Participants with a neurodegenerative condition in the NDIS

Data at 31 March 2021

ndis

Outline

Introduction and definitions

This section describes five neurodegenerative conditions considered in this report: Muscular dystrophy, Huntington's disease, Motor neurone disease, Multiple sclerosis and Parkinson's disease. Various key terms used in this report are explained as well as measures such as committed supports, payments and complaint rates.

Participants

This section presents information on the profile of participants with a neurodegenerative condition across various participant characteristics such as age, Indigenous status and gender. Scheme participation rates are also presented.

Participant experience

This section includes various measures of the Scheme as experienced by participants, including eligibility rates, Participant Service Guarantee (PSG) metrics, as well as rates of exits and complaints.

Committed supports, payments and utilisation

This section presents average annualised committed supports and utilisation of supports by participant characteristics such as age and Supported Independent Living (SIL) status, as well as the distribution and types of committed supports in participant plans. Average annualised payments by financial year are also included.

Participant goals, outcomes and satisfaction

This section presents participant goals, followed by outcomes for participants and their families and carers. Outcomes results include those recorded at Scheme entry (baseline and also longitudinal survey responses. The report concludes with results from the Participant Satisfaction Survey (PSS).

Introduction

The National Disability Insurance Scheme (NDIS) provides reasonable and necessary funding to people with a permanent and significant disability to access the supports and services they need to assist with achieving their goals and outcomes.

The purpose of this report is to present on the experience of NDIS participants with one of the following neurodegenerative conditions, using data at 31 March 2021:

- Muscular dystrophy
- Huntington's disease
- Motor neurone disease
- Multiple sclerosis
- Parkinson's disease.

Definitions
Disability types classification

Disability types used by the NDIS are based on ICD-10 (International Statistical Classification of Diseases and Related Health Problems) codes which are relevant to the Scheme.

The ICD is a classification system which is a global standard for health data, clinical documentation and statistical aggregation.

The diagnosis codes associated with the disability types in this report as are follows:

Muscular dystrophy
G71.0 - Muscular dystrophy

Huntington's disease
G10 - Huntington's disease

Motor neurone disease
G12.2 - Motor neurone disease (also called amyotrophic lateral sclerosis)

Multiple sclerosis
G35 - Multiple sclerosis

Parkinson's disease
G20 - Parkinson's disease

Definitions
Disability types description

Neurodegenerative conditions are disorders that predominantly affect cells in the brain called neurons. Neurons are specialised cells that allow the brain to communicate with the rest of the body. When neurons become damaged or die, there is a loss of brain activity leading to problems with movement or mental functioning.*

While there is a diverse range of neurodegenerative conditions, this report considers the following five common types. The description for each condition is sourced from The Brain Foundation Australia.**

Muscular dystrophy

This refers to a group of genetic (inherited) conditions that cause progressive deterioration of the body's muscles, with increasing weakness and disability.

The main different types are Duchenne muscular dystrophy, Becker-type muscular dystrophy, Myotonic dystrophy, Limb-girdle muscular dystrophy, and Facioscapulohumeral muscular dystrophy. Most forms of muscular dystrophy are chronic and progressive and persist throughout life. Early death may result from severe involvement of respiratory or cardiac muscles. Currently, there is no cure for Muscular dystrophy and no way to stop its progression.

Huntington's disease

This is an inherited disease of the brain that affects the nervous system. The classic signs of the condition include emotional, cognitive and motor disturbances. Men and women are at equal risk of inheriting the disease, and it can appear at any age though manifestations typically become evident during the fourth or fifth decades of life. It is likely that the earlier the onset the faster the disease seems to progress.

This is a progressive condition, and the duration of the illness ranges from 10 to 30 years. Symptoms are not usually presented by the person. The person often has poor insight into the changes occurring which vary from each person. There is currently no cure for Huntington's disease.

* www.wehi.edu.au/research-diseases/development-and-ageing/neurodegenerative-disorders
** https://brainfoundation.org.au/

Definitions
Disability types description cont.

Motor neurone disease

This is a name given to a group of diseases in which the nerve cells (neurons) that control the muscles degenerate and die. Early symptoms are mild and include muscle wasting, muscle weakness, fasciculations (muscle twitching), difficulty swallowing and with speech, muscle cramps and spasms. Most cases occur spontaneously though some are hereditary (about 10%).

There are different types of Motor neurone disease and symptoms vary from person to person. Patterns of weakness, the rate and pattern of progression and survival time are also variable. There is no cure nor prevention at this time. In most cases, intellect and memory are not affected by this condition, nor are the senses of sight, hearing, taste, smell, and sensation.

Multiple sclerosis

This is the most common acquired chronic neurological disease affecting young adults. It is most commonly diagnosed between the ages of 20 and 40, and in Australia every three out four people diagnosed are women.

There are three forms: relapse-remitting, secondary progressive, and progressive. While there is no cure, most people with this condition live near-normal life spans. Several studies have suggested that a person lives around seven years less than people without it. Most people with the condition tend to die from the same conditions that people without it tend to die from, such as cancer and heart disease.

Parkinson's disease

This is a progressive, degenerative neurological condition that affects the control of body movements. It causes trembling in the hands, arms, legs, jaw, and face; rigidity or stiffness of the limbs or trunk; slowness of body movements; and unstable posture and difficulty in walking. Early symptoms are subtle and occur gradually.

Parkinson's disease is a chronic, progressive illness, and no drug can prevent the progression of the disease.

https://brainfoundation.org.au/

Definitions
Key terms

Active participant: Those who have been determined eligible, have a current approved plan and have not exited the Scheme.

Carer: Someone who provides personal care, support and assistance to a person with a disability and who is not contracted as a paid or voluntary worker.

Culturally and Linguistically Diverse (CALD): Country of birth is not Australia, New Zealand, the United Kingdom, Ireland, the United States of America, Canada, or primary language spoken at home is not English.

Outcomes framework questionnaires: One way in which the Agency is measuring success for participants and their families/carers with disability across eight different life domains.

Plan: Agreements under which reasonable and necessary supports will be funded for participants.

Participant Service Guarantee (PSG): A set of target timeframes for processes within the National Disability Insurance Agency relating to the participant pathway. It is part of the Participant Services Charter which explains what participants can expect when dealing with the Agency.

Participation rate: Sometimes referred to as prevalence rate, is the number of individuals in the NDIS as a proportion of the general population who have a defined level of disability at a specified point in time or over a specified period of time and have joined the Scheme.

Supported Independent Living (SIL): Supported Independent Living (SIL) is help with and/or supervision of daily tasks to develop the skills of an individual to live as independently as possible.

Definitions
Key terms

Average committed supports: Also referred to as plan budgets. The cost of supports contained within a participant's plan, approved to be provided to support a participant's needs. This amount is annualised to allow for comparison of plans of different lengths, and averaged over the relevant NDIS population being analysed. In this report, this is based on supports allocated to active plans.

Note: In-kind supports are provided via existing Commonwealth or State/ Territory government programs delivered under existing block grant funding arrangements. Committed supports shown in this report include most in-kind supports but do not include off-system in-kind or residential aged care reconciliations.

Average payments: Payments are made to providers, participants or their nominees for supports received as part of a participant's plan. In this report, average payments represent the average cash and in-kind supports paid over the reporting period based on payments data at 31 March 2021.

Average utilisation of committed supports: Utilisation represents the proportion of committed supports in participant plans that are utilised. Utilisation is calculated as total payments (including cash and in-kind, where it can be allocated to participant plans) divided by total committed supports. In this report, average utilisation of committed supports is calculated for a 6 month period, from 30 June 2020 to 31 December 2020, allowing for payment delays of up to 3 months.

Complaint rate: Complaint rates are calculated as the number of complaints made by people who have sought access divided by the number of people who have sought access. The number of people who have sought access used in the calculation takes into account the length of time since access was sought.

Participants

As at 31 March 2021, there were **449,998** active NDIS participants with an approved plan.

Of these:

- **2,258** (**0.5%**) had Muscular dystrophy.
- **945** (**0.2%**) had Huntingdon's disease.
- **789** (**0.2%**) had Motor neurone disease.
- **8,263** (**1.8%**) had Multiple Sclerosis.
- **2,134** (**0.5%**) had Parkinson's disease.

Summary

This section presents information on the characteristics of NDIS participants with a neurodegenerative condition as their primary disability as at 31 March 2021.

Key statistics

2,470 people with **Muscular dystrophy** have ever been eligible to the Scheme	**2,423** participants with **Muscular dystrophy** have had an approved plan	**2,258** participants with **Muscular dystrophy** are currently active with an approved plan	**0.5%** of participants with an approved plan across the Scheme as a whole
1,113 people with **Huntington's disease** have ever been eligible to the Scheme	**1,082** participants with **Huntington's disease** have had an approved plan	**945** participants with **Huntington's disease** are currently active with an approved plan	**0.2%** of participants with an approved plan across the Scheme as a whole
1,534 people with **Motor neurone disease** have ever been eligible to the Scheme	**1,440** participants with **Motor neurone disease** have had an approved plan	**789** participants with **Motor neurone disease** are currently active with an approved plan	**0.2%** of participants with an approved plan across the Scheme as a whole
8,731 people with **Multiple sclerosis** have ever been eligible to the Scheme	**8,547** participants with **Multiple sclerosis** have had an approved plan	**8,263** participants with **Multiple sclerosis** are currently active with an approved plan	**1.8%** of participants with an approved plan across the Scheme as a whole
2,402 people with **Parkinson's disease** have ever been eligible to the Scheme	**2,296** participants with **Parkinson's disease** have had an approved plan	**2,134** participants with **Parkinson's disease** are currently active with an approved plan	**0.5%** of participants with an approved plan across the Scheme as a whole
488,813 people **across the Scheme as a whole** have ever been eligible to the Scheme	**467,266** participants **across the Scheme as a whole** have had an approved plan	**449,998** participants **across the Scheme as a whole** are currently active with an approved plan	

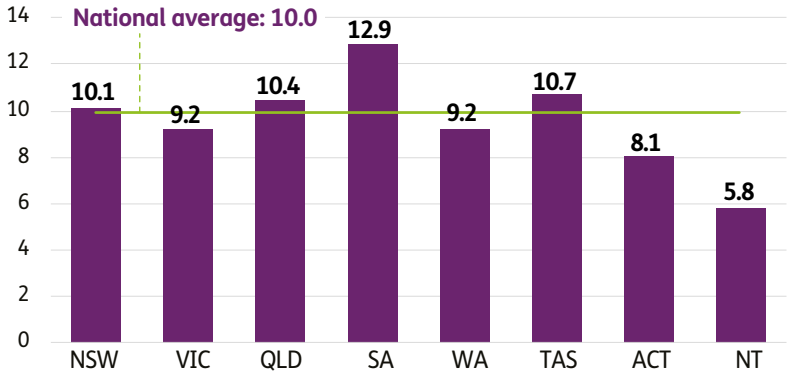
Participation rates by **State/Territory**

Participation rate refers to the proportion of the general population that are NDIS participants. For this purpose the rates are based on participants below 65 years old with the disability type being reported.

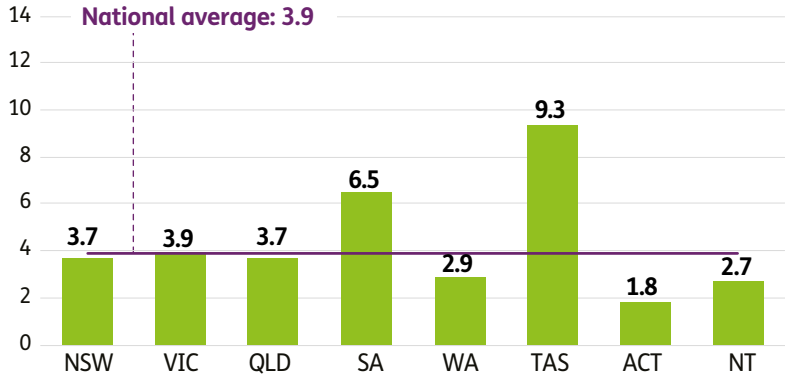
The national participation rate for participants with a neurodegenerative condition is relatively low compared to other disabilities. The participation rate is highest at 33.6 participants p er 100,000 population for Multiple sclerosis, followed by 10.0 participants per 100,000 population for Muscular dystrophy, 7.3 participants per 100,000 population for Parkinson's disease, 3.9 participants per 100,000 population for Huntington's disease, and 3.2 participants per 100,000 population for Motor neurone disease.

The participation rates for Muscular dystrophy and Motor neurone disease are highest in South Australia, while for Huntington's disease, Multiple sclerosis and Parkinson's disease, the participation rates are highest in Tasmania.

Participation rates for Muscular dystrophy by State/Territory

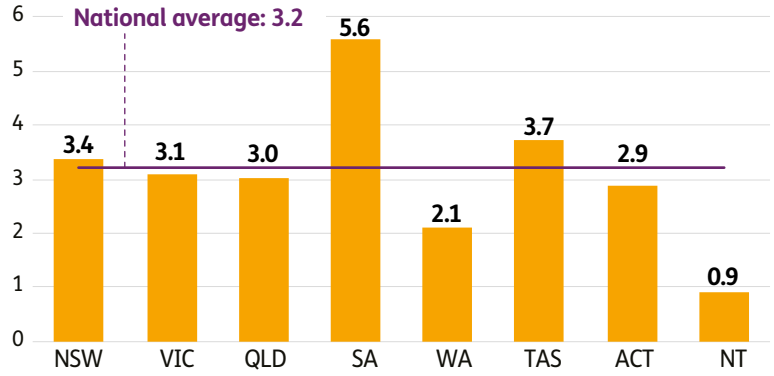


Participation rates for Huntington's disease by State/Territory

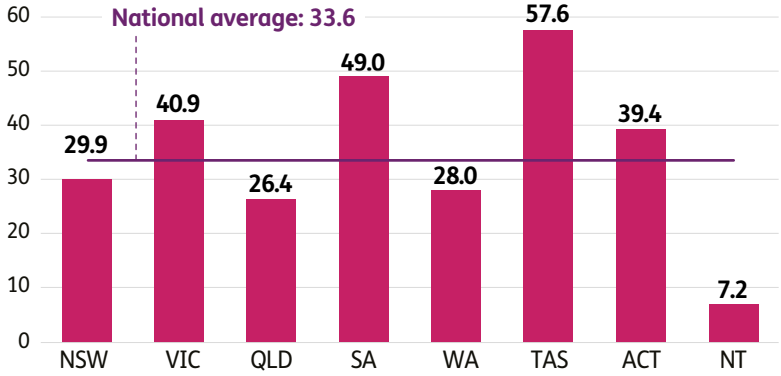


Participation rates by **State/Territory** cont.

