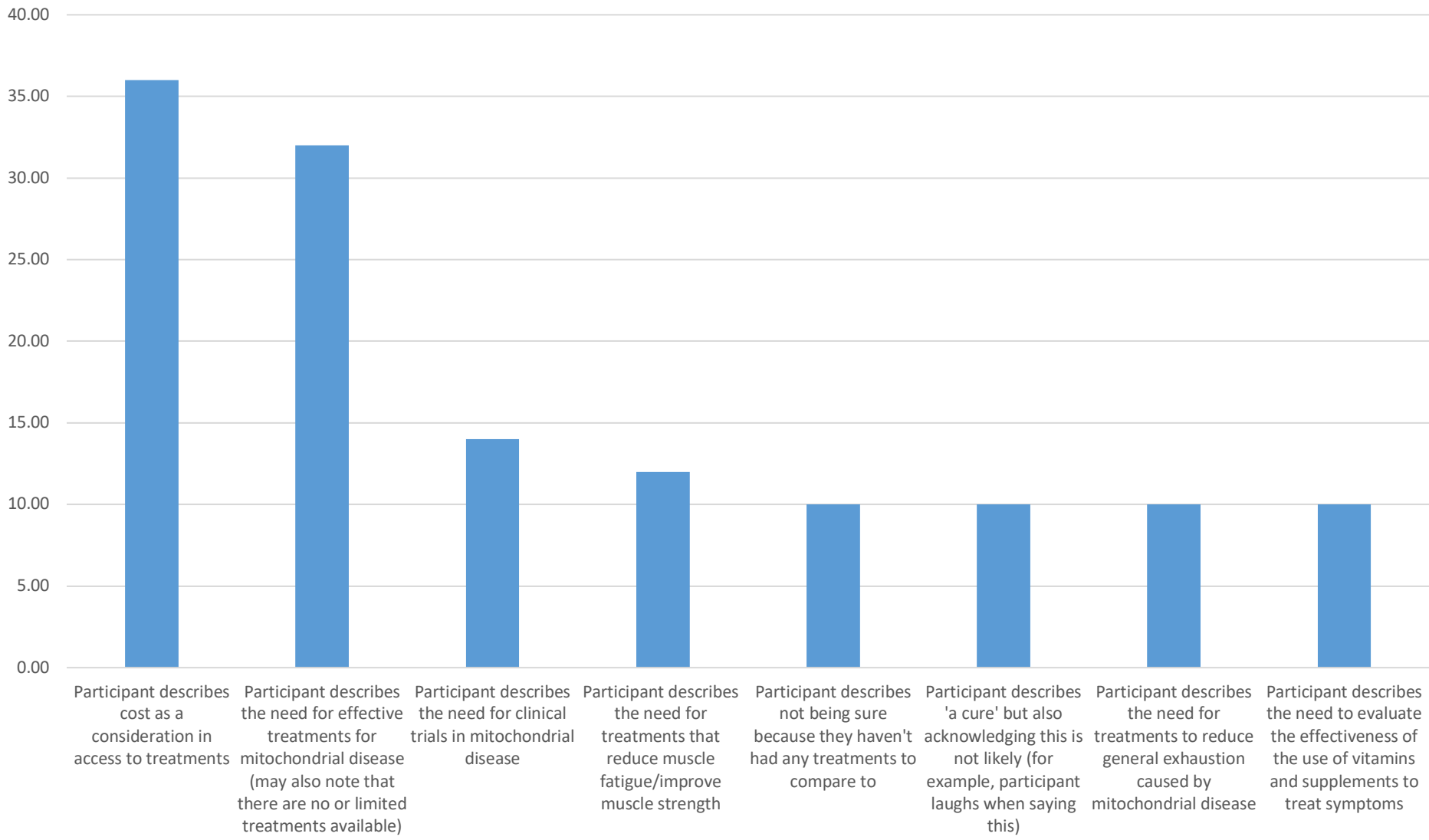


| Expectations of future treatments   | All participants |       | Social functioning (High) |       | Social functioning (Low) |       | General health (High) |       | General health (Low) |       |
|---|------------------|-------|---------------------------|-------|--------------------------|-------|-----------------------|-------|----------------------|-------|
|   | n=50             | %     | n=20                      | %     | n=30                     | %     | n=22                  | %     | n=28                 | %     |
| Participant describes cost as a consideration in access to treatments   | 18               | 36.00 | 6                         | 30.00 | 13                       | 43.33 | 8                     | 36.36 | 11                   | 39.29 |
| Participant describes the need for effective treatments for mitochondrial disease (may also note that there are no or limited treatments available) | 16               | 32.00 | 6                         | 30.00 | 11                       | 36.67 | 9                     | 40.91 | 8                    | 28.57 |
| Participant describes the need for clinical trials in mitochondrial disease   | 7                | 14.00 | 4                         | 20.00 | 3                        | 10.00 | 5                     | 22.73 | 2                    | 7.14  |
| Participant describes the need for treatments that reduce muscle fatigue/improve muscle strength  | 6                | 12.00 | 4                         | 20.00 | 2                        | 6.67  | 4                     | 18.18 | 2                    | 7.14  |
| Participant describes not being sure because they haven't had any treatments to compare to  | 5                | 10.00 | 1                         | 5.00  | 4                        | 13.33 | 1                     | 4.55  | 4                    | 14.29 |
| Participant describes 'a cure' but also acknowledging this is not likely (for example, participant laughs when saying this)                         | 5                | 10.00 | 2                         | 10.00 | 3                        | 10.00 | 3                     | 13.64 | 2                    | 7.14  |
| Participant describes the need for treatments to reduce general exhaustion caused by mitochondrial disease  | 5                | 10.00 | 2                         | 10.00 | 3                        | 10.00 | 3                     | 13.64 | 2                    | 7.14  |
| Participant describes the need to evaluate the effectiveness of the use of vitamins and supplements to treat symptoms                               | 5                | 10.00 | 3                         | 15.00 | 2                        | 6.67  | 4                     | 18.18 | 1                    | 3.57  |



| Expectations of future treatments   | All participants |       | Under 18 |       | 24-44 |       | 45-54 |       | 55-64 |       | 65-74+ |       |
|---|------------------|-------|----------|-------|-------|-------|-------|-------|-------|-------|--------|-------|
|   | n=50             | %     | n=6      | %     | n=14  | %     | n=9   | %     | n=11  | %     | n=10   | %     |
| Participant describes cost as a consideration in access to treatments   | 18               | 36.00 | 4        | 66.67 | 7     | 50.00 | 1     | 11.11 | 4     | 36.36 | 3      | 30.00 |
| Participant describes the need for effective treatments for mitochondrial disease (may also note that there are no or limited treatments available) | 16               | 32.00 | 4        | 66.67 | 6     | 42.86 | 3     | 33.33 | 1     | 9.09  | 3      | 30.00 |
| Participant describes the need for clinical trials in mitochondrial disease   | 7                | 14.00 | 0        | 0.00  | 2     | 14.29 | 2     | 22.22 | 2     | 18.18 | 1      | 10.00 |
| Participant describes the need for treatments that reduce muscle fatigue/improve muscle strength  | 6                | 12.00 | 0        | 0.00  | 2     | 14.29 | 2     | 22.22 | 0     | 0.00  | 2      | 20.00 |
| Participant describes not being sure because they haven't had any treatments to compare to  | 5                | 10.00 | 0        | 0.00  | 1     | 7.14  | 0     | 0.00  | 4     | 36.36 | 0      | 0.00  |
| Participant describes 'a cure' but also acknowledging this is not likely (for example, participant laughs when saying this)                         | 5                | 10.00 | 0        | 0.00  | 0     | 0.00  | 2     | 22.22 | 2     | 18.18 | 1      | 10.00 |
| Participant describes the need for treatments to reduce general exhaustion caused by mitochondrial disease  | 5                | 10.00 | 0        | 0.00  | 3     | 21.43 | 0     | 0.00  | 1     | 9.09  | 1      | 10.00 |
| Participant describes the need to evaluate the effectiveness of the use of vitamins and supplements to treat symptoms                               | 5                | 10.00 | 1        | 16.67 | 2     | 14.29 | 1     | 11.11 | 0     | 0.00  | 1      | 10.00 |





| Expectations of future information   | All participants |       | Metropolitan |       | Rural |       | SEIFA (High) |       | SEIFA (Low) |       |
|--|------------------|-------|--------------|-------|-------|-------|--------------|-------|-------------|-------|
|  | n=50             | %     | n=30         | %     | n=20  | %     | n=27         | %     | n=23        | %     |
| Participant describes being satisfied with current information. No recommendation.   | 11               | 22.00 | 5            | 16.67 | 6     | 30.00 | 7            | 25.93 | 4           | 17.39 |
| Participant describes the need for information about their specific type of mitochondrial disease  | 9                | 18.00 | 6            | 20.00 | 3     | 15.00 | 5            | 18.52 | 4           | 17.39 |
| Participant describes the need for healthcare professionals to deliver accurate, comprehensive and honest information (including prognostic information) | 9                | 18.00 | 6            | 20.00 | 4     | 20.00 | 6            | 22.22 | 4           | 17.39 |
| Participant describes the need for centralised and reliable information  | 6                | 12.00 | 3            | 10.00 | 3     | 15.00 | 4            | 14.81 | 2           | 8.70  |
| Participant describes the need for information in relation to genetic predisposition and/or hereditary factors   | 4                | 8.00  | 2            | 6.67  | 2     | 10.00 | 3            | 11.11 | 1           | 4.35  |
| Participant describes the need to increase public awareness with more information available on the condition   | 4                | 8.00  | 3            | 10.00 | 2     | 10.00 | 5            | 18.52 | 0           | 0.00  |
| Participants describes the need to provide information about research programs for treatments  | 4                | 8.00  | 2            | 6.67  | 2     | 10.00 | 3            | 11.11 | 1           | 4.35  |
| Participant recommends providing education programs for front line healthcare professionals to be aware of mitochondrial disease                         | 4                | 8.00  | 4            | 13.33 | 0     | 0.00  | 2            | 7.41  | 2           | 8.70  |



| Expectations of future information   | All participants |       | High school or trade |       | University |       | Hearing impairment |       | Eye or visual impairment |       |
|--|------------------|-------|----------------------|-------|------------|-------|--------------------|-------|--------------------------|-------|
|  | n=50             | %     | n=26                 | %     | n=24       | %     | n=24               | %     | n=34                     | %     |
| Participant describes being satisfied with current information. No recommendation.   | 11               | 22.00 | 5                    | 19.23 | 6          | 25.00 | 4                  | 16.67 | 6                        | 17.65 |
| Participant describes the need for information about their specific type of mitochondrial disease  | 9                | 18.00 | 5                    | 19.23 | 4          | 16.67 | 2                  | 8.33  | 6                        | 17.65 |
| Participant describes the need for healthcare professionals to deliver accurate, comprehensive and honest information (including prognostic information) | 9                | 18.00 | 5                    | 19.23 | 5          | 20.83 | 4                  | 16.67 | 7                        | 20.59 |
| Participant describes the need for centralised and reliable information  | 6                | 12.00 | 4                    | 15.38 | 2          | 8.33  | 5                  | 20.83 | 4                        | 11.76 |
| Participant describes the need for information in relation to genetic predisposition and/or hereditary factors   | 4                | 8.00  | 2                    | 7.69  | 2          | 8.33  | 2                  | 8.33  | 4                        | 11.76 |
| Participant describes the need to increase public awareness with more information available on the condition   | 4                | 8.00  | 3                    | 11.54 | 2          | 8.33  | 3                  | 12.50 | 3                        | 8.82  |
| Participants describes the need to provide information about research programs for treatments  | 4                | 8.00  | 4                    | 15.38 | 0          | 0.00  | 3                  | 12.50 | 4                        | 11.76 |
| Participant recommends providing education programs for front line healthcare professionals to be aware of mitochondrial disease                         | 4                | 8.00  | 1                    | 3.85  | 3          | 12.50 | 3                  | 12.50 | 3                        | 8.82  |



| Expectations of future information   | All participants |       | Physical function (High) |       | Physical function (Low) |       | Emotional well-being (High) |       | Emotional well-being (Low) |       |
|--|------------------|-------|--------------------------|-------|-------------------------|-------|-----------------------------|-------|----------------------------|-------|
|  | n=50             | %     | n=22                     | %     | n=28                    | %     | n=26                        | %     | n=24                       | %     |
| Participant describes being satisfied with current information. No recommendation.   | 11               | 22.00 | 4                        | 18.18 | 7                       | 25.00 | 5                           | 19.23 | 6                          | 25.00 |
| Participant describes the need for information about their specific type of mitochondrial disease  | 9                | 18.00 | 3                        | 13.64 | 6                       | 21.43 | 4                           | 15.38 | 5                          | 20.83 |
| Participant describes the need for healthcare professionals to deliver accurate, comprehensive and honest information (including prognostic information) | 9                | 18.00 | 4                        | 18.18 | 6                       | 21.43 | 7                           | 26.92 | 3                          | 12.50 |
| Participant describes the need for centralised and reliable information  | 6                | 12.00 | 4                        | 18.18 | 2                       | 7.14  | 2                           | 7.69  | 4                          | 16.67 |
| Participant describes the need for information in relation to genetic predisposition and/or hereditary factors   | 4                | 8.00  | 1                        | 4.55  | 3                       | 10.71 | 4                           | 15.38 | 0                          | 0.00  |
| Participant describes the need to increase public awareness with more information available on the condition   | 4                | 8.00  | 2                        | 9.09  | 3                       | 10.71 | 4                           | 15.38 | 1                          | 4.17  |
| Participants describes the need to provide information about research programs for treatments  | 4                | 8.00  | 3                        | 13.64 | 1                       | 3.57  | 2                           | 7.69  | 2                          | 8.33  |
| Participant recommends providing education programs for front line healthcare professionals to be aware of mitochondrial disease                         | 4                | 8.00  | 1                        | 4.55  | 3                       | 10.71 | 3                           | 11.54 | 1                          | 4.17  |



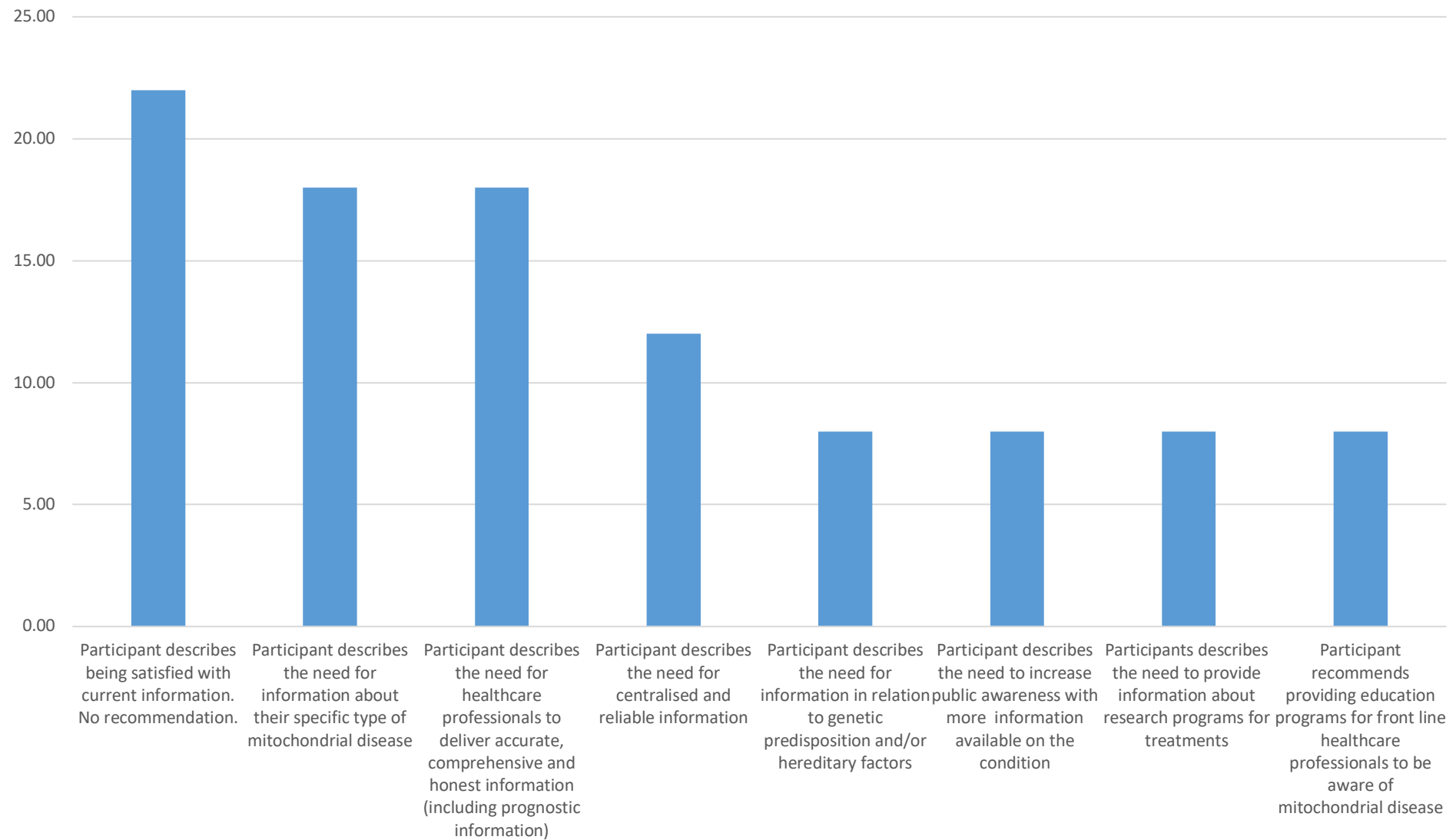


| Expectations of future information   | All participants |       | Social functioning (High) |       | Social functioning (Low) |       | General health (High) |              | General health (Low) |       |
|--|------------------|-------|---------------------------|-------|--------------------------|-------|-----------------------|--------------|----------------------|-------|
|  | n=50             | %     | n=20                      | %     | n=30                     | %     | n=22                  | %            | n=28                 | %     |
| Participant describes being satisfied with current information. No recommendation.   | 11               | 22.00 | 3                         | 15.00 | 8                        | 26.67 | 5                     | 22.73        | 6                    | 21.43 |
| Participant describes the need for information about their specific type of mitochondrial disease  | 9                | 18.00 | 4                         | 20.00 | 5                        | 16.67 | 3                     | 13.64        | 6                    | 21.43 |
| Participant describes the need for healthcare professionals to deliver accurate, comprehensive and honest information (including prognostic information) | 9                | 18.00 | 3                         | 15.00 | 7                        | 23.33 | 7                     | <b>31.82</b> | 3                    | 10.71 |
| Participant describes the need for centralised and reliable information  | 6                | 12.00 | 2                         | 10.00 | 4                        | 13.33 | 2                     | 9.09         | 4                    | 14.29 |
| Participant describes the need for information in relation to genetic predisposition and/or hereditary factors   | 4                | 8.00  | 2                         | 10.00 | 2                        | 6.67  | 2                     | 9.09         | 2                    | 7.14  |
| Participant describes the need to increase public awareness with more information available on the condition   | 4                | 8.00  | 3                         | 15.00 | 2                        | 6.67  | 2                     | 9.09         | 3                    | 10.71 |
| Participants describes the need to provide information about research programs for treatments  | 4                | 8.00  | 3                         | 15.00 | 1                        | 3.33  | 2                     | 9.09         | 2                    | 7.14  |
| Participant recommends providing education programs for front line healthcare professionals to be aware of mitochondrial disease                         | 4                | 8.00  | 2                         | 10.00 | 2                        | 6.67  | 1                     | 4.55         | 3                    | 10.71 |



| Expectations of future information   | All participants |       | Under 18 |       | 24-44 |       | 45-54 |       | 55-64 |       | 65-74+ |       |
|--|------------------|-------|----------|-------|-------|-------|-------|-------|-------|-------|--------|-------|
|  | n=50             | %     | n=6      | %     | n=14  | %     | n=9   | %     | n=11  | %     | n=10   | %     |
| Participant describes being satisfied with current information. No recommendation.   | 11               | 22.00 | 0        | 0.00  | 2     | 14.29 | 2     | 22.22 | 4     | 36.36 | 3      | 30.00 |
| Participant describes the need for information about their specific type of mitochondrial disease  | 9                | 18.00 | 2        | 33.33 | 3     | 21.43 | 2     | 22.22 | 2     | 18.18 | 0      | 0.00  |
| Participant describes the need for healthcare professionals to deliver accurate, comprehensive and honest information (including prognostic information) | 9                | 18.00 | 3        | 50.00 | 2     | 14.29 | 0     | 0.00  | 3     | 27.27 | 2      | 20.00 |
| Participant describes the need for centralised and reliable information  | 6                | 12.00 | 1        | 16.67 | 1     | 7.14  | 1     | 11.11 | 1     | 9.09  | 2      | 20.00 |
| Participant describes the need for information in relation to genetic predisposition and/or hereditary factors   | 4                | 8.00  | 0        | 0.00  | 2     | 14.29 | 0     | 0.00  | 1     | 9.09  | 1      | 10.00 |
| Participant describes the need to increase public awareness with more information available on the condition   | 4                | 8.00  | 2        | 33.33 | 1     | 7.14  | 0     | 0.00  | 0     | 0.00  | 2      | 20.00 |
| Participants describes the need to provide information about research programs for treatments  | 4                | 8.00  | 0        | 0.00  | 0     | 0.00  | 2     | 22.22 | 1     | 9.09  | 1      | 10.00 |
| Participant recommends providing education programs for front line healthcare professionals to be aware of mitochondrial disease                         | 4                | 8.00  | 1        | 16.67 | 2     | 14.29 | 1     | 11.11 | 0     | 0.00  | 0      | 0.00  |





| Expectations of future health professional communication   | All participants |       | Metropolitan |       | Rural |       | SEIFA (High) |       | SEIFA (Low) |       |
|--|------------------|-------|--------------|-------|-------|-------|--------------|-------|-------------|-------|
|  | n=50             | %     | n=30         | %     | n=20  | %     | n=27         | %     | n=23        | %     |
| Participant recommends healthcare professional education in relation to mitochondrial disease and more understanding of the impact and implications of the condition | 16               | 32.00 | 8            | 26.67 | 9     | 45.00 | 7            | 25.93 | 10          | 43.48 |
| Participant recommends healthcare professionals being more proactive and attentive   | 9                | 18.00 | 6            | 20.00 | 3     | 15.00 | 5            | 18.52 | 4           | 17.39 |
| Participant does not have a recommendation as they have been satisfied with communication (Open communication)   | 9                | 18.00 | 5            | 16.67 | 4     | 20.00 | 4            | 14.81 | 5           | 21.74 |
| Participant recommends healthcare professionals need to have more empathy  | 7                | 14.00 | 3            | 10.00 | 4     | 20.00 | 4            | 14.81 | 3           | 13.04 |
| Participant recommends centralised and coordinated care across specialists and allied health professionals (including more communication between doctors)            | 6                | 12.00 | 3            | 10.00 | 3     | 15.00 | 3            | 11.11 | 3           | 13.04 |
| Participant recommends that healthcare professionals ensure information is easily accessible   | 6                | 12.00 | 4            | 13.33 | 2     | 10.00 | 2            | 7.41  | 4           | 17.39 |