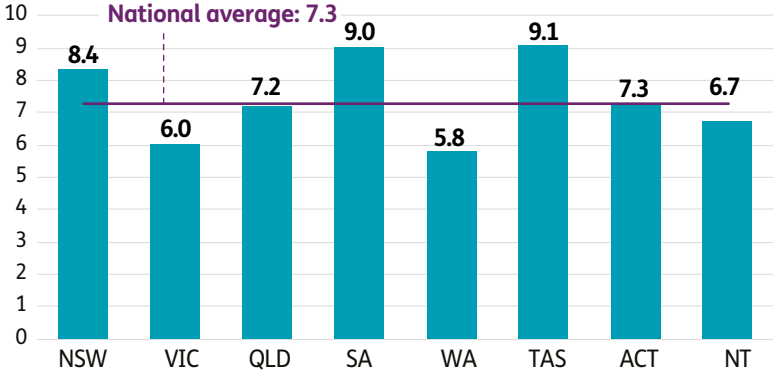
Participation rates for Motor neurone disease by State/Territory



Participation rates for Multiple sclerosis by State/Territory



Participation rates for Parkinson's disease by State/Territory

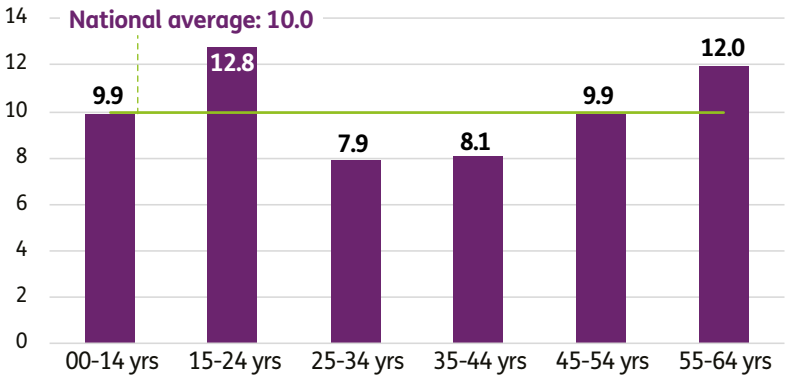


Participation rates by **age group**

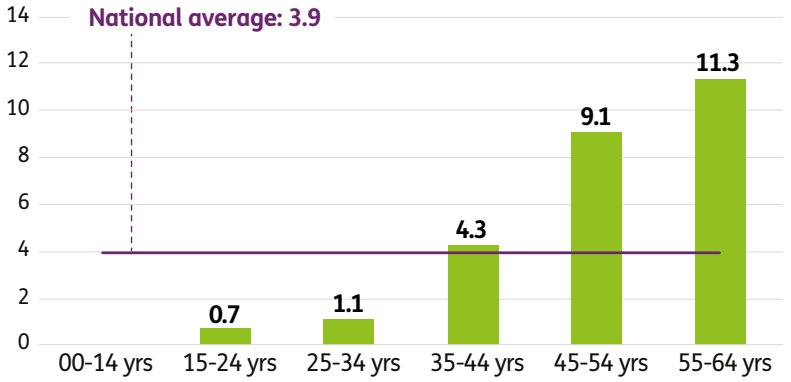
The rate of participation in the NDIS varies by age, and this variation differs significantly across disability types.

For participants with Muscular dystrophy, the participation rates are relatively even across the age groups, with slightly higher rates for younger participants aged below 25 years, and for participants aged 45-64 years. For participants with Huntington's disease, Motor neurone disease or Multiple sclerosis, the participation rates are very low at the younger ages, with a steep increase from around the age of 35 years. For participants with Parkinson's disease, the participation rates remain low until around 55 years of age.

Participation rates for Muscular dystrophy by age group



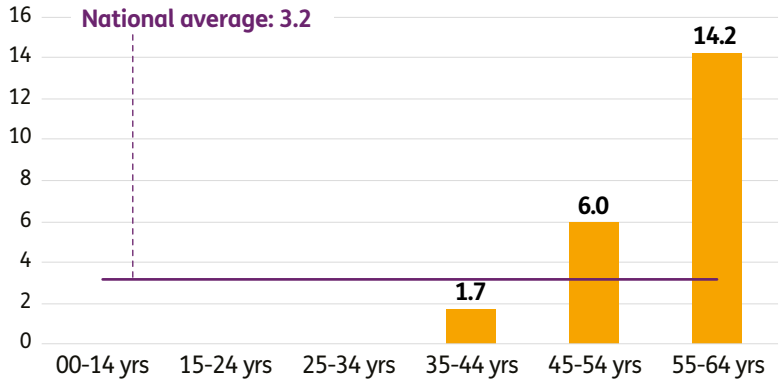
Participation rates for Huntington's disease by age group



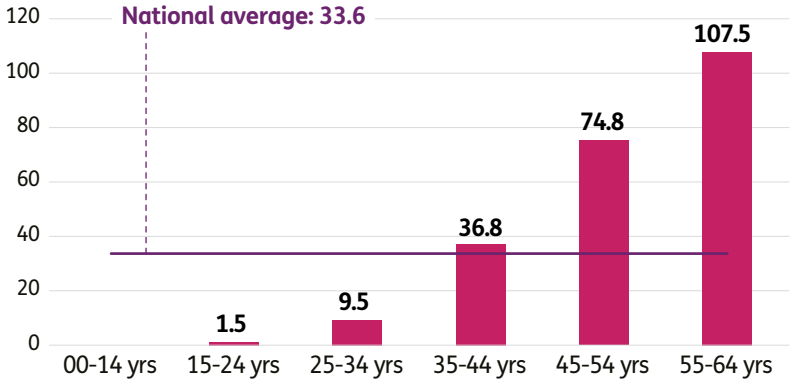
Note: The participation rates are not shown for age groups with 20 or less participants.

Participation rates by **age group** cont.

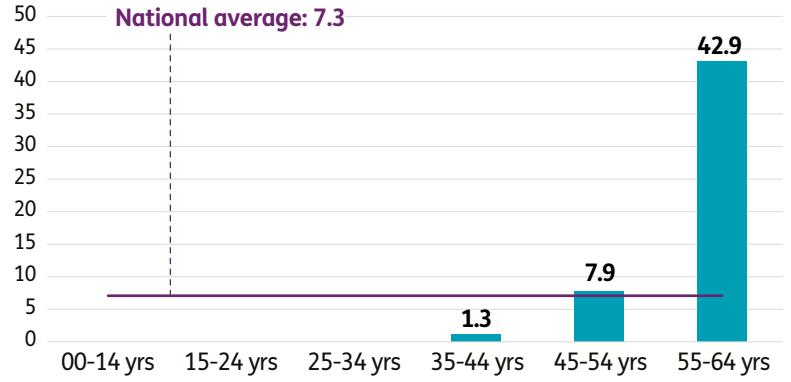
Participation rates for Motor neurone disease by age group



Participation rates for Multiple sclerosis by age group



Participation rates for Parkinson's disease by age group



Note: The participation rates are not shown for age groups with 20 or less participants.

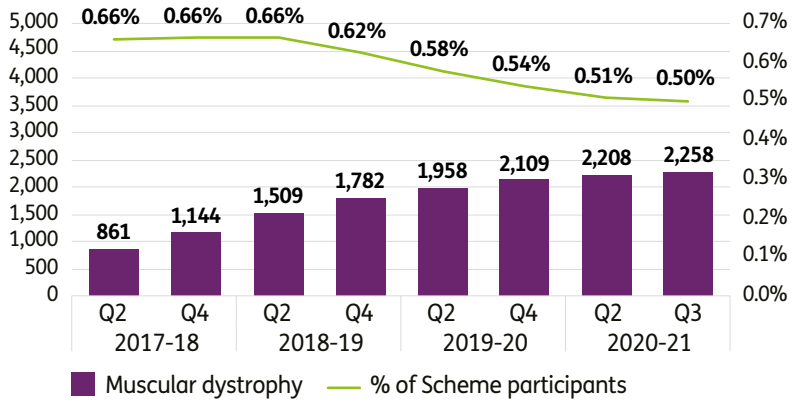
Participants by **over time**

For those with a neurodegenerative condition except for Parkinson's disease, the number of active participants with an approved plan continues to increase at a decreasing rate compared to the Scheme as a whole. The proportions of these participants increased up to December 2018 or June 2019 and have decreased subsequently. For participants with Parkinson's disease, the number of active participants continues to increase at a higher rate than the Scheme overall, with the proportion of participants increasing steadily since December 2017.

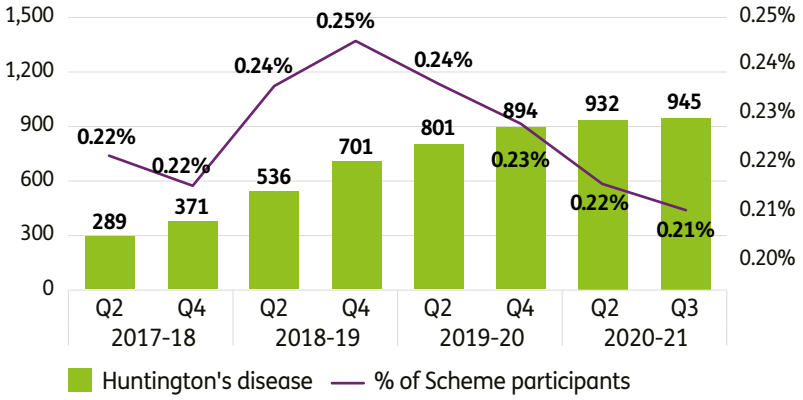
At 31 March 2021, there were:

- 2,258 participants (0.5% of the Scheme) with Muscular dystrophy.
- 945 participants (0.2% of the Scheme) with Huntington's disease.
- 789 participants (0.2% of the Scheme) with Motor neurone disease.
- 8,263 participants (1.8% of the Scheme) with Multiple sclerosis.
- 2,134 participants (0.5% of the Scheme) with Parkinson's disease.

Active participants with Muscular dystrophy over time

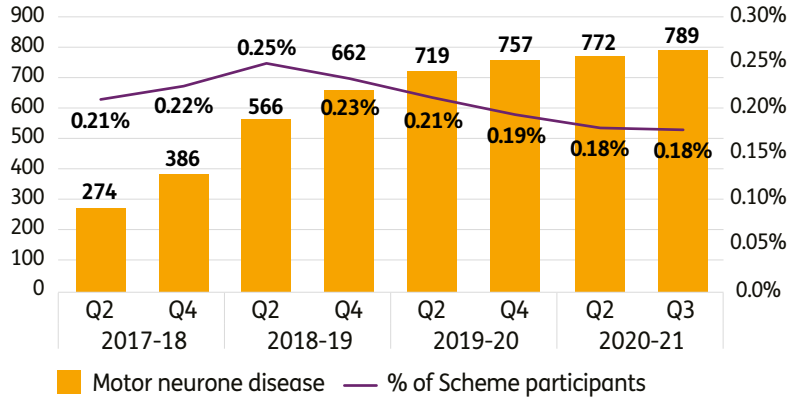


Active participants with Huntington's disease over time

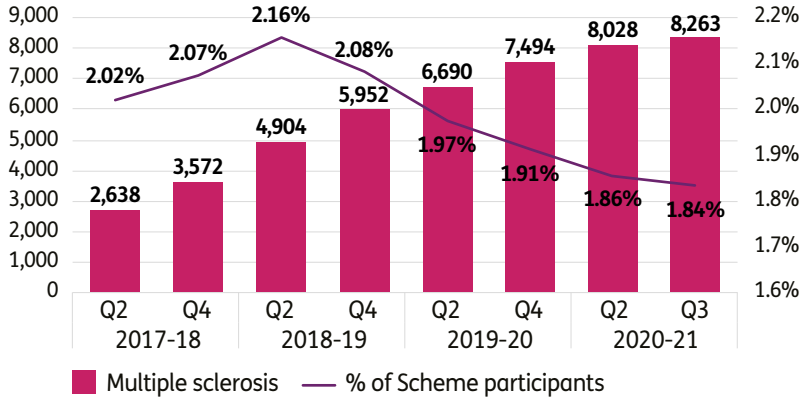


Participants
over time cont.