## Expectations of future health professional communication (Table a)

| Expectations of future health professional communication   | All participants |       | High school or trade |       | University |       | Hearing impairment |       | Eye or visual impairment |       |
|--|------------------|-------|----------------------|-------|------------|-------|--------------------|-------|--------------------------|-------|
|  | n=50             | %     | n=26                 | %     | n=24       | %     | n=24               | %     | n=34                     | %     |
| Participant recommends healthcare professional education in relation to mitochondrial disease and more understanding of the impact and implications of the condition | 16               | 32.00 | 10                   | 38.46 | 7          | 29.17 | 9                  | 37.50 | 10                       | 29.41 |
| Participant recommends healthcare professionals being more proactive and attentive   | 9                | 18.00 | 4                    | 15.38 | 5          | 20.83 | 6                  | 25.00 | 7                        | 20.59 |
| Participant does not have a recommendation as they have been satisfied with communication (Open communication)   | 9                | 18.00 | 4                    | 15.38 | 5          | 20.83 | 3                  | 12.50 | 7                        | 20.59 |
| Participant recommends healthcare professionals need to have more empathy  | 7                | 14.00 | 3                    | 11.54 | 4          | 16.67 | 4                  | 16.67 | 6                        | 17.65 |
| Participant recommends centralised and coordinated care across specialists and allied health professionals (including more communication between doctors)            | 6                | 12.00 | 3                    | 11.54 | 3          | 12.50 | 3                  | 12.50 | 4                        | 11.76 |
| Participant recommends that healthcare professionals ensure information is easily accessible   | 6                | 12.00 | 1                    | 3.85  | 5          | 20.83 | 2                  | 8.33  | 5                        | 14.71 |



## Expectations of future health professional communication (Table b)

| Expectations of future health professional communication   | All participants |       | Physical function (High) |       | Physical function (Low) |       | Emotional well-being (High) |       | Emotional well-being (Low) |       |
|--|------------------|-------|--------------------------|-------|-------------------------|-------|-----------------------------|-------|----------------------------|-------|
|  | n=50             | %     | n=22                     | %     | n=28                    | %     | n=26                        | %     | n=24                       | %     |
| Participant recommends healthcare professional education in relation to mitochondrial disease and more understanding of the impact and implications of the condition | 16               | 32.00 | 8                        | 36.36 | 9                       | 32.14 | 7                           | 26.92 | 10                         | 41.67 |
| Participant recommends healthcare professionals being more proactive and attentive   | 9                | 18.00 | 3                        | 13.64 | 6                       | 21.43 | 5                           | 19.23 | 4                          | 16.67 |
| Participant does not have a recommendation as they have been satisfied with communication (Open communication)   | 9                | 18.00 | 4                        | 18.18 | 5                       | 17.86 | 6                           | 23.08 | 3                          | 12.50 |
| Participant recommends healthcare professionals need to have more empathy  | 7                | 14.00 | 4                        | 18.18 | 3                       | 10.71 | 5                           | 19.23 | 2                          | 8.33  |
| Participant recommends centralised and coordinated care across specialists and allied health professionals (including more communication between doctors)            | 6                | 12.00 | 1                        | 4.55  | 5                       | 17.86 | 3                           | 11.54 | 3                          | 12.50 |
| Participant recommends that healthcare professionals ensure information is easily accessible   | 6                | 12.00 | 3                        | 13.64 | 3                       | 10.71 | 2                           | 7.69  | 4                          | 16.67 |



## Expectations of future health professional communication (Table c)

| Expectations of future health professional communication   | All participants |       | Social functioning (High) |       | Social functioning (Low) |       | General health (High) |       | General health (Low) |       |
|--|------------------|-------|---------------------------|-------|--------------------------|-------|-----------------------|-------|----------------------|-------|
|  | n=50             | %     | n=20                      | %     | n=30                     | %     | n=22                  | %     | n=28                 | %     |
| Participant recommends healthcare professional education in relation to mitochondrial disease and more understanding of the impact and implications of the condition | 16               | 32.00 | 7                         | 35.00 | 10                       | 33.33 | 8                     | 36.36 | 9                    | 32.14 |
| Participant recommends healthcare professionals being more proactive and attentive   | 9                | 18.00 | 4                         | 20.00 | 5                        | 16.67 | 2                     | 9.09  | 7                    | 25.00 |
| Participant does not have a recommendation as they have been satisfied with communication (Open communication)   | 9                | 18.00 | 5                         | 25.00 | 4                        | 13.33 | 2                     | 9.09  | 7                    | 25.00 |
| Participant recommends healthcare professionals need to have more empathy  | 7                | 14.00 | 3                         | 15.00 | 4                        | 13.33 | 3                     | 13.64 | 4                    | 14.29 |
| Participant recommends centralised and coordinated care across specialists and allied health professionals (including more communication between doctors)            | 6                | 12.00 | 2                         | 10.00 | 4                        | 13.33 | 2                     | 9.09  | 4                    | 14.29 |
| Participant recommends that healthcare professionals ensure information is easily accessible   | 6                | 12.00 | 2                         | 10.00 | 4                        | 13.33 | 4                     | 18.18 | 2                    | 7.14  |



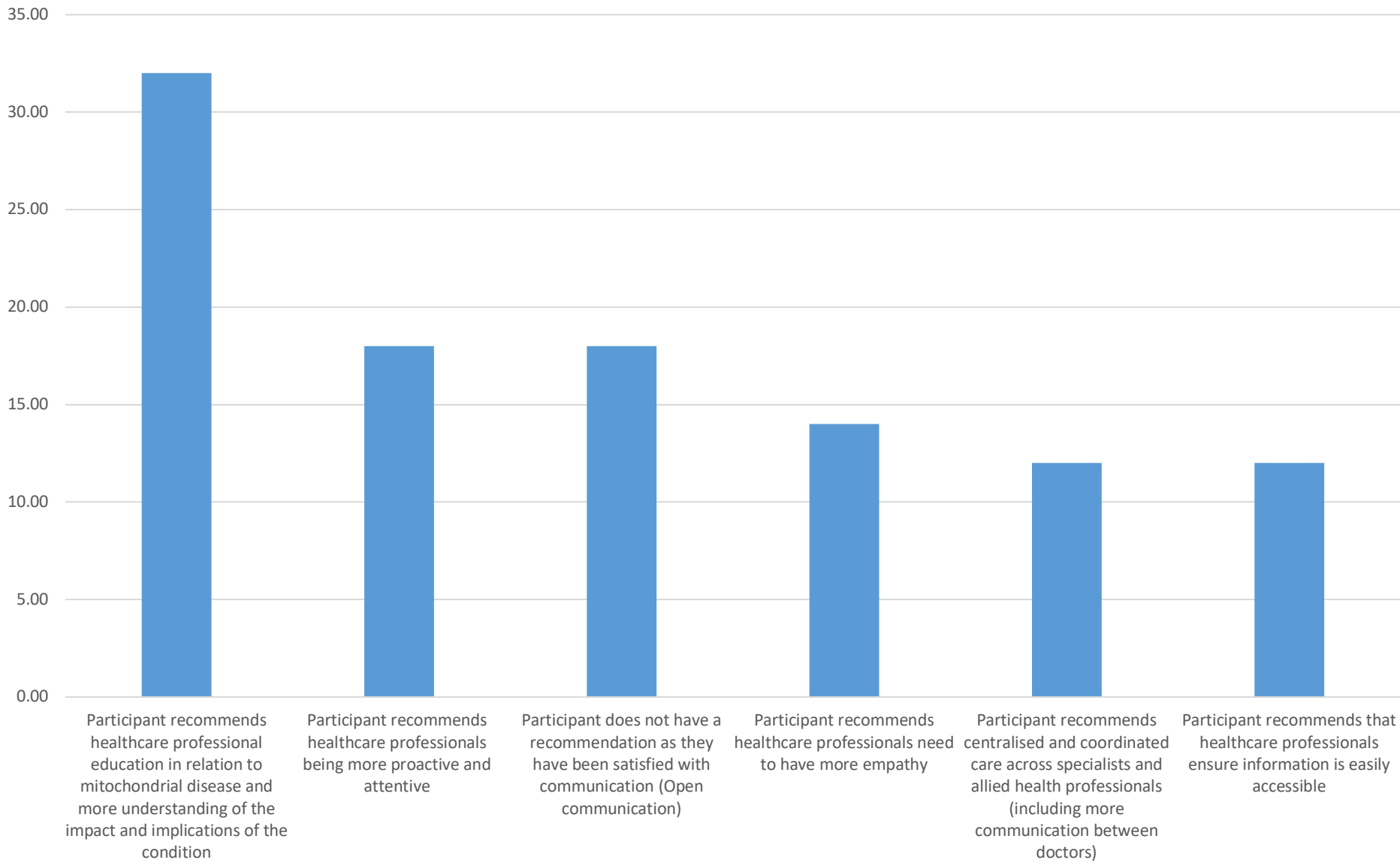
## Expectations of future health professional communication (Table d)

| Expectations of future health professional communication   | All participants |       | Under 18 |       | 24-44 |       | 45-54 |       | 55-64 |       | 65-74+ |       |
|--|------------------|-------|----------|-------|-------|-------|-------|-------|-------|-------|--------|-------|
|  | n=50             | %     | n=6      | %     | n=14  | %     | n=9   | %     | n=11  | %     | n=10   | %     |
| Participant recommends healthcare professional education in relation to mitochondrial disease and more understanding of the impact and implications of the condition | 16               | 32.00 | 2        | 33.33 | 4     | 28.57 | 3     | 33.33 | 4     | 36.36 | 4      | 40.00 |
| Participant recommends healthcare professionals being more proactive and attentive   | 9                | 18.00 | 1        | 16.67 | 2     | 14.29 | 3     | 33.33 | 2     | 18.18 | 1      | 10.00 |
| Participant does not have a recommendation as they have been satisfied with communication (Open communication)   | 9                | 18.00 | 0        | 0.00  | 2     | 14.29 | 2     | 22.22 | 3     | 27.27 | 2      | 20.00 |
| Participant recommends healthcare professionals need to have more empathy  | 7                | 14.00 | 1        | 16.67 | 2     | 14.29 | 2     | 22.22 | 2     | 18.18 | 0      | 0.00  |
| Participant recommends centralised and coordinated care across specialists and allied health professionals (including more communication between doctors)            | 6                | 12.00 | 1        | 16.67 | 3     | 21.43 | 1     | 11.11 | 0     | 0.00  | 1      | 10.00 |
| Participant recommends that healthcare professionals ensure information is easily accessible   | 6                | 12.00 | 0        | 0.00  | 2     | 14.29 | 0     | 0.00  | 1     | 9.09  | 3      | 30.00 |



## Expectations of future health professional communication (Table e)





| Expectations of future care and support   | All participants |       | Metropolitan |       | Rural |       | SEIFA (High) |       | SEIFA (Low) |       |
|---|------------------|-------|--------------|-------|-------|-------|--------------|-------|-------------|-------|
|   | n=50             | %     | n=30         | %     | n=20  | %     | n=27         | %     | n=23        | %     |
| Participant recommends centralised and coordinated care across specialists and allied health professionals (including more communication between doctors) | 13               | 26.00 | 7            | 23.33 | 6     | 30.00 | 9            | 33.33 | 4           | 17.39 |
| Participant recommends support groups to help patients noting that it is difficult due to the diversity within the patient population                     | 7                | 14.00 | 5            | 16.67 | 2     | 10.00 | 6            | 22.22 | 1           | 4.35  |
| Participant recommends more equity in access to services and support for adults with rare disease   | 7                | 14.00 | 5            | 16.67 | 2     | 10.00 | 4            | 14.81 | 3           | 13.04 |
| Participant recommends caseworkers be employed to support patients navigate health, medical and emotional needs   | 6                | 12.00 | 3            | 10.00 | 3     | 15.00 | 1            | 3.70  | 5           | 21.74 |
| Participant recommends greater and/or more access to home care/support at home  | 4                | 8.00  | 3            | 10.00 | 1     | 5.00  | 3            | 11.11 | 1           | 4.35  |
| Participant recommends having reliable information available (via patient organisations)  | 4                | 8.00  | 2            | 6.67  | 2     | 10.00 | 2            | 7.41  | 2           | 8.70  |



| Expectations of future care and support   | All participants |       | High school or trade |       | University |       | Hearing impairment |       | Eye or visual impairment |       |
|---|------------------|-------|----------------------|-------|------------|-------|--------------------|-------|--------------------------|-------|
|   | n=50             | %     | n=26                 | %     | n=24       | %     | n=24               | %     | n=34                     | %     |
| Participant recommends centralised and coordinated care across specialists and allied health professionals (including more communication between doctors) | 13               | 26.00 | 1                    | 3.85  | 12         | 50.00 | 11                 | 45.83 | 7                        | 20.59 |
| Participant recommends support groups to help patients noting that it is difficult due to the diversity within the patient population                     | 7                | 14.00 | 5                    | 19.23 | 2          | 8.33  | 3                  | 12.50 | 5                        | 14.71 |
| Participant recommends more equity in access to services and support for adults with rare disease   | 7                | 14.00 | 3                    | 11.54 | 4          | 16.67 | 4                  | 16.67 | 5                        | 14.71 |
| Participant recommends caseworkers be employed to support patients navigate health, medical and emotional needs   | 6                | 12.00 | 1                    | 3.85  | 5          | 20.83 | 5                  | 20.83 | 4                        | 11.76 |
| Participant recommends greater and/or more access to home care/support at home  | 4                | 8.00  | 3                    | 11.54 | 1          | 4.17  | 2                  | 8.33  | 2                        | 5.88  |
| Participant recommends having reliable information available (via patient organisations)  | 4                | 8.00  | 2                    | 7.69  | 2          | 8.33  | 2                  | 8.33  | 4                        | 11.76 |



| Expectations of future care and support   | All participants |       | Physical function (High) |       | Physical function (Low) |       | Emotional well-being (High) |       | Emotional well-being (Low) |       |
|---|------------------|-------|--------------------------|-------|-------------------------|-------|-----------------------------|-------|----------------------------|-------|
|   | n=50             | %     | n=22                     | %     | n=28                    | %     | n=26                        | %     | n=24                       | %     |
| Participant recommends centralised and coordinated care across specialists and allied health professionals (including more communication between doctors) | 13               | 26.00 | 6                        | 27.27 | 7                       | 25.00 | 8                           | 30.77 | 5                          | 20.83 |
| Participant recommends support groups to help patients noting that it is difficult due to the diversity within the patient population                     | 7                | 14.00 | 4                        | 18.18 | 3                       | 10.71 | 5                           | 19.23 | 2                          | 8.33  |
| Participant recommends more equity in access to services and support for adults with rare disease   | 7                | 14.00 | 3                        | 13.64 | 4                       | 14.29 | 4                           | 15.38 | 3                          | 12.50 |
| Participant recommends caseworkers be employed to support patients navigate health, medical and emotional needs   | 6                | 12.00 | 3                        | 13.64 | 3                       | 10.71 | 4                           | 15.38 | 2                          | 8.33  |
| Participant recommends greater and/or more access to home care/support at home  | 4                | 8.00  | 1                        | 4.55  | 3                       | 10.71 | 1                           | 3.85  | 3                          | 12.50 |
| Participant recommends having reliable information available (via patient organisations)  | 4                | 8.00  | 3                        | 13.64 | 1                       | 3.57  | 1                           | 3.85  | 3                          | 12.50 |

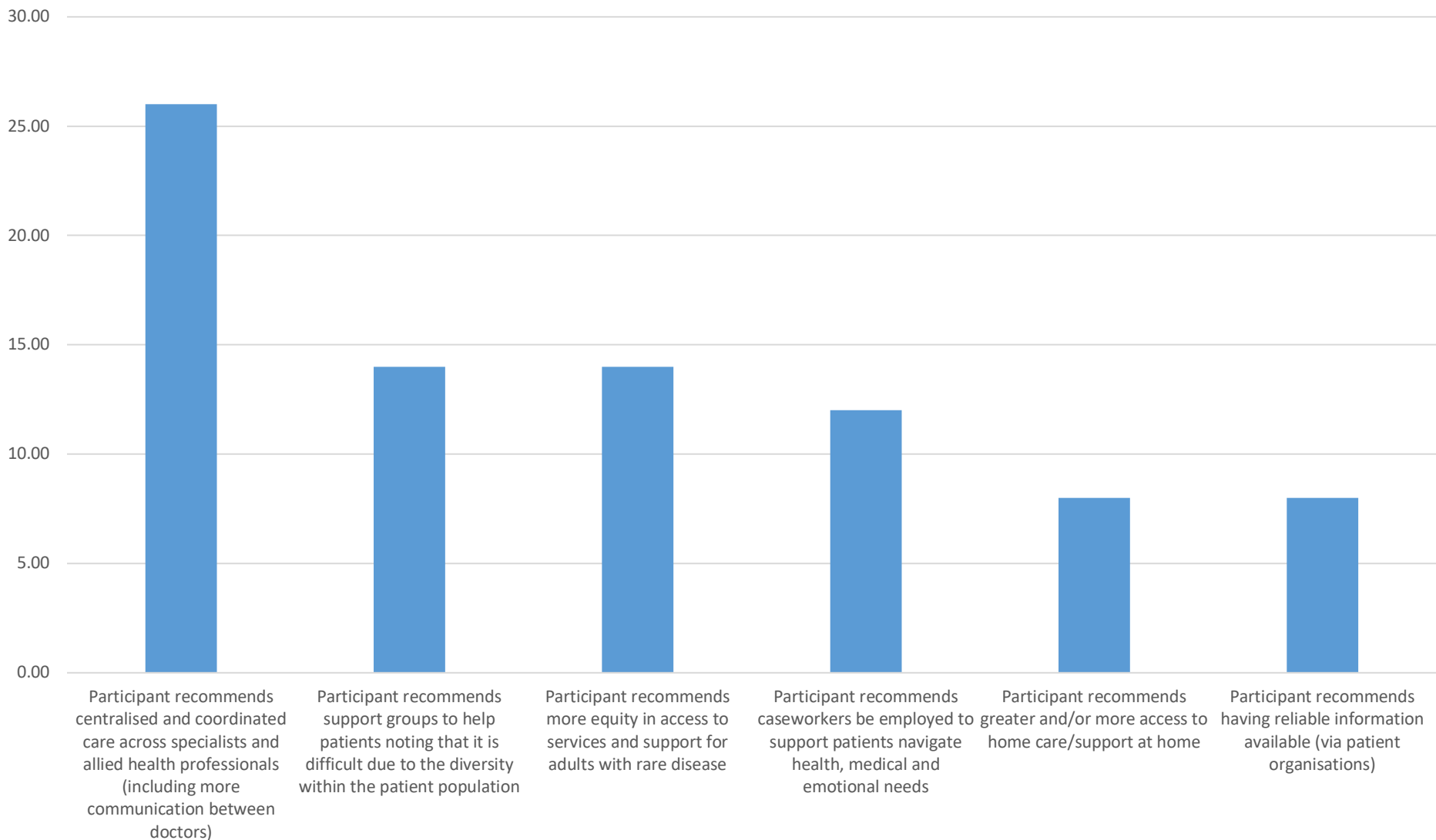


| Expectations of future care and support   | All participants |       | Social functioning (High) |       | Social functioning (Low) |       | General health (High) |       | General health (Low) |       |
|---|------------------|-------|---------------------------|-------|--------------------------|-------|-----------------------|-------|----------------------|-------|
|   | n=50             | %     | n=20                      | %     | n=30                     | %     | n=22                  | %     | n=28                 | %     |
| Participant recommends centralised and coordinated care across specialists and allied health professionals (including more communication between doctors) | 13               | 26.00 | 4                         | 20.00 | 9                        | 30.00 | 6                     | 27.27 | 7                    | 25.00 |
| Participant recommends support groups to help patients noting that it is difficult due to the diversity within the patient population                     | 7                | 14.00 | 5                         | 25.00 | 2                        | 6.67  | 4                     | 18.18 | 3                    | 10.71 |
| Participant recommends more equity in access to services and support for adults with rare disease   | 7                | 14.00 | 2                         | 10.00 | 5                        | 16.67 | 2                     | 9.09  | 5                    | 17.86 |
| Participant recommends caseworkers be employed to support patients navigate health, medical and emotional needs   | 6                | 12.00 | 2                         | 10.00 | 4                        | 13.33 | 5                     | 22.73 | 1                    | 3.57  |
| Participant recommends greater and/or more access to home care/support at home  | 4                | 8.00  | 0                         | 0.00  | 4                        | 13.33 | 1                     | 4.55  | 3                    | 10.71 |
| Participant recommends having reliable information available (via patient organisations)  | 4                | 8.00  | 3                         | 15.00 | 1                        | 3.33  | 2                     | 9.09  | 2                    | 7.14  |