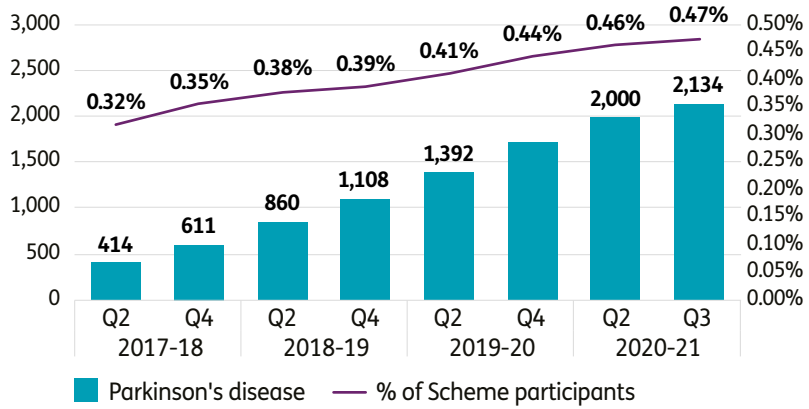
Active participants with Motor neurone disease over time



Active participants with Multiple sclerosis over time



Active participants with Parkinson's disease over time



Participants by **age group**

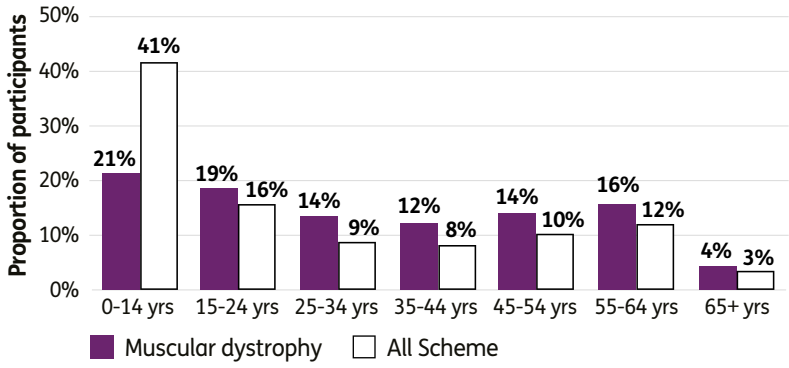
The distribution of active participants by age group is considerably older for participants with a neurodegenerative condition than the Scheme as a whole:

- 60% of active participants with Muscular dystrophy are aged 25 and over
- 97% of active participants with Huntington's disease are aged 25 or over
- 99% of active participants with Motor neurone disease are aged 25 or over
- 99% of active participants with Multiple sclerosis are aged 25 or over
- 100% of active participants with Parkinson's disease are aged 25 or over

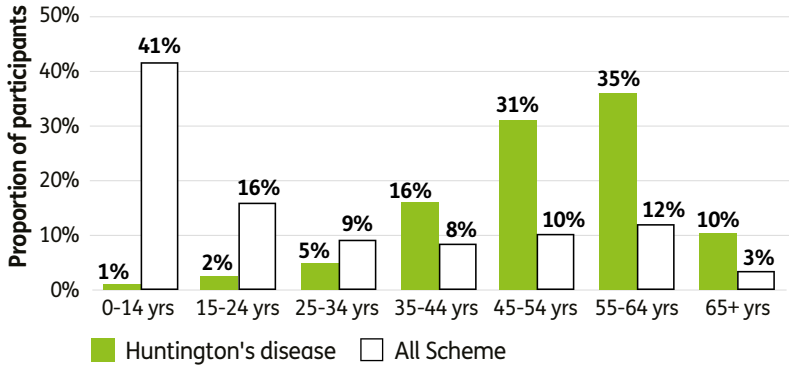
These compare with 43% for the Scheme overall.

Active participants with Muscular dystrophy have the highest proportion of children compared to other neurodegenerative conditions in this report. However, the age distribution for children and those below 25 are still different compared to the Scheme as a whole as 21% of active participants with Muscular dystrophy are aged 0 to 14 and a further 19% are aged 15 to 24, compared with 41% and 16% respectively across all active participants in the Scheme.

Distribution of active participants by age group - Muscular dystrophy compared with the Scheme as a whole

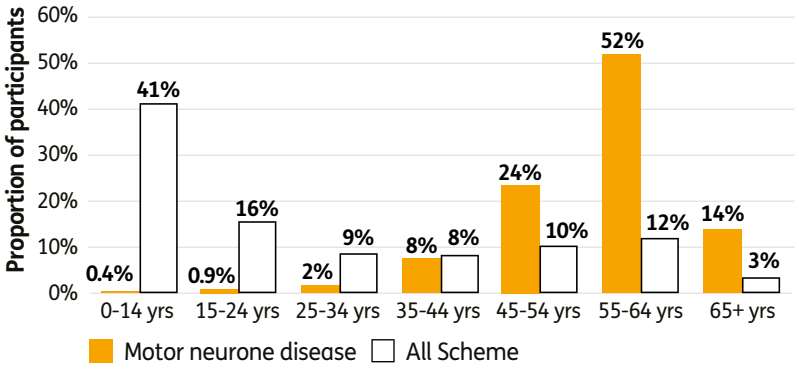


Distribution of active participants by age group - Huntington's disease compared with the Scheme as a whole

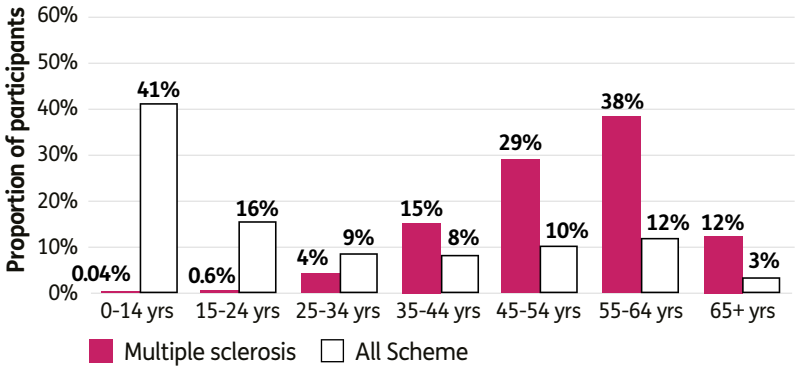


Participants by **age group** cont.

Distribution of active participants by age group - Motor neurone disease compared with the Scheme as a whole

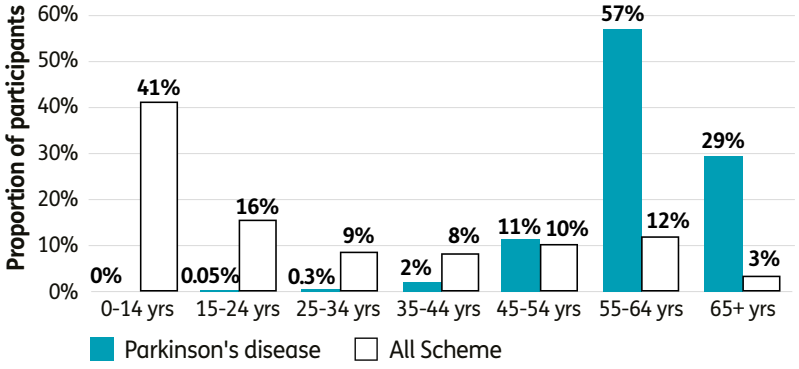


Distribution of active participants by age group - Multiple sclerosis compared with the Scheme as a whole



Active participants with Parkinson's disease have the highest proportion of older participants compared to other neurodegenerative conditions in this report, with 86% aged 55 and over.

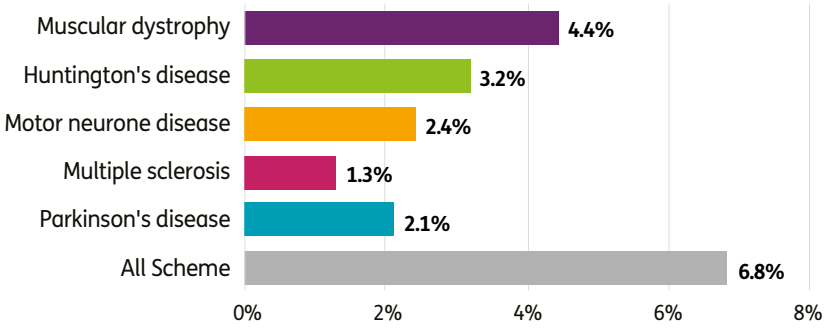
Distribution of active participants by age group - Parkinson's disease compared with the Scheme as a whole



Participants by
Indigenous and CALD status

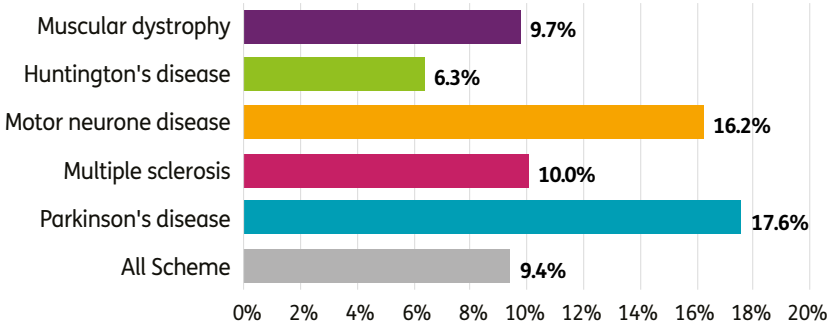
The proportion of active participants with a neurodegenerative condition that identify as Aboriginal and/or Torres Strait Islander is lower than the Scheme as a whole. This proportion is lowest for active participants with Multiple sclerosis at 1.3%, compared with the overall Scheme proportion of 6.8%.

Proportion of active participants with an approved plan who identify as Aboriginal and/or Torres Strait Islander



The proportion of active participants that identify as Culturally and Linguistically Diverse (CALD) is generally higher for those with a neurodegenerative condition than for the Scheme as a whole (9.4%). This proportion is double for active participants with Parkinson's disease (17.6%) and below the Scheme overall for participants with Huntington's disease (6.3%)

Proportion of active participants with an approved plan who identify as Culturally and Linguistically Diverse



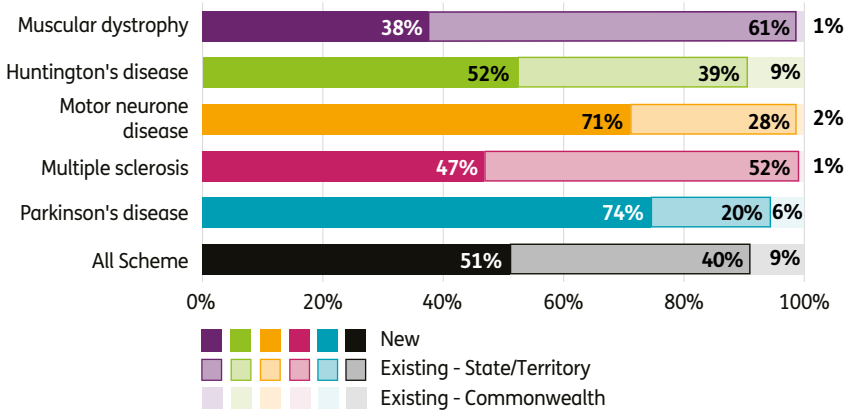
Participants by
Existing/New status, by level of function

Participants with a neurodegenerative condition of Muscular dystrophy or Multiple sclerosis have higher proportions of participants who previously received existing State/Territory or Commonwealth services prior to entering the Scheme, at 62% and 53% respectively, compared with 49% for the Scheme overall.

At 31 March 2021, around half of all participants did not receive government support before joining the NDIS (New). In comparison, the proportions are:

- 38% for Muscular dystrophy
- 52% for Huntington's disease
- 71% for Motor neurone disease
- 47% for Multiple sclerosis
- 74% for Parkinson's disease.

Active participants by Existing/ New status

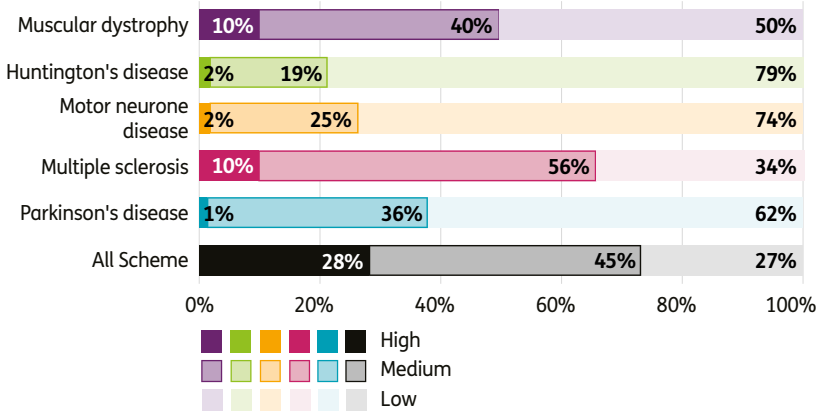


A participant's level of function is assessed across a range of domains such as self-care, mobility and communication. Overall level of function is a broad measure to gauge high level relativities between participant cohorts.

Over half of all participants with a neurodegenerative condition, except for Multiple sclerosis, have a low level of function compared to the Scheme as a whole (27%):

- 50% for Muscular dystrophy
- 79% for Huntington's disease
- 74% for Motor neurone disease
- 34% for Multiple sclerosis
- 62% for Parkinson's disease.

Active participants by level of function

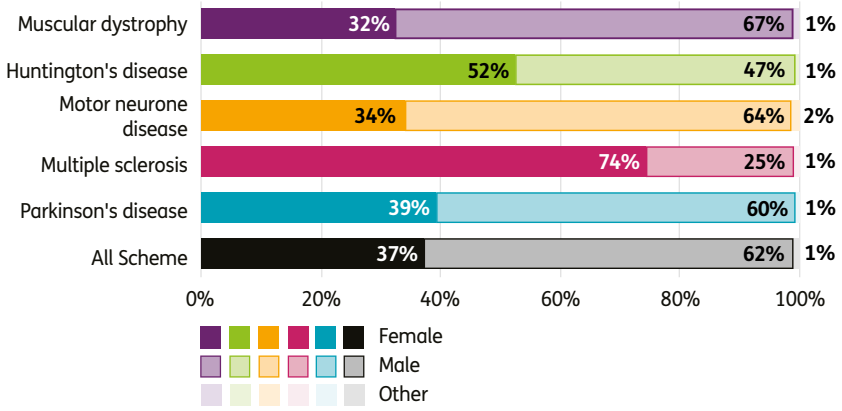


Participants by
gender and remoteness

Across the Scheme overall, 37% of participants with an approved plan identify as female and 62% identify as male. However, the distribution varies by neurodegenerative condition.

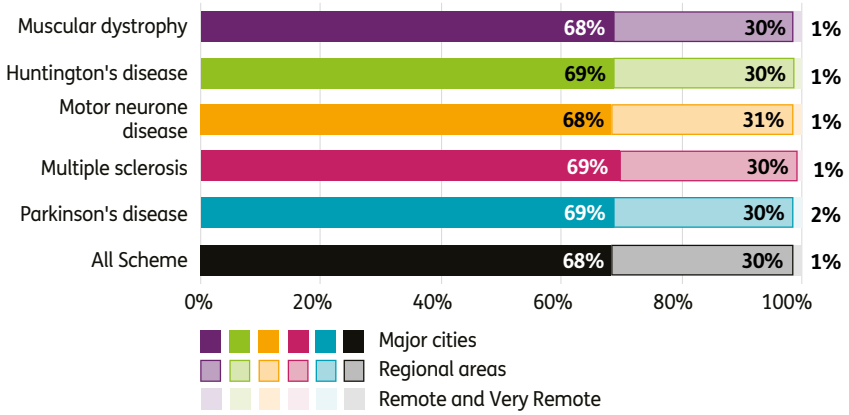
The proportion of participants with Multiple sclerosis who identify as female is the highest at 74%, followed by Huntington's disease at 52%. In contrast, the majority of the other participants with a neurodegenerative condition identify as male.