| Expectations of future care and support   | All participants |       | Under 18 |       | 24-44 |       | 45-54 |       | 55-64 |       | 65-74+ |       |
|---|------------------|-------|----------|-------|-------|-------|-------|-------|-------|-------|--------|-------|
|   | n=50             | %     | n=6      | %     | n=14  | %     | n=9   | %     | n=11  | %     | n=10   | %     |
| Participant recommends centralised and coordinated care across specialists and allied health professionals (including more communication between doctors) | 13               | 26.00 | 0        | 0.00  | 3     | 21.43 | 3     | 33.33 | 6     | 54.55 | 1      | 10.00 |
| Participant recommends support groups to help patients noting that it is difficult due to the diversity within the patient population                     | 7                | 14.00 | 1        | 16.67 | 1     | 7.14  | 2     | 22.22 | 1     | 9.09  | 2      | 20.00 |
| Participant recommends more equity in access to services and support for adults with rare disease   | 7                | 14.00 | 1        | 16.67 | 2     | 14.29 | 3     | 33.33 | 1     | 9.09  | 0      | 0.00  |
| Participant recommends caseworkers be employed to support patients navigate health, medical and emotional needs   | 6                | 12.00 | 1        | 16.67 | 3     | 21.43 | 1     | 11.11 | 1     | 9.09  | 0      | 0.00  |
| Participant recommends greater and/or more access to home care/support at home  | 4                | 8.00  | 1        | 16.67 | 0     | 0.00  | 0     | 0.00  | 2     | 18.18 | 1      | 10.00 |
| Participant recommends having reliable information available (via patient organisations)  | 4                | 8.00  | 0        | 0.00  | 2     | 14.29 | 0     | 0.00  | 1     | 9.09  | 1      | 10.00 |





| Aspects of the Australian health system that patients are grateful for   | All participants |       | Metropolitan |       | Rural |       | SEIFA (High) |       | SEIFA (Low) |       |
|--|------------------|-------|--------------|-------|-------|-------|--------------|-------|-------------|-------|
|  | n=50             | %     | n=30         | %     | n=20  | %     | n=27         | %     | n=23        | %     |
| Participant describes being grateful for Medicare (Access to specialists)  | 17               | 34.00 | 8            | 26.67 | 9     | 45.00 | 7            | 25.93 | 10          | 43.48 |
| Participant describes being grateful for the compassion and support shown by healthcare professionals  | 16               | 32.00 | 11           | 36.67 | 6     | 30.00 | 9            | 33.33 | 8           | 34.78 |
| Participant describes being grateful for Medicare (Access to allied health professionals)  | 10               | 20.00 | 4            | 13.33 | 6     | 30.00 | 3            | 11.11 | 7           | 30.43 |
| Participant describes being grateful for their healthcare card and the financial relief it provides  | 7                | 14.00 | 2            | 6.67  | 5     | 25.00 | 3            | 11.11 | 4           | 17.39 |
| Participant describes being grateful for subsidised diagnostic tests   | 6                | 12.00 | 4            | 13.33 | 2     | 10.00 | 5            | 18.52 | 1           | 4.35  |
| Participant describes being grateful for government initiatives that support ongoing health and quality of life (for example NDIS, Better Start Program and At home nursing services)  | 6                | 12.00 | 3            | 10.00 | 3     | 15.00 | 5            | 18.52 | 1           | 4.35  |
| Participant describes frustration at the lack of specialists and specialised services in regional areas and the financial cost incurred when travelling to metropolitan areas for care | 5                | 10.00 | 2            | 6.67  | 3     | 15.00 | 2            | 7.41  | 3           | 13.04 |
| Participant describes frustration at the lack of services tailored towards mitochondria disease  | 5                | 10.00 | 4            | 13.33 | 1     | 5.00  | 4            | 14.81 | 1           | 4.35  |
| Participant describes being grateful for the quality of specialist expertise in Australia  | 5                | 10.00 | 5            | 16.67 | 0     | 0.00  | 3            | 11.11 | 2           | 8.70  |



## Aspects of the Australian health system that patients are grateful for (Table a)



| Aspects of the Australian health system that patients are grateful for   | All participants |       | High school or trade |       | University |       | Hearing impairment |       | Eye or visual impairment |       |
|--|------------------|-------|----------------------|-------|------------|-------|--------------------|-------|--------------------------|-------|
|  | n=50             | %     | n=26                 | %     | n=24       | %     | n=24               | %     | n=34                     | %     |
| Participant describes being grateful for Medicare (Access to specialists)  | 17               | 34.00 | 7                    | 26.92 | 10         | 41.67 | 10                 | 41.67 | 10                       | 29.41 |
| Participant describes being grateful for the compassion and support shown by healthcare professionals  | 16               | 32.00 | 6                    | 23.08 | 11         | 45.83 | 9                  | 37.50 | 10                       | 29.41 |
| Participant describes being grateful for Medicare (Access to allied health professionals)  | 10               | 20.00 | 4                    | 15.38 | 6          | 25.00 | 5                  | 20.83 | 8                        | 23.53 |
| Participant describes being grateful for their healthcare card and the financial relief it provides  | 7                | 14.00 | 2                    | 7.69  | 5          | 20.83 | 6                  | 25.00 | 4                        | 11.76 |
| Participant describes being grateful for subsidised diagnostic tests   | 6                | 12.00 | 4                    | 15.38 | 2          | 8.33  | 3                  | 12.50 | 4                        | 11.76 |
| Participant describes being grateful for government initiatives that support ongoing health and quality of life (for example NDIS, Better Start Program and At home nursing services)  | 6                | 12.00 | 5                    | 19.23 | 1          | 4.17  | 4                  | 16.67 | 6                        | 17.65 |
| Participant describes frustration at the lack of specialists and specialised services in regional areas and the financial cost incurred when travelling to metropolitan areas for care | 5                | 10.00 | 3                    | 11.54 | 2          | 8.33  | 1                  | 4.17  | 2                        | 5.88  |
| Participant describes frustration at the lack of services tailored towards mitochondria disease  | 5                | 10.00 | 2                    | 7.69  | 3          | 12.50 | 3                  | 12.50 | 2                        | 5.88  |
| Participant describes being grateful for the quality of specialist expertise in Australia  | 5                | 10.00 | 1                    | 3.85  | 4          | 16.67 | 1                  | 4.17  | 3                        | 8.82  |



## Aspects of the Australian health system that patients are grateful for (Table b)

| Aspects of the Australian health system that patients are grateful for   | All participants |       | Physical function (High) |       | Physical function (Low) |       | Emotional well-being (High) |       | Emotional well-being (Low) |       |
|--|------------------|-------|--------------------------|-------|-------------------------|-------|-----------------------------|-------|----------------------------|-------|
|  | n=50             | %     | n=22                     | %     | n=28                    | %     | n=26                        | %     | n=24                       | %     |
| Participant describes being grateful for Medicare (Access to specialists)  | 17               | 34.00 | 6                        | 27.27 | 11                      | 39.29 | 10                          | 38.46 | 7                          | 29.17 |
| Participant describes being grateful for the compassion and support shown by healthcare professionals  | 16               | 32.00 | 12                       | 54.55 | 5                       | 17.86 | 8                           | 30.77 | 9                          | 37.50 |
| Participant describes being grateful for Medicare (Access to allied health professionals)  | 10               | 20.00 | 3                        | 13.64 | 7                       | 25.00 | 6                           | 23.08 | 4                          | 16.67 |
| Participant describes being grateful for their healthcare card and the financial relief it provides  | 7                | 14.00 | 0                        | 0.00  | 7                       | 25.00 | 3                           | 11.54 | 4                          | 16.67 |
| Participant describes being grateful for subsidised diagnostic tests   | 6                | 12.00 | 5                        | 22.73 | 1                       | 3.57  | 5                           | 19.23 | 1                          | 4.17  |
| Participant describes being grateful for government initiatives that support ongoing health and quality of life (for example NDIS, Better Start Program and At home nursing services)  | 6                | 12.00 | 2                        | 9.09  | 4                       | 14.29 | 4                           | 15.38 | 2                          | 8.33  |
| Participant describes frustration at the lack of specialists and specialised services in regional areas and the financial cost incurred when travelling to metropolitan areas for care | 5                | 10.00 | 0                        | 0.00  | 5                       | 17.86 | 1                           | 3.85  | 4                          | 16.67 |
| Participant describes frustration at the lack of services tailored towards mitochondria disease  | 5                | 10.00 | 3                        | 13.64 | 2                       | 7.14  | 2                           | 7.69  | 3                          | 12.50 |
| Participant describes being grateful for the quality of specialist expertise in Australia  | 5                | 10.00 | 3                        | 13.64 | 2                       | 7.14  | 3                           | 11.54 | 2                          | 8.33  |



## Aspects of the Australian health system that patients are grateful for (Table c)

| Aspects of the Australian health system that patients are grateful for   | All participants |       | Social functioning (High) |       | Social functioning (Low) |       | General health (High) |       | General health (Low) |       |
|--|------------------|-------|---------------------------|-------|--------------------------|-------|-----------------------|-------|----------------------|-------|
|  | n=50             | %     | n=20                      | %     | n=30                     | %     | n=22                  | %     | n=28                 | %     |
| Participant describes being grateful for Medicare (Access to specialists)  | 17               | 34.00 | 6                         | 30.00 | 11                       | 36.67 | 6                     | 27.27 | 11                   | 39.29 |
| Participant describes being grateful for the compassion and support shown by healthcare professionals  | 16               | 32.00 | 6                         | 30.00 | 11                       | 36.67 | 11                    | 50.00 | 6                    | 21.43 |
| Participant describes being grateful for Medicare (Access to allied health professionals)  | 10               | 20.00 | 5                         | 25.00 | 5                        | 16.67 | 4                     | 18.18 | 6                    | 21.43 |
| Participant describes being grateful for their healthcare card and the financial relief it provides  | 7                | 14.00 | 0                         | 0.00  | 7                        | 23.33 | 2                     | 9.09  | 5                    | 17.86 |
| Participant describes being grateful for subsidised diagnostic tests   | 6                | 12.00 | 5                         | 25.00 | 1                        | 3.33  | 4                     | 18.18 | 2                    | 7.14  |
| Participant describes being grateful for government initiatives that support ongoing health and quality of life (for example NDIS, Better Start Program and At home nursing services)  | 6                | 12.00 | 3                         | 15.00 | 3                        | 10.00 | 1                     | 4.55  | 5                    | 17.86 |
| Participant describes frustration at the lack of specialists and specialised services in regional areas and the financial cost incurred when travelling to metropolitan areas for care | 5                | 10.00 | 1                         | 5.00  | 4                        | 13.33 | 2                     | 9.09  | 3                    | 10.71 |
| Participant describes frustration at the lack of services tailored towards mitochondria disease  | 5                | 10.00 | 2                         | 10.00 | 3                        | 10.00 | 4                     | 18.18 | 1                    | 3.57  |
| Participant describes being grateful for the quality of specialist expertise in Australia  | 5                | 10.00 | 2                         | 10.00 | 3                        | 10.00 | 2                     | 9.09  | 3                    | 10.71 |

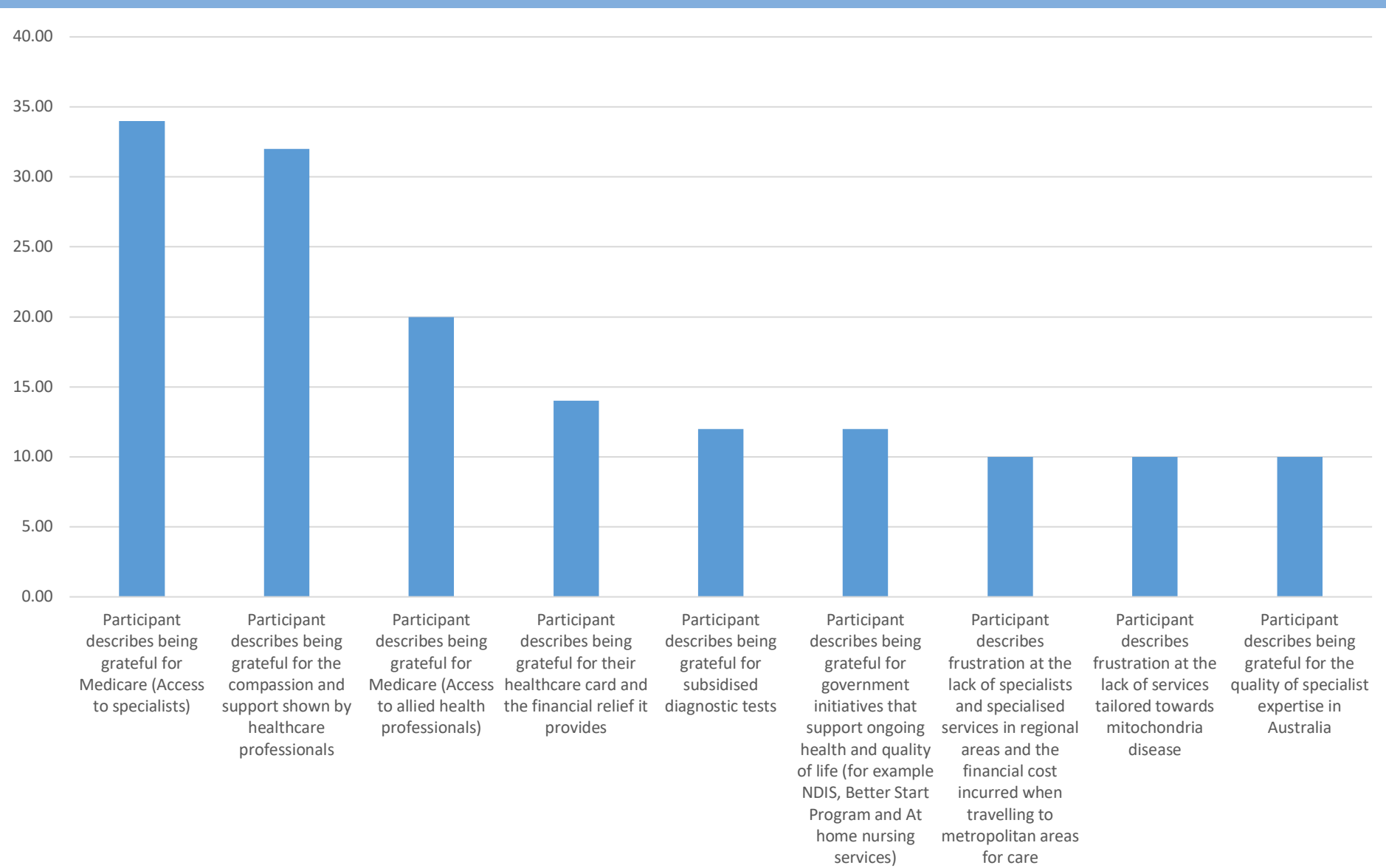


## Aspects of the Australian health system that patients are grateful for (Table d)

| Aspects of the Australian health system that patients are grateful for   | All participants |       | Under 18 |       | 24-44 |       | 45-54 |       | 55-64 |       | 65-74+ |       |
|--|------------------|-------|----------|-------|-------|-------|-------|-------|-------|-------|--------|-------|
|  | n=50             | %     | n=6      | %     | n=14  | %     | n=9   | %     | n=11  | %     | n=10   | %     |
| Participant describes being grateful for Medicare (Access to specialists)  | 17               | 34.00 | 2        | 33.33 | 7     | 50.00 | 1     | 11.11 | 4     | 36.36 | 3      | 30.00 |
| Participant describes being grateful for the compassion and support shown by healthcare professionals  | 16               | 32.00 | 4        | 66.67 | 5     | 35.71 | 1     | 11.11 | 4     | 36.36 | 3      | 30.00 |
| Participant describes being grateful for Medicare (Access to allied health professionals)  | 10               | 20.00 | 2        | 33.33 | 3     | 21.43 | 1     | 11.11 | 2     | 18.18 | 2      | 20.00 |
| Participant describes being grateful for their healthcare card and the financial relief it provides  | 7                | 14.00 | 1        | 16.67 | 1     | 7.14  | 0     | 0.00  | 3     | 27.27 | 2      | 20.00 |
| Participant describes being grateful for subsidised diagnostic tests   | 6                | 12.00 | 0        | 0.00  | 3     | 21.43 | 1     | 11.11 | 1     | 9.09  | 1      | 10.00 |
| Participant describes being grateful for government initiatives that support ongoing health and quality of life (for example NDIS, Better Start Program and At home nursing services)  | 6                | 12.00 | 2        | 33.33 | 0     | 0.00  | 2     | 22.22 | 1     | 9.09  | 1      | 10.00 |
| Participant describes frustration at the lack of specialists and specialised services in regional areas and the financial cost incurred when travelling to metropolitan areas for care | 5                | 10.00 | 0        | 0.00  | 0     | 0.00  | 0     | 0.00  | 1     | 9.09  | 4      | 40.00 |
| Participant describes frustration at the lack of services tailored towards mitochondria disease  | 5                | 10.00 | 0        | 0.00  | 0     | 0.00  | 2     | 22.22 | 1     | 9.09  | 2      | 20.00 |
| Participant describes being grateful for the quality of specialist expertise in Australia  | 5                | 10.00 | 1        | 16.67 | 2     | 14.29 | 0     | 0.00  | 2     | 18.18 | 0      | 0.00  |



## Aspects of the Australian health system that patients are grateful for (Table e)



| Aspects of the Australian health system that   | All participants |       | Metropolitan |       | Rural |       | SEIFA (High) |       | SEIFA (Low) |       |
|--|------------------|-------|--------------|-------|-------|-------|--------------|-------|-------------|-------|
|  | n=50             | %     | n=30         | %     | n=20  | %     | n=27         | %     | n=23        | %     |
| Participant's message is to support more research (General - no specific area)   | 20               | 40.00 | 9            | 30.00 | 11    | 55.00 | 11           | 40.74 | 9           | 39.13 |
| Participant's message is to provide more education to the healthcare professionals (Particularly education about managing the condition) | 15               | 30.00 | 8            | 26.67 | 7     | 35.00 | 7            | 25.93 | 8           | 34.78 |
| Participant's message is increase awareness of mitochondrial disease among the community   | 12               | 24.00 | 8            | 26.67 | 4     | 20.00 | 6            | 22.22 | 6           | 26.09 |
| Participant's message is to provide more holistic and multidisciplinary/allied health care   | 12               | 24.00 | 7            | 23.33 | 5     | 25.00 | 5            | 18.52 | 7           | 30.43 |
| Participant's message is to support more funding (General - no specific area)  | 11               | 22.00 | 8            | 26.67 | 3     | 15.00 | 7            | 25.93 | 4           | 17.39 |
| Participant's message is to improve treatments by following the example of other countries that have more advanced systems               | 8                | 16.00 | 5            | 16.67 | 4     | 20.00 | 6            | 22.22 | 3           | 13.04 |



|  | All participants |       | High school or trade |       | University |       | Hearing impairment |       | Eye or visual impairment |       |
|--|------------------|-------|----------------------|-------|------------|-------|--------------------|-------|--------------------------|-------|
|  | n=50             | %     | n=26                 | %     | n=24       | %     | n=24               | %     | n=34                     | %     |
| Participant's message is to support more research (General - no specific area)   | 20               | 40.00 | 9                    | 34.62 | 11         | 45.83 | 9                  | 37.50 | 12                       | 35.29 |
| Participant's message is to provide more education to the healthcare professionals (Particularly education about managing the condition) | 15               | 30.00 | 8                    | 30.77 | 7          | 29.17 | 10                 | 41.67 | 9                        | 26.47 |
| Participant's message is increase awareness of mitochondrial disease among the community   | 12               | 24.00 | 9                    | 34.62 | 3          | 12.50 | 7                  | 29.17 | 10                       | 29.41 |
| Participant's message is to provide more holistic and multidisciplinary/allied health care   | 12               | 24.00 | 5                    | 19.23 | 7          | 29.17 | 6                  | 25.00 | 9                        | 26.47 |
| Participant's message is to support more funding (General - no specific area)  | 11               | 22.00 | 3                    | 11.54 | 8          | 33.33 | 9                  | 37.50 | 7                        | 20.59 |
| Participant's message is to improve treatments by following the example of other countries that have more advanced systems               | 8                | 16.00 | 4                    | 15.38 | 5          | 20.83 | 4                  | 16.67 | 5                        | 14.71 |



|  | All participants |       | Physical function (High) |       | Physical function (Low) |       | Emotional well-being (High) |       | Emotional well-being (Low) |       |
|--|------------------|-------|--------------------------|-------|-------------------------|-------|-----------------------------|-------|----------------------------|-------|
|  | n=50             | %     | n=22                     | %     | n=28                    | %     | n=26                        | %     | n=24                       | %     |
| Participant's message is to support more research (General - no specific area)   | 20               | 40.00 | 9                        | 40.91 | 11                      | 39.29 | 11                          | 42.31 | 9                          | 37.50 |
| Participant's message is to provide more education to the healthcare professionals (Particularly education about managing the condition) | 15               | 30.00 | 5                        | 22.73 | 10                      | 35.71 | 6                           | 23.08 | 9                          | 37.50 |
| Participant's message is increase awareness of mitochondrial disease among the community   | 12               | 24.00 | 7                        | 31.82 | 5                       | 17.86 | 8                           | 30.77 | 4                          | 16.67 |
| Participant's message is to provide more holistic and multidisciplinary/allied health care   | 12               | 24.00 | 3                        | 13.64 | 9                       | 32.14 | 5                           | 19.23 | 7                          | 29.17 |
| Participant's message is to support more funding (General - no specific area)  | 11               | 22.00 | 6                        | 27.27 | 5                       | 17.86 | 6                           | 23.08 | 5                          | 20.83 |
| Participant's message is to improve treatments by following the example of other countries that have more advanced systems               | 8                | 16.00 | 4                        | 18.18 | 5                       | 17.86 | 4                           | 15.38 | 5                          | 20.83 |