Distribution of active participants by gender



Based on geographical remoteness, active participants across all neurodegenerative conditions predominantly live in major cities. The proportions are very similar in comparison to the Scheme as a whole.

Distribution of active participants by geographical remoteness



PART 2

Participant experience

A higher proportion of individuals who present to the NDIS with a neurodegenerative condition, except Parkinson's disease, meet the access criteria relative to individuals with other disabilities.

The Agency has commenced measuring a number of metrics under the Participant Service Guarantee. Results on achieving target timeframes for those with a neurodegenerative condition are included in this section, along with comparisons with the experience of the Scheme overall.

Results for these disability types are also presented in relation to other aspects of the participant experience in the NDIS including methods of plan management, participant exits from the Scheme, and participant complaints.

Summary

This section presents information on the experience of NDIS participants with a neurodegenerative condition as their primary disability as at 31 March 2021.

Key statistics

93% of access decisions among participants with **Muscular dystrophy** are 'access met'	**100%** of access decisions for those with **Muscular dystrophy** were made within 14 days	**76%** of initial plans were approved within 56 days for participants with **Muscular dystrophy** aged 7 and above	**13%** is the annualised rate of participant complaints for those with **Muscular dystrophy**
97% of access decisions among participants with **Huntington's disease** are 'access met'	**100%** of access decisions for those with **Huntington's disease** were made within 14 days	**42%** of initial plans were approved within 56 days for participants with **Huntington's disease** aged 7 and above	**10%** is the annualised rate of participant complaints for those with **Huntington's disease**
97% of access decisions among participants with **Motor neurone disease** are 'access met'	**100%** of access decisions for those with **Motor neurone disease** were made within 14 days	**88%** of initial plans were approved within 56 days for participants with **Motor neurone disease** aged 7 and above	**13%** is the annualised rate of participant complaints for those with **Motor neurone disease**
87% of access decisions among participants with **Multiple sclerosis** are 'access met'	**100%** of access decisions for those with **Multiple sclerosis** were made within 14 days	**79%** of initial plans were approved within 56 days for participants with **Multiple sclerosis** aged 7 and above	**12%** is the annualised rate of participant complaints for those with **Multiple sclerosis**
82% of access decisions among participants with **Parkinson's disease** are 'access met'	**86%** of access decisions for those with **Parkinson's disease** were made within 14 days	**87%** of initial plans were approved within 56 days for participants with **Parkinson's disease** aged 7 and above	**9%** is the annualised rate of participant complaints for those with **Parkinson's disease**
85% of of access decisions among participants **across the Scheme as a whole** are 'access met'	**98%** of access decisions for those **across the Scheme as a whole** were made within 14 days	**79%** of initial plans were approved within 56 days for participants **across the Scheme as a whole** aged 7 and above	**5%** is the annualised rate of participant complaints **across the Scheme as a whole**

Access decisions and PSG Access metrics

The proportions of access decisions resulting in 'access met' are higher for individuals with a neurodegenerative condition than the Scheme overall, with the exception of Parkinson's disease.

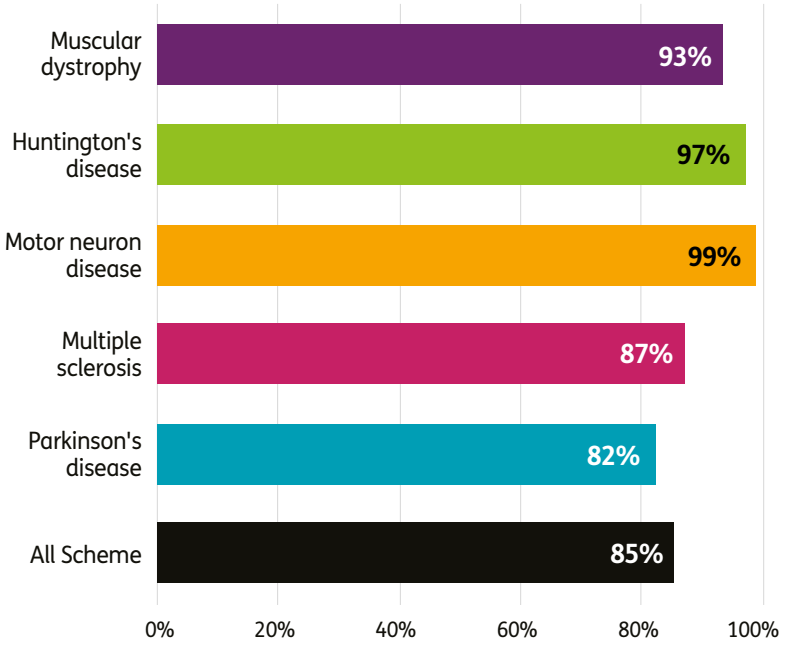
Participants with Motor neurone disease have the highest overall rate of 'access met' decisions at 99%, compared with 85% for the Scheme overall. The rates for participants with Huntington's disease, Muscular dystrophy and Multiple sclerosis are 97%, 93% and 87% respectively. Participants with Parkinson's disease have a lower proportion of 'access met' decisions compared to the Scheme as a whole at 82%.

The Participant Service Guarantee (PSG) is a set of target timeframes for Agency processes. It is part of the Participant Services Charter* which explains what participants can expect when dealing with the Agency.

An access related PSG metric is making an access decision within 14 days of final information being provided. Results for this metric are not graphed here.

The Agency's performance against this metric is positive with the target being achieved for 98% of decisions across the March 2020 to the March 2021 quarters. For participants with Muscular dystrophy, Huntington's disease and Motor neurone disease, performance has been higher than the overall Scheme performance at 100% across the last four quarters. For those with Multiple sclerosis and Parkinson's disease, the performance has been largely positive, at 96% or higher. However, the experience in the latest quarter for participants with Parkinson's disease is considerably poorer at 86%, noting that the number of decisions is relatively small.

Proportion of 'access met' decisions



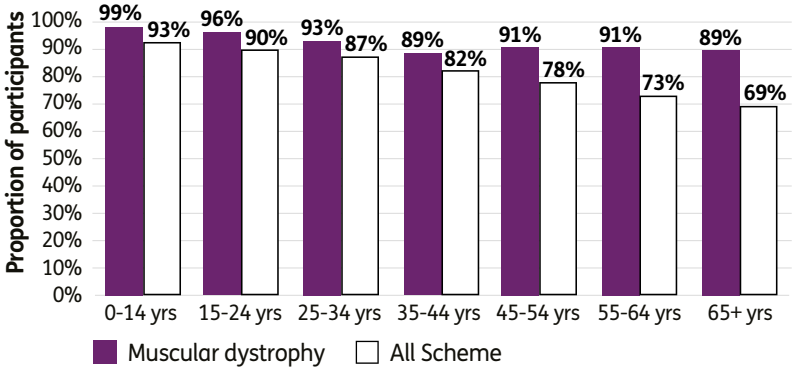
* More information about the Participant Services Charter and the Participant Service Guarantee can be found here: **Service charter | NDIS**

Access decisions by **age group**

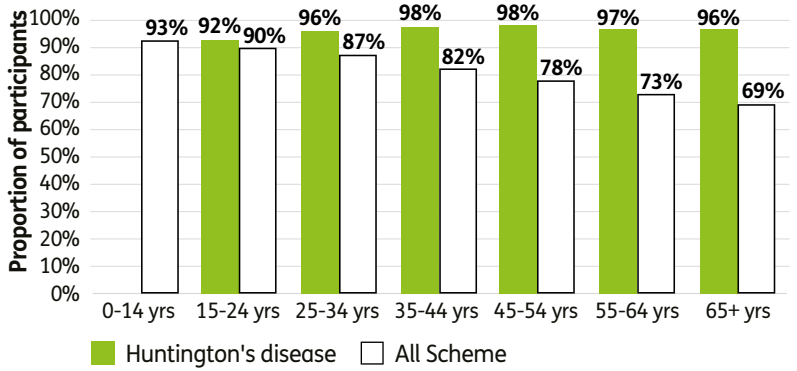
Across all decisions made to determine access to the NDIS, the proportion of 'access met' decisions is generally higher for children and decreases steadily as age increases.

For participants with a neurodegenerative condition, the proportions of 'access met' decisions do not vary greatly by age, and are higher than the Scheme experience for all age groups, except Multiple sclerosis for ages 15 to 34 years.

Proportion of 'access met' decisions by age group - Muscular dystrophy



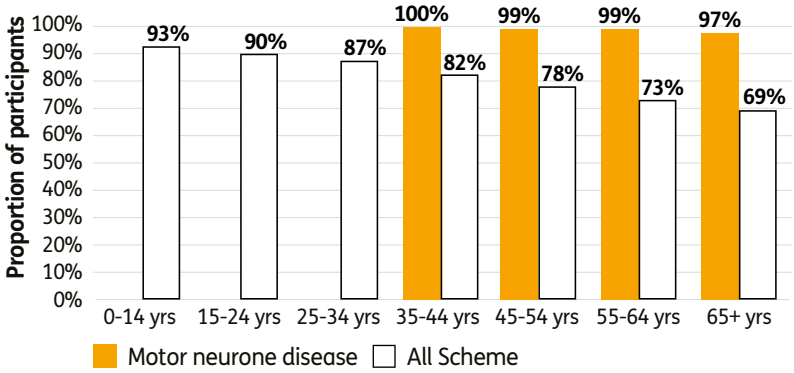
Proportion of 'access met' decisions by age group - Huntington's disease



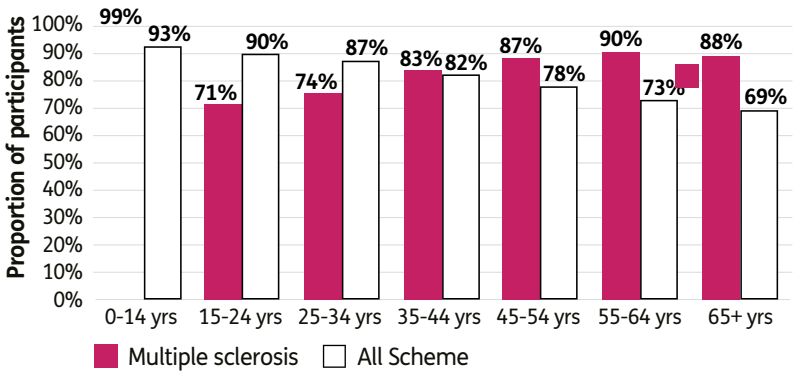
Note: The proportion of 'access met' decisions is not shown for age groups with 20 or less people for whom an access decision has been made.

Access decisions by **age group** cont.

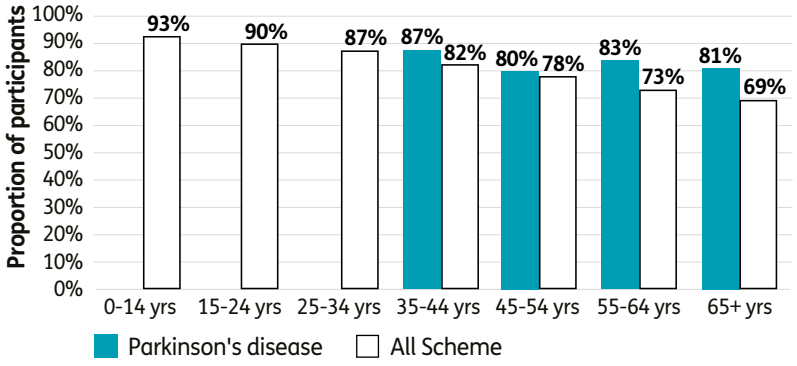
Proportion of 'access met' decisions by age group - Motor neurone disease



Proportion of 'access met' decisions by age group - Multiple sclerosis



Proportion of 'access met' decisions by age group - Parkinson's disease



Note: The proportion of 'access met' decisions is not shown for age groups with 20 or less people for whom an access decision has been made.

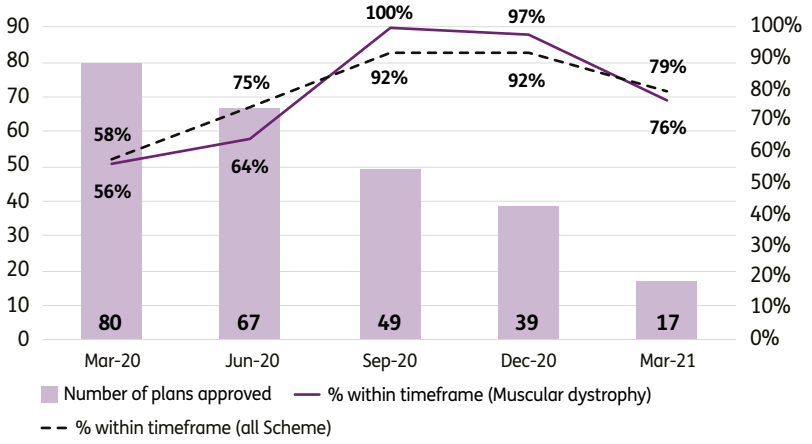
Participant Service Guarantee
Planning metrics

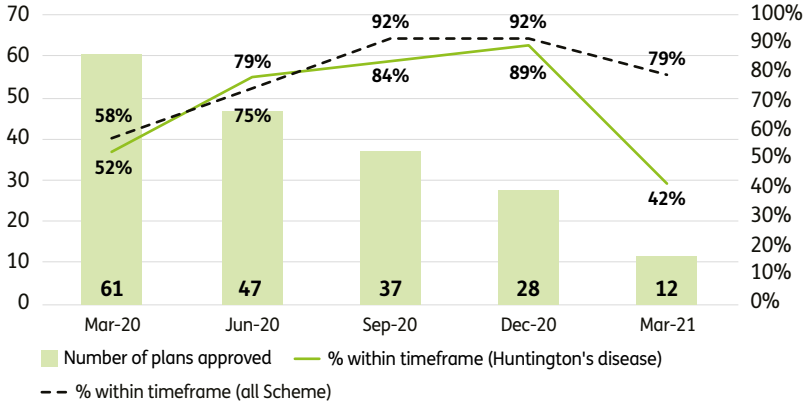
Under the PSG, the Agency will target to approve an initial plan for each participant aged 7 years and over within 56 days of the access decision being made (the target changed from 70 days previously to a stricter 56 days from 1 February 2021).