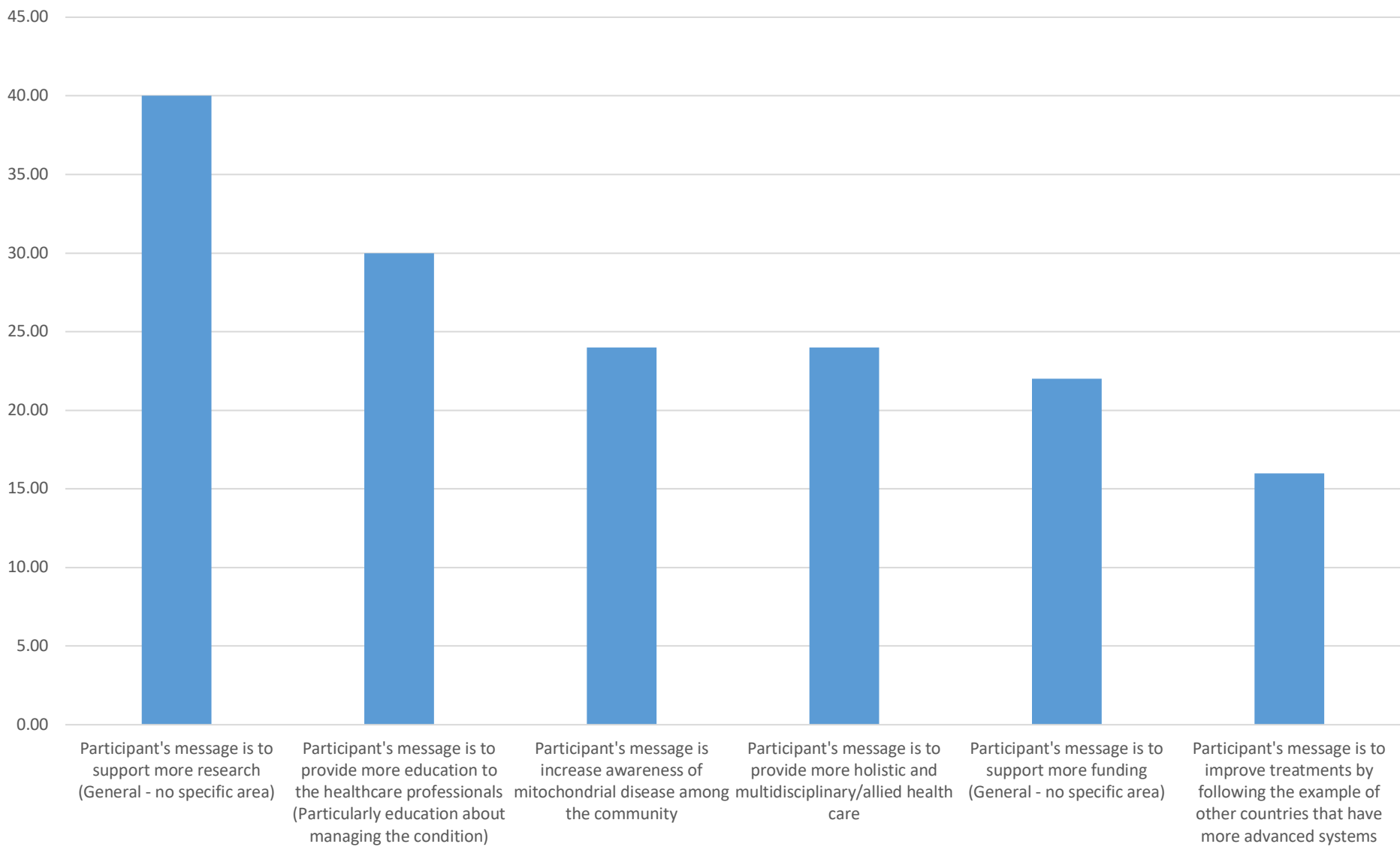


|  | All participants |       | Social functioning (High) |       | Social functioning (Low) |       | General health (High) |       | General health (Low) |       |
|--|------------------|-------|---------------------------|-------|--------------------------|-------|-----------------------|-------|----------------------|-------|
|  | n=50             | %     | n=20                      | %     | n=30                     | %     | n=22                  | %     | n=28                 | %     |
| Participant's message is to support more research (General - no specific area)   | 20               | 40.00 | 10                        | 50.00 | 10                       | 33.33 | 10                    | 45.45 | 10                   | 35.71 |
| Participant's message is to provide more education to the healthcare professionals (Particularly education about managing the condition) | 15               | 30.00 | 4                         | 20.00 | 11                       | 36.67 | 4                     | 18.18 | 11                   | 39.29 |
| Participant's message is increase awareness of mitochondrial disease among the community   | 12               | 24.00 | 5                         | 25.00 | 7                        | 23.33 | 5                     | 22.73 | 7                    | 25.00 |
| Participant's message is to provide more holistic and multidisciplinary/allied health care   | 12               | 24.00 | 4                         | 20.00 | 8                        | 26.67 | 4                     | 18.18 | 8                    | 28.57 |
| Participant's message is to support more funding (General - no specific area)  | 11               | 22.00 | 6                         | 30.00 | 5                        | 16.67 | 5                     | 22.73 | 6                    | 21.43 |
| Participant's message is to improve treatments by following the example of other countries that have more advanced systems               | 8                | 16.00 | 2                         | 10.00 | 7                        | 23.33 | 5                     | 22.73 | 4                    | 14.29 |



|  | All participants |       | Under 18 |       | 24-44 |       | 45-54 |       | 55-64 |       | 65-74+ |       |
|--|------------------|-------|----------|-------|-------|-------|-------|-------|-------|-------|--------|-------|
|  | n=50             | %     | n=6      | %     | n=14  | %     | n=9   | %     | n=11  | %     | n=10   | %     |
| Participant's message is to support more research (General - no specific area)   | 20               | 40.00 | 1        | 16.67 | 5     | 35.71 | 5     | 55.56 | 5     | 45.45 | 4      | 40.00 |
| Participant's message is to provide more education to the healthcare professionals (Particularly education about managing the condition) | 15               | 30.00 | 1        | 16.67 | 3     | 21.43 | 5     | 55.56 | 3     | 27.27 | 3      | 30.00 |
| Participant's message is increase awareness of mitochondrial disease among the community   | 12               | 24.00 | 2        | 33.33 | 5     | 35.71 | 3     | 33.33 | 0     | 0.00  | 2      | 20.00 |
| Participant's message is to provide more holistic and multidisciplinary/allied health care   | 12               | 24.00 | 1        | 16.67 | 3     | 21.43 | 2     | 22.22 | 4     | 36.36 | 2      | 20.00 |
| Participant's message is to support more funding (General - no specific area)  | 11               | 22.00 | 1        | 16.67 | 4     | 28.57 | 2     | 22.22 | 3     | 27.27 | 1      | 10.00 |
| Participant's message is to improve treatments by following the example of other countries that have more advanced systems               | 8                | 16.00 | 2        | 33.33 | 1     | 7.14  | 1     | 11.11 | 2     | 18.18 | 3      | 30.00 |







## **SECTION 10: ADVICE FROM CURRENT PATIENTS TO PATIENTS IN THE FUTURE**

The International Centre for Community-Driven Research

| Advice to patients in the future  | All participants |       | Metropolitan |       | Rural |       | SEIFA (High) |       | SEIFA (Low) |       |
|---|------------------|-------|--------------|-------|-------|-------|--------------|-------|-------------|-------|
|   | n=50             | %     | n=30         | %     | n=20  | %     | n=27         | %     | n=23        | %     |
| Participant's advice is to ask questions and learn as much as you can   | 14               | 28.00 | 9            | 30.00 | 6     | 30.00 | 7            | 25.93 | 8           | 34.78 |
| Participant's advice is to talk to AMDF for information and support and to be part of the community                                   | 8                | 16.00 | 6            | 20.00 | 3     | 15.00 | 3            | 11.11 | 6           | 26.09 |
| Participant's advice is to seek help (General)  | 8                | 16.00 | 6            | 20.00 | 2     | 10.00 | 4            | 14.81 | 4           | 17.39 |
| Participant's advice is to seek help - find the right specialist as it is a rare disease and be comfortable with your healthcare team | 8                | 16.00 | 7            | 23.33 | 1     | 5.00  | 4            | 14.81 | 4           | 17.39 |
| Participant's advice is to seek help (Psychological support)  | 7                | 14.00 | 4            | 13.33 | 3     | 15.00 | 3            | 11.11 | 4           | 17.39 |
| Participant's advice is to share your story to help others and help you find your path  | 6                | 12.00 | 4            | 13.33 | 3     | 15.00 | 2            | 7.41  | 5           | 21.74 |
| Participant's advice is to be hopeful   | 6                | 12.00 | 5            | 16.67 | 2     | 10.00 | 5            | 18.52 | 2           | 8.70  |
| Participant's advice is to take one day at a time and appreciate each day   | 5                | 10.00 | 3            | 10.00 | 2     | 10.00 | 4            | 14.81 | 1           | 4.35  |
| Participant's advice is to be a strong advocate for your or your child's health and wellbeing   | 5                | 10.00 | 3            | 10.00 | 2     | 10.00 | 1            | 3.70  | 4           | 17.39 |



| Advice to patients in the future  | All participants |       | High school or trade |       | University |       | Hearing impairment |       | Eye or visual impairment |       |
|---|------------------|-------|----------------------|-------|------------|-------|--------------------|-------|--------------------------|-------|
|   | n=50             | %     | n=26                 | %     | n=24       | %     | n=24               | %     | n=34                     | %     |
| Participant's advice is to ask questions and learn as much as you can   | 14               | 28.00 | 9                    | 34.62 | 6          | 25.00 | 6                  | 25.00 | 12                       | 35.29 |
| Participant's advice is to talk to AMDF for information and support and to be part of the community                                   | 8                | 16.00 | 6                    | 23.08 | 3          | 12.50 | 3                  | 12.50 | 7                        | 20.59 |
| Participant's advice is to seek help (General)  | 8                | 16.00 | 4                    | 15.38 | 4          | 16.67 | 6                  | 25.00 | 6                        | 17.65 |
| Participant's advice is to seek help - find the right specialist as it is a rare disease and be comfortable with your healthcare team | 8                | 16.00 | 4                    | 15.38 | 4          | 16.67 | 3                  | 12.50 | 7                        | 20.59 |
| Participant's advice is to seek help (Psychological support)  | 7                | 14.00 | 2                    | 7.69  | 5          | 20.83 | 3                  | 12.50 | 3                        | 8.82  |
| Participant's advice is to share your story to help others and help you find your path  | 6                | 12.00 | 6                    | 23.08 | 1          | 4.17  | 3                  | 12.50 | 4                        | 11.76 |
| Participant's advice is to be hopeful   | 6                | 12.00 | 2                    | 7.69  | 5          | 20.83 | 5                  | 20.83 | 3                        | 8.82  |
| Participant's advice is to take one day at a time and appreciate each day   | 5                | 10.00 | 2                    | 7.69  | 3          | 12.50 | 3                  | 12.50 | 3                        | 8.82  |
| Participant's advice is to be a strong advocate for your or your child's health and wellbeing   | 5                | 10.00 | 0                    | 0.00  | 5          | 20.83 | 4                  | 16.67 | 4                        | 11.76 |



| Advice to patients in the future  | All participants |       | Physical function (High) |       | Physical function (Low) |       | Emotional well-being (High) |       | Emotional well-being (Low) |       |
|---|------------------|-------|--------------------------|-------|-------------------------|-------|-----------------------------|-------|----------------------------|-------|
|   | n=50             | %     | n=22                     | %     | n=28                    | %     | n=26                        | %     | n=24                       | %     |
| Participant's advice is to ask questions and learn as much as you can   | 14               | 28.00 | 8                        | 36.36 | 7                       | 25.00 | 6                           | 23.08 | 9                          | 37.50 |
| Participant's advice is to talk to AMDF for information and support and to be part of the community                                   | 8                | 16.00 | 4                        | 18.18 | 5                       | 17.86 | 5                           | 19.23 | 4                          | 16.67 |
| Participant's advice is to seek help (General)  | 8                | 16.00 | 4                        | 18.18 | 4                       | 14.29 | 4                           | 15.38 | 4                          | 16.67 |
| Participant's advice is to seek help - find the right specialist as it is a rare disease and be comfortable with your healthcare team | 8                | 16.00 | 5                        | 22.73 | 3                       | 10.71 | 3                           | 11.54 | 5                          | 20.83 |
| Participant's advice is to seek help (Psychological support)  | 7                | 14.00 | 1                        | 4.55  | 6                       | 21.43 | 5                           | 19.23 | 2                          | 8.33  |
| Participant's advice is to share your story to help others and help you find your path  | 6                | 12.00 | 3                        | 13.64 | 4                       | 14.29 | 2                           | 7.69  | 5                          | 20.83 |
| Participant's advice is to be hopeful   | 6                | 12.00 | 2                        | 9.09  | 5                       | 17.86 | 4                           | 15.38 | 3                          | 12.50 |
| Participant's advice is to take one day at a time and appreciate each day   | 5                | 10.00 | 0                        | 0.00  | 5                       | 17.86 | 4                           | 15.38 | 1                          | 4.17  |
| Participant's advice is to be a strong advocate for your or your child's health and wellbeing   | 5                | 10.00 | 4                        | 18.18 | 1                       | 3.57  | 3                           | 11.54 | 2                          | 8.33  |