The proportion of applications achieving the target timeframe has increased for the Scheme overall from 58% in the March 2020 quarter to 92% in the December 2020 quarter. The proportion has dropped to 79% in the March 2021 quarter, due to the stricter timeframe of 56 days applied*. The trend for participants with a neurodegenerative condition follows a similar pattern.

For participants with Motor neurone disease, Multiple sclerosis and Parkinson's disease, the performance is consistently better than the Scheme overall. For participants with Muscular dystrophy and Huntington's disease, the performance is lower than the Scheme as a whole in the March 2021 quarter, although the number of plans approved are relatively low.

Approve a plan for participants (aged 7 or over) within 70 days of access decision (56 days in the March 2021 quarter)



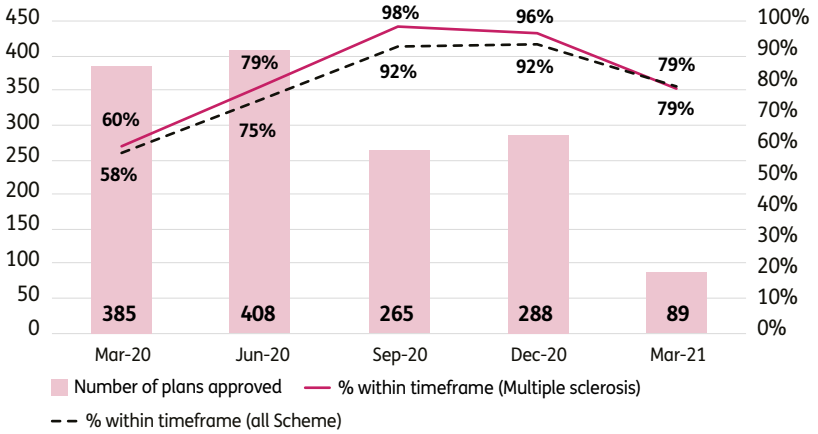


* The Scheme metric for March 2021 (79%) is based on the methodology of assuming the stricter metric of 56 days over the entire quarter (for simplicity). However, if the analysis applied the more lenient 70 days target for January and the stricter 56 days for February and March, then the proportion of applications that achieved this time frame would have been 82%.

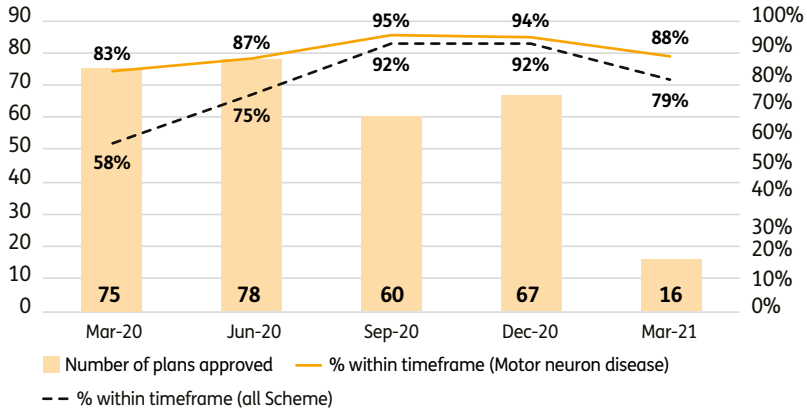
Note: Results for prior periods have been restated using data at 31 March 2021.

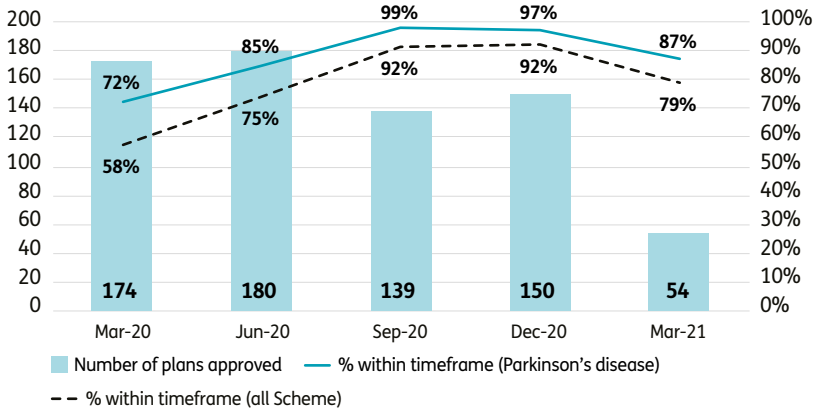
Participant Service Guarantee
Planning metrics cont.

Separately, there is a PSG target to approve an initial plan for each ECEI participant aged 0 to 6 years within 90 days of the access being made. However, there are insufficient results to report on the target timeframes for participants aged 0 to 6 with a neurodegenerative condition receiving an initial plan. This is driven by the majority of participants with a neurodegenerative condition being adults. Results for this metric are not presented here.



Approve a plan for participants (aged 7 or over) within 70 days of access decision (56 days in the March 2021 quarter)





Note: Results for prior periods have been restated using data at 31 March 2021.

Participant Service Guarantee

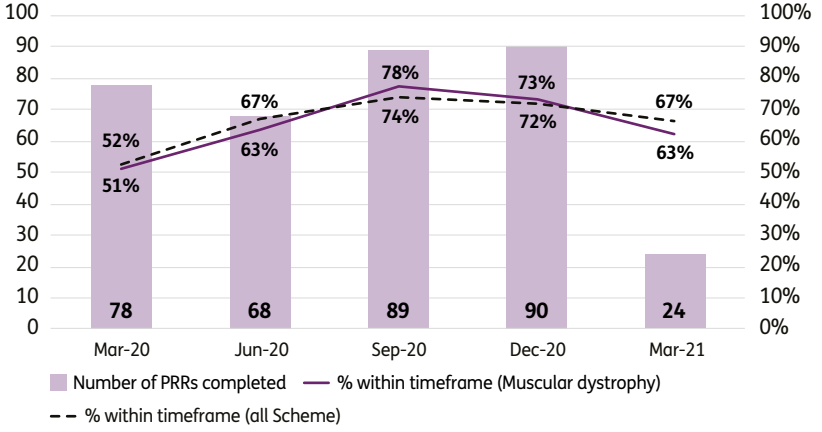
Participant Requested Review metrics

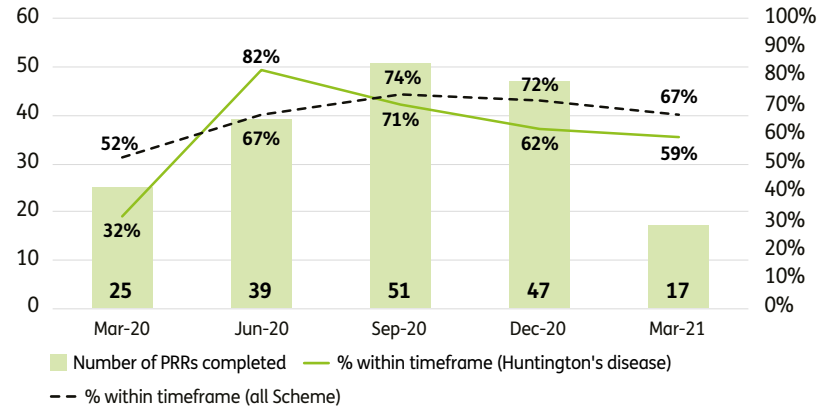
There are two PSG metrics being measured in relation to Participant Requested Reviews (PRRs).

The first is making a decision on whether to conduct a PRR within 21 days of a request being received. This has been achieved in 100% of applications in each of the last four quarters for participants with a neurodegenerative condition, and also for the Scheme overall. Results for this metric are not presented here.

There is a further target under the PSG of completing a PRR within 42 days of making the decision to conduct the review. The Agency's performance against this target timeframe has generally improved over the year to December 2020 before decreasing to 67% in the March 2021 quarter.

Complete a Participant Requested Review within 42 days of making the decision to conduct the review

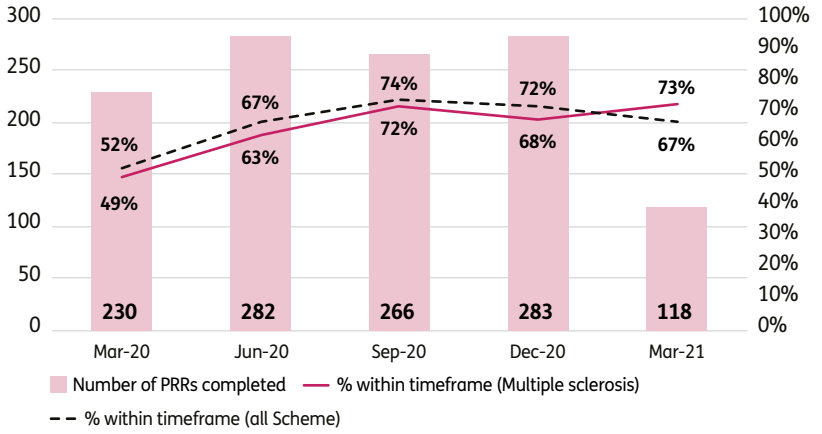




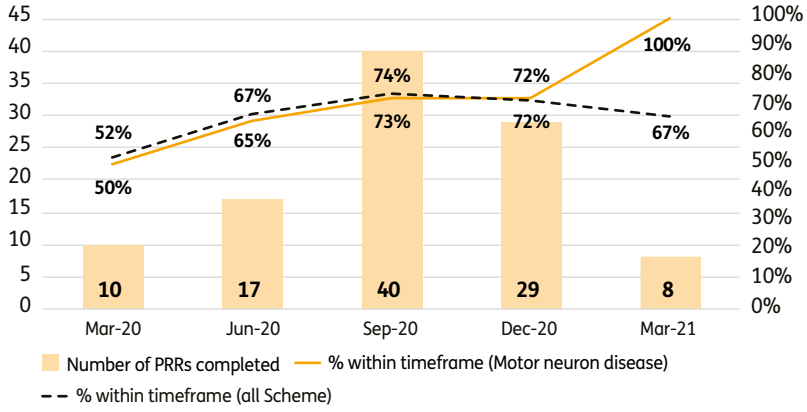
Note: Results for prior periods have been restated using data at 31 March 2021.

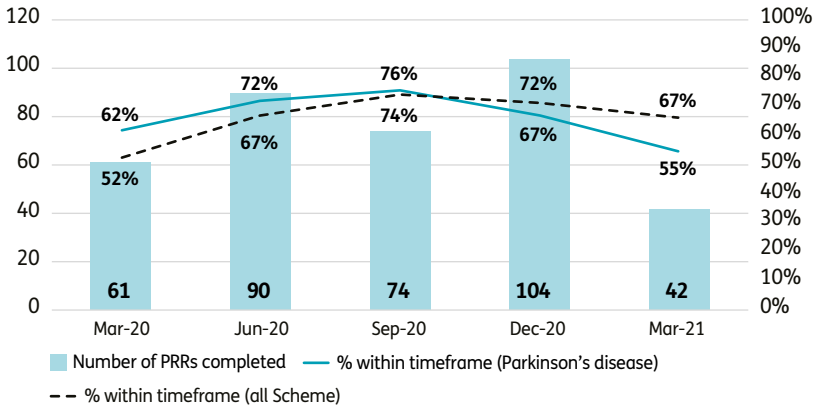
Participant Requested Review metrics cont.

The performance for participants with a neurodegenerative condition mirrors the Scheme experience relatively closely for the December 2020 and prior quarters. For the March 2021 quarter, the proportions meeting the target timeframe are higher than the Scheme overall for participants with Motor neurone disease and Multiple sclerosis at 100% and 73% respectively, and lower for participants with Muscular dystrophy, Huntington's disease and Parkinson's disease at 63%, 59% and 55% respectively.



Complete a Participant Requested Review within 42 days of making the decision to conduct the review





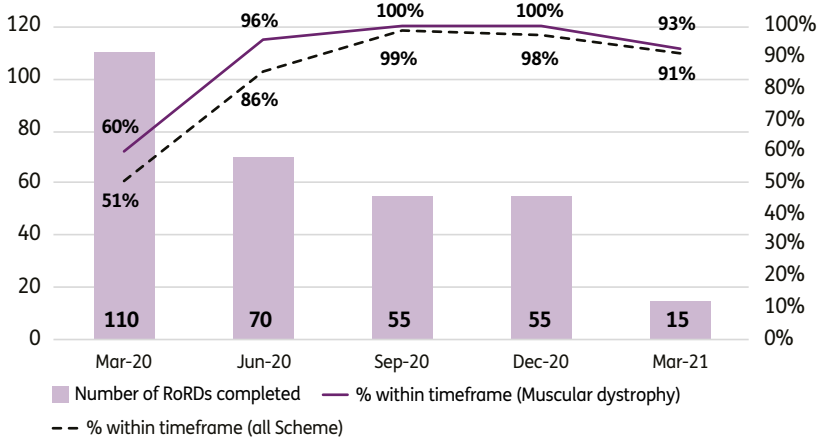
Note: Results for prior periods have been restated using data at 31 March 2021.

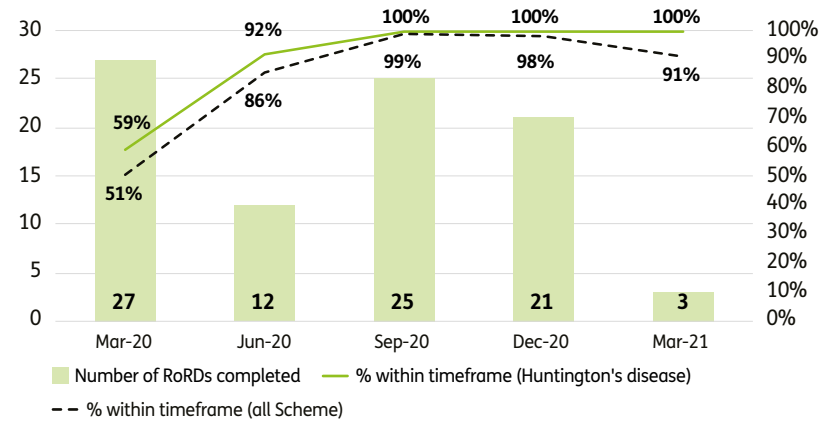
Participant Service Guarantee
Review of Reviewable Decision metrics

A Review of a Reviewable Decision (RoRD) is an internal review of a decision the Agency has made about a participant under Section 100 of the NDIS Act. Under the PSG, the Agency will aim to complete a RoRD within 90 days of the request to conduct the review being received.

The performance of the Agency in achieving this target timeframe has improved for the overall Scheme since March 2020, but has deteriorated after 31 December 2020 to 91% in the most recent quarter. For participants with a neurodegenerative condition, the performance has been consistently better than the Scheme overall since March 2020, increasing to 100% or close to 100% in the March 2021 quarter. Note however, the number of reviewable decisions in the latest quarter is low for each of the conditions.

Complete an Review of a Reviewable Decision within 90 days of the request being received



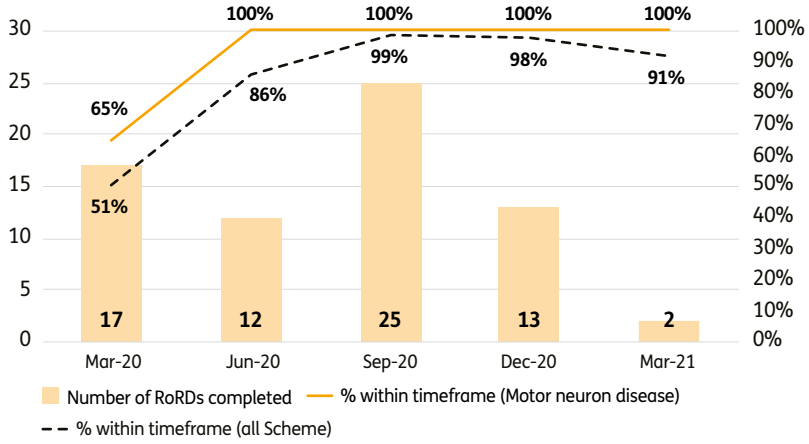


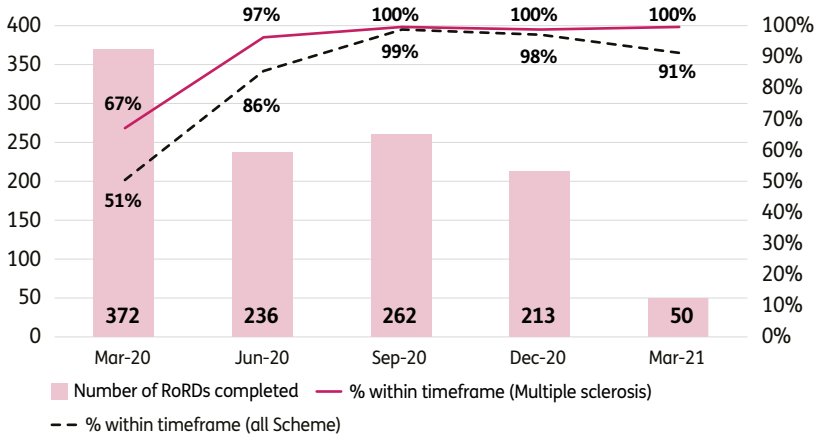
Note: Results for prior periods have been restated using data at 31 March 2021.

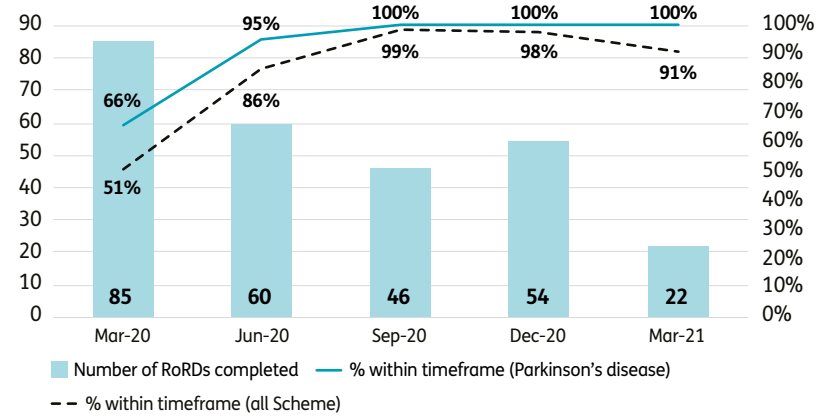
Participant Service Guarantee

Review of Reviewable Decision metrics cont.

Complete an Review of a Reviewable Decision within 90 days of the request being received







Note: Results for prior periods have been restated using data at 31 March 2021.

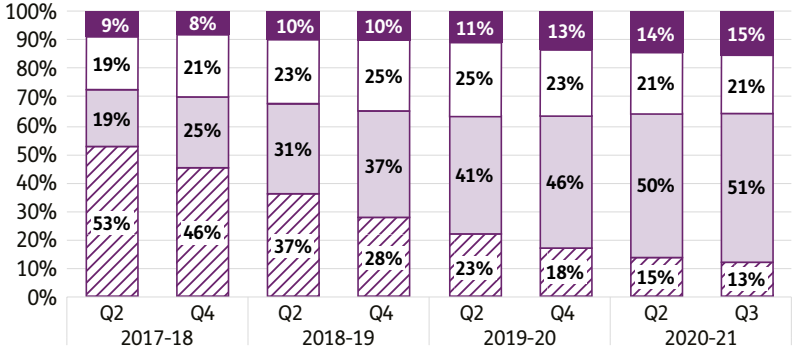
Participants by
plan management type

There is a continuing trend for more participants to self-manage their plans or use a plan management provider, and for less participants to have their plan Agency-managed. This is the case for participants with a neurodegenerative condition and for the Scheme overall.

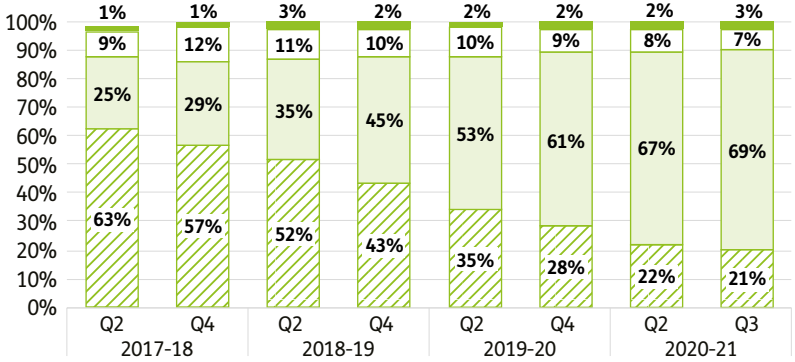
At 31 March 2021, a higher proportion of participants with a neurodegenerative condition used a plan manager compared to 47% for the Scheme overall, at 69% for Huntington's disease and Motor neurone disease, 63% for Parkinson's disease, 55% for Multiple sclerosis and 51% for Muscular dystrophy.

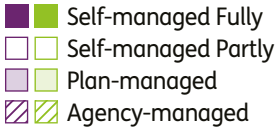
The proportion of participants who fully or partly self-managed their plans were lower than the Scheme average of 31% for participants with Huntington's disease (10%), Motor neurone disease (27%) and Parkinson's disease (27%), and higher for those with Muscular dystrophy (36%) and Multiple sclerosis (35%).

Distribution of participants with Muscular dystrophy by plan management type



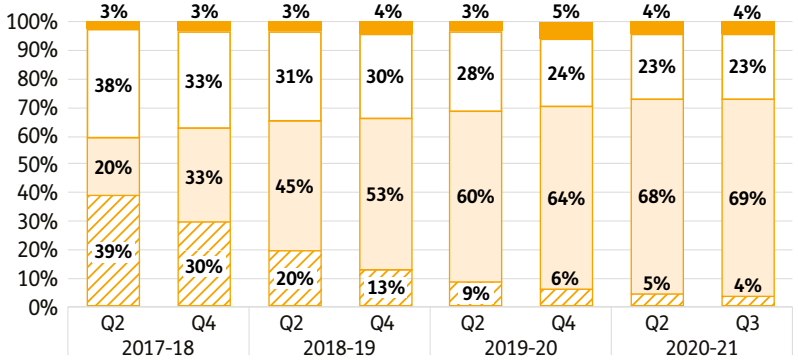
Distribution of participants with Huntington's disease by plan management type



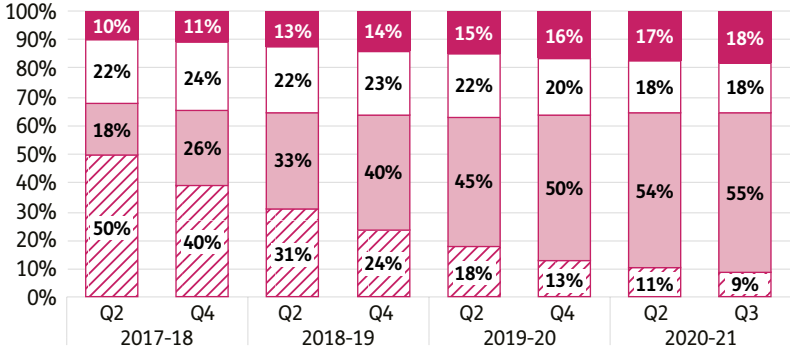


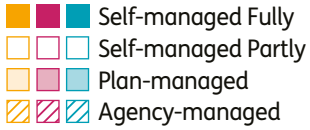
Participants by
plan management type cont.

Distribution of participants with Motor neurone disease by plan management type

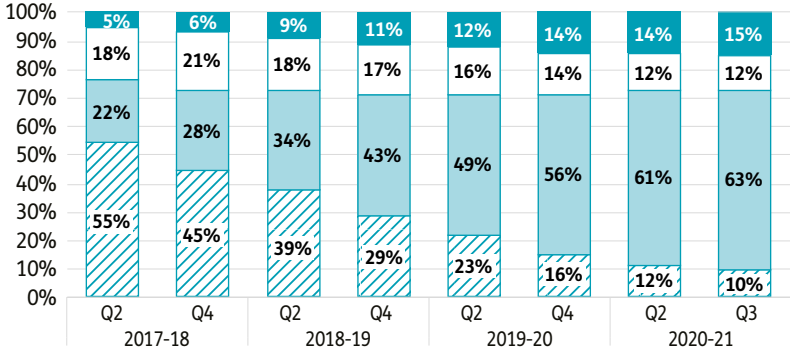


Distribution of participants with Multiple sclerosis by plan management type





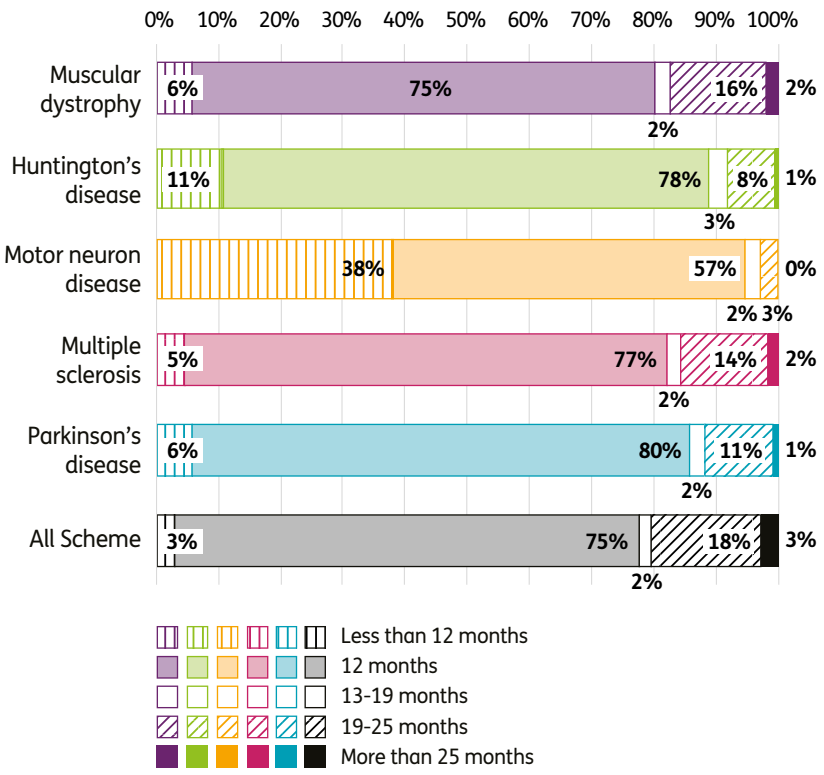
Distribution of participants with Parkinson's disease by plan management type



Plan duration

For participants across the Scheme as a whole, around three quarters (75%) have plans with a one-year duration. This proportion is similar or slightly higher for participants with Muscular dystrophy (75%), Huntington's disease (78%), Multiple sclerosis (77%), and Parkinson's disease (80%). On the contrary, only 57% of participants with Motor neurone disease have plans with a one-year duration, with a high proportion (38%) having plans with a duration of less than 12 months (mostly 6-9 months). This likely reflects the rapidly progressing nature of the condition and the complexity of each individual case involved. A shorter plan would allow a more frequent review of the changing needs of the participant over time.

Distribution of plan duration in active plans



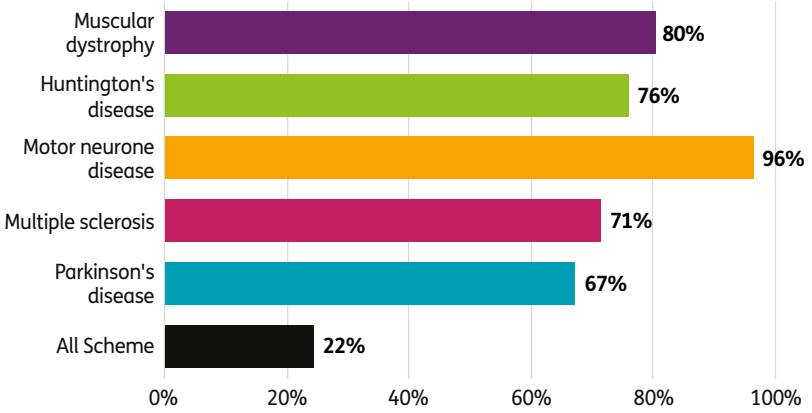
Assistive technology and support coordination in plans

Participants with a neurodegenerative condition are more likely to have assistive technology and support coordination in their plan.

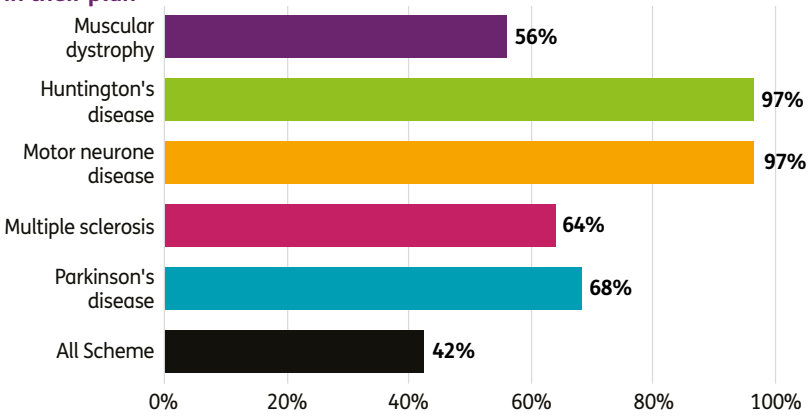
Assistive technology is in 22% of active plans across the Scheme overall, while for participants with a neurodegenerative condition, this proportion is three to four times higher, at 96% for participants with Motor neurone disease, 80% for those with Muscular dystrophy, 76% for those with Huntington's disease, 71% for those with Multiple sclerosis, and 67% for those with Parkinson's disease.

Support coordination is in 42% of active plans across the Scheme overall, while for participants with a neurodegenerative condition, this proportion is higher at 56% and above. The proportion is particularly high for participants with Huntington's disease and Motor neurone disease at 97%. This is consistent with NDIA practice guidelines of including coordination of supports for participants requiring intensive and frequent support in progressing through the NDIS pathway.

Proportion of active participants who have assistive technology in their plan



Proportion of active participants who have support coordination in their plan

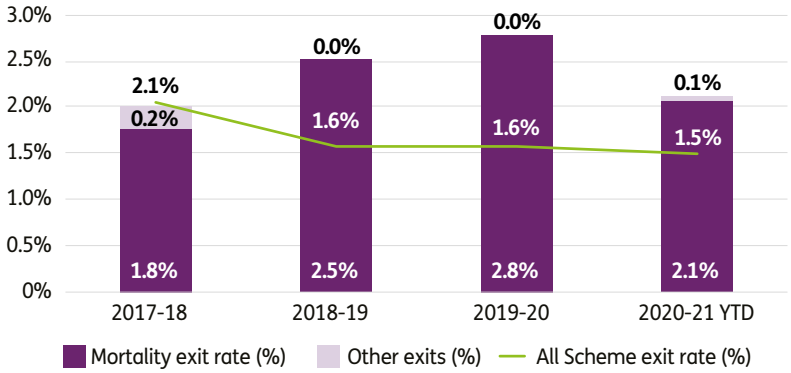


Scheme exit rates over time

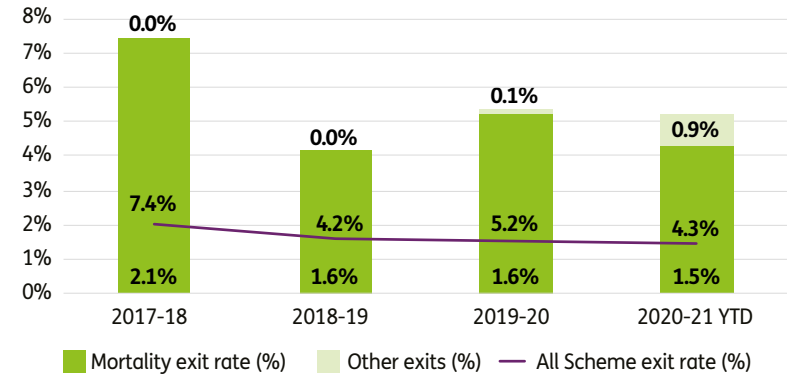
The rates at which NDIS participants exit the Scheme vary over time and are also impacted by other factors including disability type. Exit rates due to mortality are monitored separately to those for other reasons such as participant initiated withdrawal or no longer requiring supports.

Participants with Motor neurone disease, Huntington's disease and Parkinson's disease have much higher exit rates compared with the Scheme overall, as do those with Muscular dystrophy since 2018-19. However, participants with Multiple sclerosis have lower exit rates. Across the five disability types, there is a much greater proportion of mortality exits compared to non-mortality exits.

Annualised exit rates for participants with Muscular dystrophy who have ever had an approved plan over time

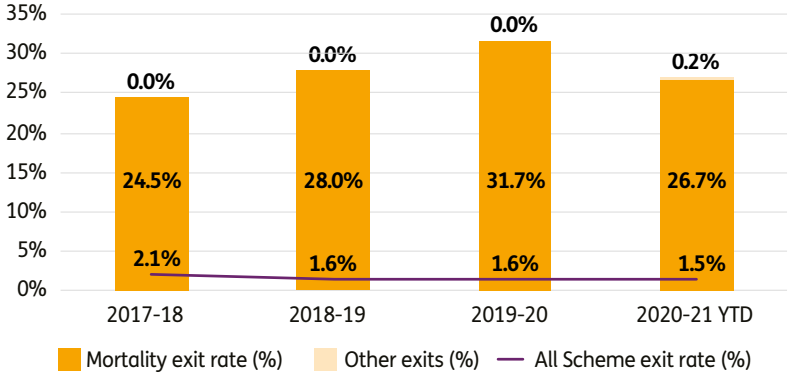


Annualised exit rates for participants with Huntington's disease who have ever had an approved plan over time

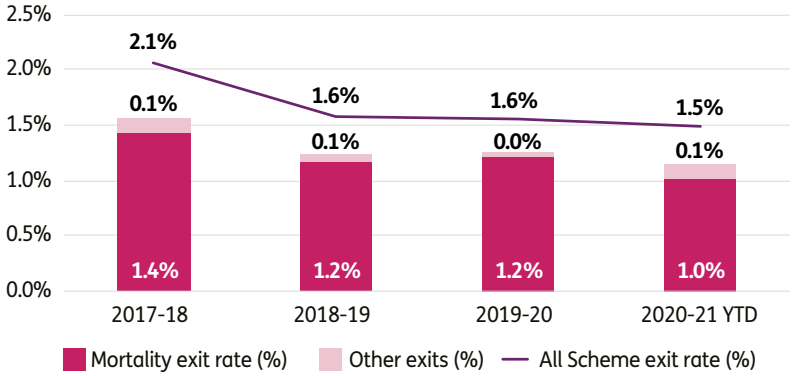


Scheme exit rates over time cont.

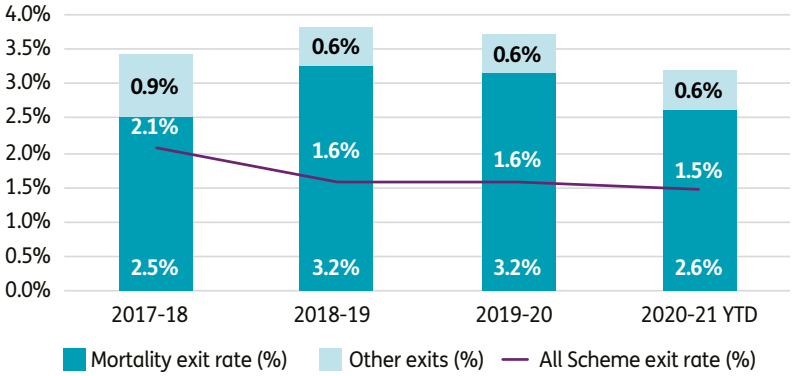
Annualised exit rates for participants with Motor neurone disease who have ever had an approved plan over time



Annualised exit rates for participants with Multiple sclerosis who have ever had an approved plan over time



Annualised exit rates for participants with Parkinson's disease who have ever had an approved plan over time



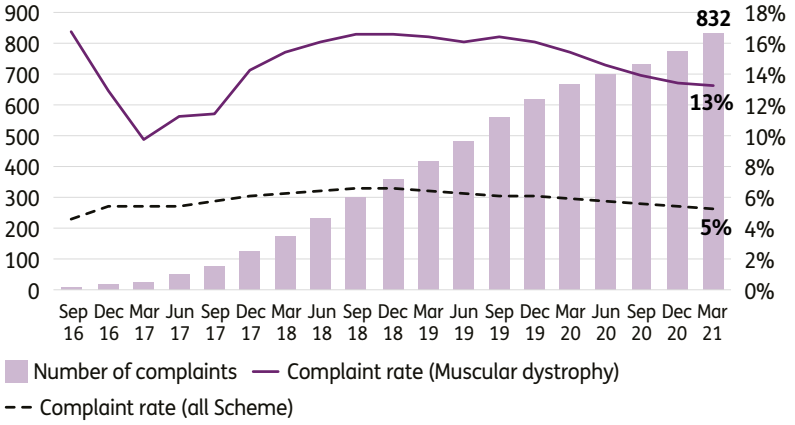
Complaint rates

For each of the five disability types, the annualised rate of complaints (measured as the number of complaints as a proportion of access requests) is high compared with the Scheme overall.

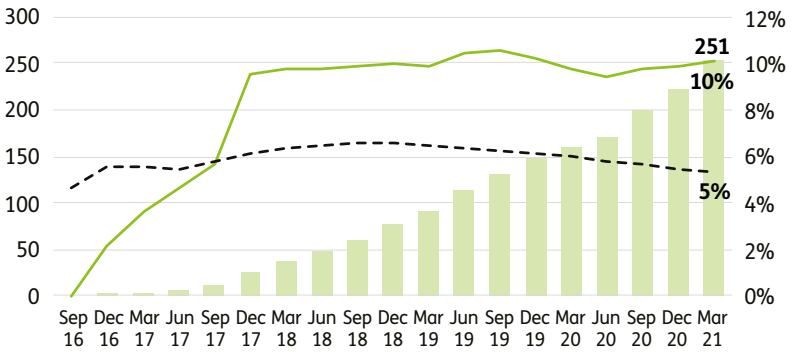
The rates of complaints have declined over the past year for all participants with a neurodegenerative condition, except for Huntington's disease where the rate has increased slightly. However, in March 2021, the rates of complaints were still relatively high for participants with a neurodegenerative condition, at 13% for participants with Muscular dystrophy and Motor neurone disease, 12% for Multiple sclerosis, 10% for Huntington's disease and 9% for Parkinson's disease, compared with the overall Scheme experience of 5%.

The Agency aims to resolve complaints within 21 days of receiving them. Since December 2019, the proportion of complaints where this target was achieved has improved significantly for the Scheme as a whole, from 58% in the December 2019 quarter to 91% in the March 2021 quarter. Results for participants with a neurodegenerative condition are in line with the Scheme overall, noting there is a degree of volatility due to low numbers.

Cumulative number and rate of complaints - Muscular dystrophy

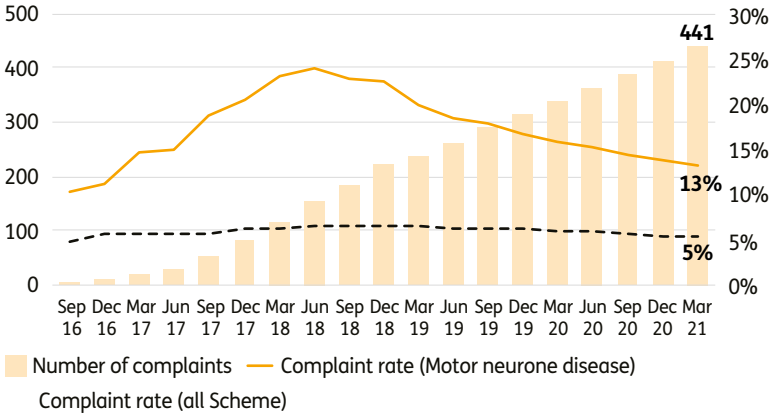


Cumulative number and rate of complaints - Huntington's disease

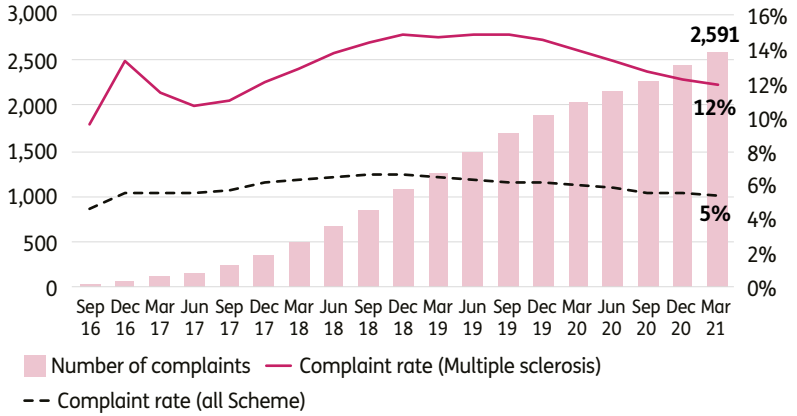


Complaint rates cont.

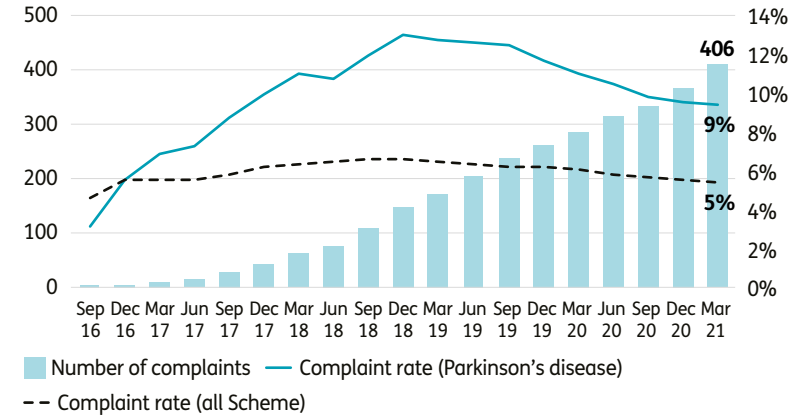
Cumulative number and rate of complaints - Motor neurone disease



Cumulative number and rate of complaints - Multiple sclerosis



Cumulative number and rate of complaints - Parkinson's disease



PART 3

Committed supports, payments and utilisation

Committed supports and payments to participants with a neurodegenerative condition are increasing in line with the growing Scheme.

The total committed supports for the 2020-21 financial year to date (1 July 2020 - 31 March 2021) were:

- $211m for participants with Muscular dystrophy
- $150m for participants with Huntington's disease
- $149m for participants with Motor neurone disease
- $660m for participants with Multiple sclerosis, and
- $176m for participants with Parkinson's disease.

Among the five neurodegenerative conditions, the rate of utilisation of committed supports is highest for participants with Muscular dystrophy at 67%, and lowest for those with Motor neurone disease at 57%.

These compare to the Scheme average of 68%.

Summary

This section presents information on the amounts of supports committed in participant plans for participants with a neurodegenerative condition as their primary disability. Utilisation rates, which are the proportion of committed supports actually used, are also presented.

Key statistics

Participants with Muscular dystrophy	**$230** million of supports in respect of 2019-20 financial year	**$211** million of supports in respect of 2020-21 financial year to date	**67%** of supports utilised
Participants with Huntington's disease	**$148** million of supports in respect of 2019-20 financial year	**$150** million of supports in respect of 2020-21 financial year to date	**65%** of supports utilised
Participants with Motor neurone disease	**$157** million of supports in respect of 2019-20 financial year	**$149** million of supports in respect of 2020-21 financial year to date	**57%** of supports utilised
Participants with Mutliple sclerosis	**$699** million of supports in respect of 2019-20 financial year	**$660** million of supports in respect of 2020-21 financial year to date	**64%** of supports utilised
Participants with Parkinson's disease	**$158** million of supports in respect of 2019-20 financial year	**$176** million of supports in respect of 2020-21 financial year to date	**61%** of supports utilised
The Scheme as a whole	**$24,572** million of supports in respect of 2019-20 financial year	**$23,615** million of supports in respect of 2020-21 financial year to date	**68%** of supports utilised

Trend in committed supports

Participants with a neurodegenerative condition have significantly higher average annualised committed supports compared with the Scheme overall. In particular, participants with Motor neurone disease have the highest average annualised committed supports, followed by Huntington's disease.

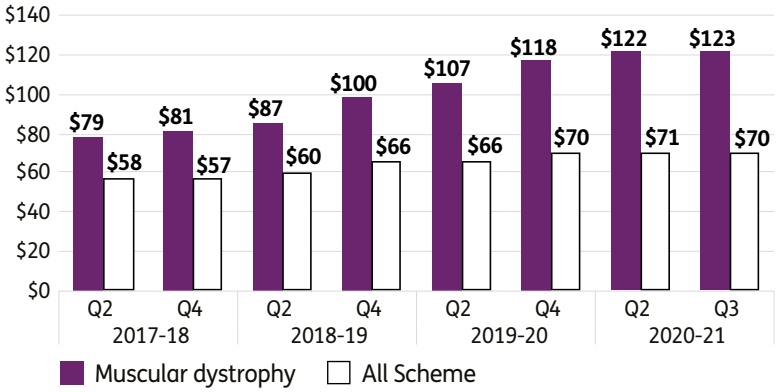
At 31 March 2021, the average annualised committed supports were:

- $242,000 for participants with Motor neurone disease
- $212,000 for participants with Huntington's disease
- $123,000 for participants with Muscular dystrophy
- $116,000 for participants with Parkinson's disease, and
- $108,000 for participants with Multiple sclerosis.

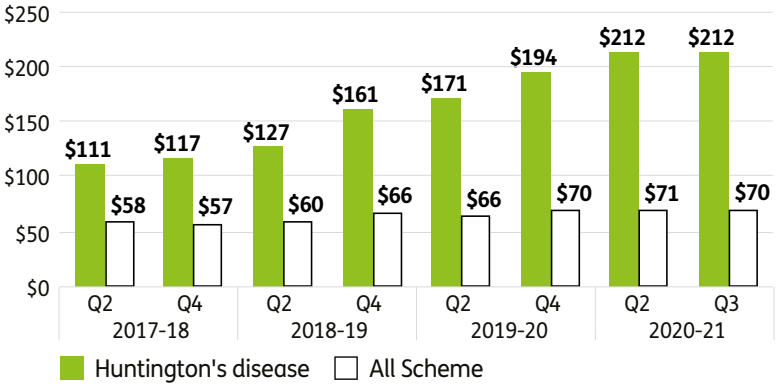
These compare to the average annualised committed supports of $70,000 across the Scheme.

Average annualised committed supports have increased over time. The rate of increase for participants with a neurodegenerative condition is higher than for the Scheme as a whole, and is the highest for participants with Huntington's disease.

Trend in average annualised committed supports for participants with Muscular dystrophy over time (in $'000s)

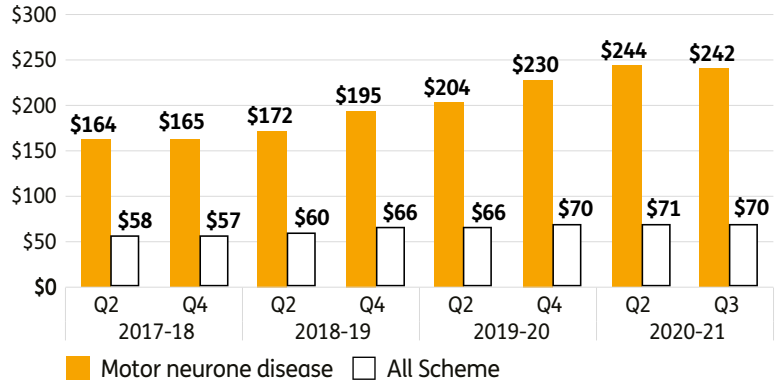


Trend in average annualised committed supports for participants with Huntington's disease over time (in $'000s)

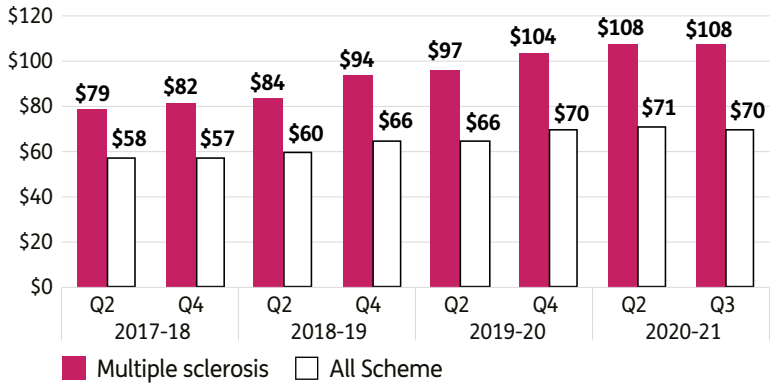


Trend in committed supports cont.

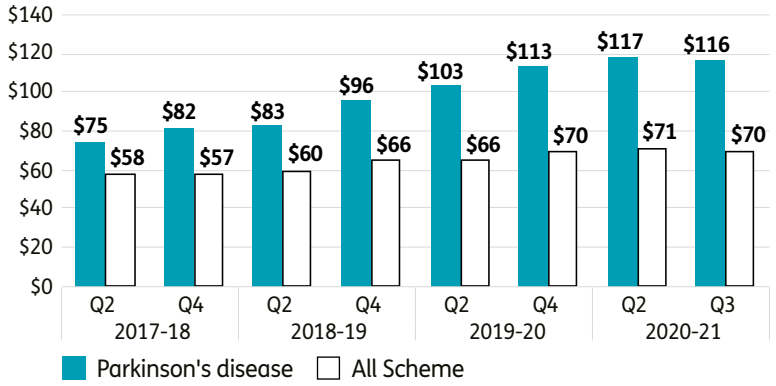
Trend in average annualised committed supports for participants with Motor neurone disease over time (in $'000s)



Trend in average annualised committed supports for participants with Multiple sclerosis over time (in $'000s)



Trend in average annualised committed supports for participants with Parkinson's disease over time (in $'000s)

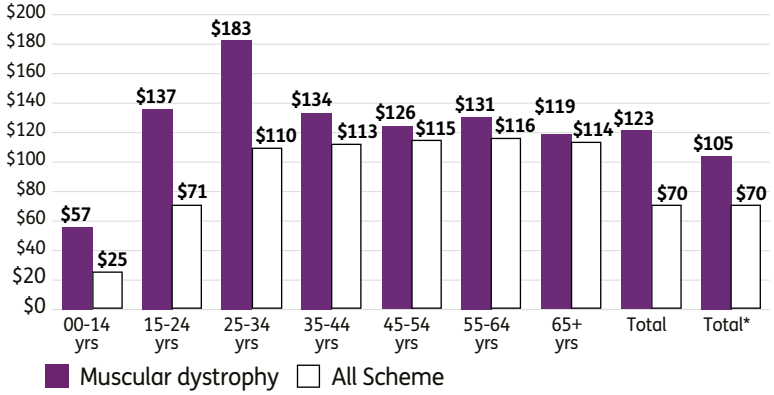


Committed supports by **age group**

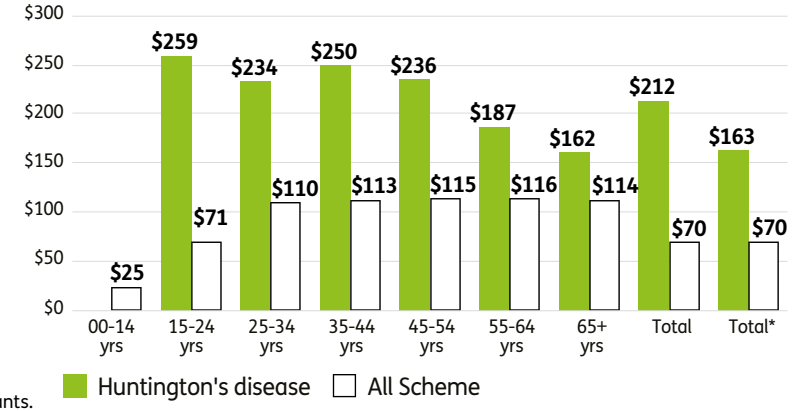
The average annualised committed supports for participants with Muscular dystrophy, Huntington's disease and Motor neurone disease are higher than Scheme average at each age group, and are significantly higher in the case of Huntington's disease and Motor neurone disease. For participants with Multiple sclerosis and Parkinson's disease, the average annualised committed supports are closer to Scheme average.

The average annualised committed supports for participants with Muscular dystrophy are highest at ages 25 to 34. For those with Huntington's disease and Motor neurone disease, amounts are highest at ages 15 to 54 and ages 35 to 54 respectively. Participants with Multiple sclerosis and Parkinson's disease have high average amounts in ages 45 and up

Average annualised committed supports for participants with Muscular dystrophy by age group (in $000's)



Average annualised committed supports for participants with Huntington's disease by age group (in $000's)

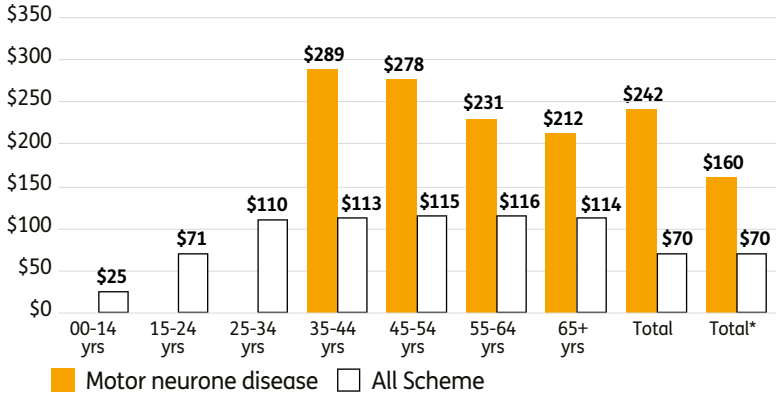


* Total in the charts refers to the average annualised committed supports based on the age distribution of all Scheme participants. This has an effect of reducing the average for each of the five disability types.

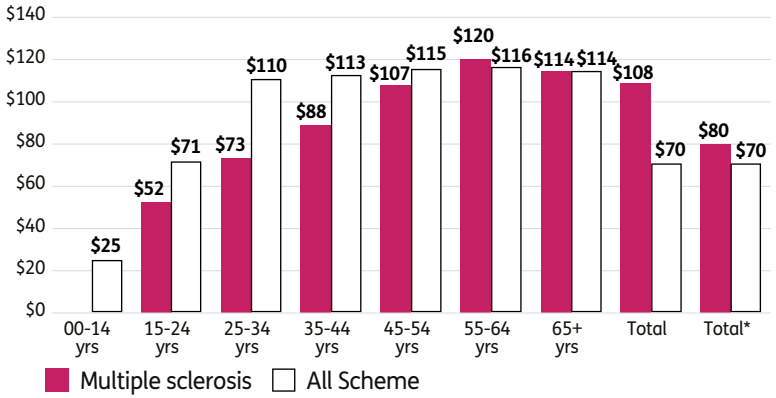
The average annualised committed supports are not shown for age groups with 20 or less participants.

Committed supports by **age group** cont.

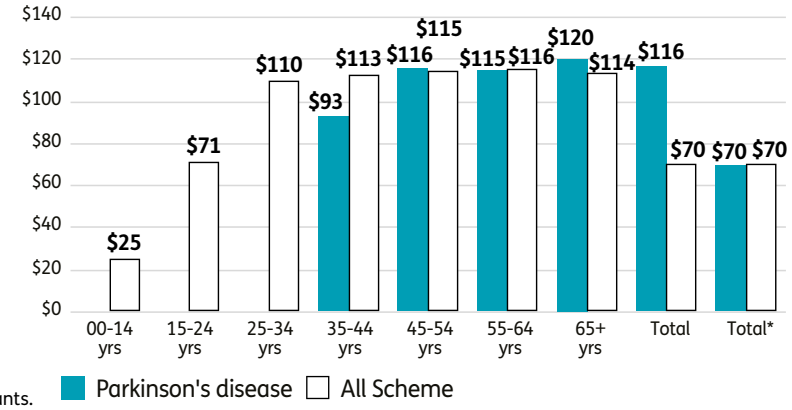
Average annualised committed supports for participants with