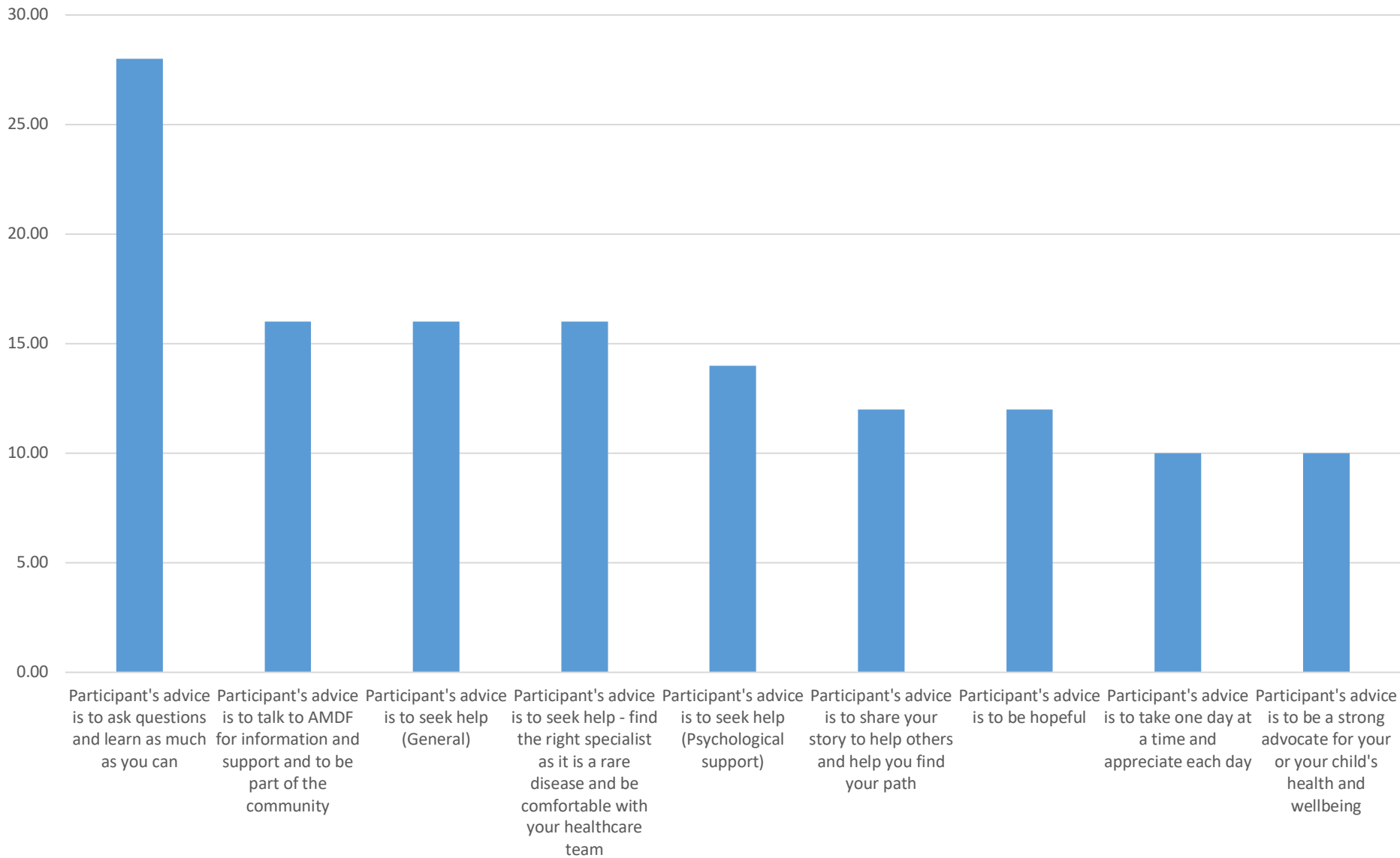
| Advice to patients in the future  | All participants |       | Social functioning (High) |       | Social functioning (Low) |       | General health (High) |       | General health (Low) |       |
|---|------------------|-------|---------------------------|-------|--------------------------|-------|-----------------------|-------|----------------------|-------|
|   | n=50             | %     | n=20                      | %     | n=30                     | %     | n=22                  | %     | n=28                 | %     |
| Participant's advice is to ask questions and learn as much as you can   | 14               | 28.00 | 7                         | 35.00 | 8                        | 26.67 | 6                     | 27.27 | 9                    | 32.14 |
| Participant's advice is to talk to AMDF for information and support and to be part of the community                                   | 8                | 16.00 | 6                         | 30.00 | 3                        | 10.00 | 5                     | 22.73 | 4                    | 14.29 |
| Participant's advice is to seek help (General)  | 8                | 16.00 | 5                         | 25.00 | 3                        | 10.00 | 2                     | 9.09  | 6                    | 21.43 |
| Participant's advice is to seek help - find the right specialist as it is a rare disease and be comfortable with your healthcare team | 8                | 16.00 | 4                         | 20.00 | 4                        | 13.33 | 2                     | 9.09  | 6                    | 21.43 |
| Participant's advice is to seek help (Psychological support)  | 7                | 14.00 | 5                         | 25.00 | 2                        | 6.67  | 2                     | 9.09  | 5                    | 17.86 |
| Participant's advice is to share your story to help others and help you find your path  | 6                | 12.00 | 2                         | 10.00 | 5                        | 16.67 | 2                     | 9.09  | 5                    | 17.86 |
| Participant's advice is to be hopeful   | 6                | 12.00 | 3                         | 15.00 | 4                        | 13.33 | 2                     | 9.09  | 5                    | 17.86 |
| Participant's advice is to take one day at a time and appreciate each day   | 5                | 10.00 | 0                         | 0.00  | 5                        | 16.67 | 1                     | 4.55  | 4                    | 14.29 |
| Participant's advice is to be a strong advocate for your or your child's health and wellbeing   | 5                | 10.00 | 2                         | 10.00 | 3                        | 10.00 | 3                     | 13.64 | 2                    | 7.14  |





| Advice to patients in the future  | All participants |       | Under 18 |       | 24-44 |       | 45-54 |       | 55-64 |       | 65-74+ |       |
|---|------------------|-------|----------|-------|-------|-------|-------|-------|-------|-------|--------|-------|
|   | n=50             | %     | n=6      | %     | n=14  | %     | n=9   | %     | n=11  | %     | n=10   | %     |
| Participant's advice is to ask questions and learn as much as you can   | 14               | 28.00 | 2        | 33.33 | 6     | 42.86 | 2     | 22.22 | 3     | 27.27 | 2      | 20.00 |
| Participant's advice is to talk to AMDF for information and support and to be part of the community                                   | 8                | 16.00 | 1        | 16.67 | 3     | 21.43 | 3     | 33.33 | 2     | 18.18 | 0      | 0.00  |
| Participant's advice is to seek help (General)  | 8                | 16.00 | 0        | 0.00  | 4     | 28.57 | 2     | 22.22 | 1     | 9.09  | 1      | 10.00 |
| Participant's advice is to seek help - find the right specialist as it is a rare disease and be comfortable with your healthcare team | 8                | 16.00 | 0        | 0.00  | 4     | 28.57 | 3     | 33.33 | 1     | 9.09  | 0      | 0.00  |
| Participant's advice is to seek help (Psychological support)  | 7                | 14.00 | 1        | 16.67 | 4     | 28.57 | 0     | 0.00  | 1     | 9.09  | 1      | 10.00 |
| Participant's advice is to share your story to help others and help you find your path  | 6                | 12.00 | 1        | 16.67 | 3     | 21.43 | 1     | 11.11 | 1     | 9.09  | 1      | 10.00 |
| Participant's advice is to be hopeful   | 6                | 12.00 | 2        | 33.33 | 1     | 7.14  | 3     | 33.33 | 1     | 9.09  | 0      | 0.00  |
| Participant's advice is to take one day at a time and appreciate each day   | 5                | 10.00 | 1        | 16.67 | 1     | 7.14  | 1     | 11.11 | 1     | 9.09  | 1      | 10.00 |
| Participant's advice is to be a strong advocate for your or your child's health and wellbeing   | 5                | 10.00 | 0        | 0.00  | 3     | 21.43 | 0     | 0.00  | 2     | 18.18 | 0      | 0.00  |







The International Centre for Community-Driven Research

# SECTION 12: NEXT STEPS

At the end of each PEEK study, ICCDR identifies three key areas that, if improved, would significantly increase the quality of life and/or the ability for individuals to better manage their own health.

In relation to the mitochondrial disease community, these three areas are:

1. Mechanisms to support health professional education, including those that support patients in explaining their condition to new health professionals that they may encounter
2. Case management services to provide holistic management of mitochondrial disease to patient and their families and ensure continuity of care across health services
3. Information that empowers patients, particularly at diagnosis; and ensure that all information is available in formats that are appropriate to those with visual and hearing impairments



| Area of evaluation  | 2018 data |        |
|---|-----------|--------|
| <b>Baseline health</b>  | Mean      | Median |
| Physical functioning  | 32.50     | 43.75  |
| Role functioning/physical   | 12.50     | 0.00   |
| Role functioning/emotional  | 43.33     | 33.33  |
| Energy/fatigue  | 22.50*    | 25.00  |
| Emotional well-being  | 64.00     | 68.00  |
| Social functioning  | 39.75     | 37.50  |
| Pain  | 46.90     | 45.00  |
| General health  | 28.00     | 25.00  |
| Health change   | 35.50     | 25.00  |
| <b>Percentage of participants that have accessed My Health Record</b>                   | 10.00%    |        |
| <b>Percentage of participants that have a discussion about biomarkers/genetic tests</b> | 42.00%    |        |
| <b>Knowledge of condition and treatments (Partners in Health)</b>                       | Mean      | Median |
| Knowledge   | 23.32     | 24.00  |
| Coping  | 13.40*    | 13.00  |
| Recognition and management of symptoms  | 18.76*    | 19.00  |
| Adherence to treatment  | 13.18     | 14.00  |
| Total score   | 68.66     | 71.50  |
| <b>Care Coordination and care received</b>  | Mean      | Median |
| Communication   | 33.40*    | 36.00  |
| Navigation  | 22.28*    | 21.50  |
| Total Score   | 55.68*    | 57.00  |
| Care coordination global measure  | 4.76      | 5.00   |
| Quality of care global measure  | 5.52      | 6.00   |
| <b>Fear of progression</b>  | Mean      | Median |
| Total Score   | 34.10*    | 34.00  |

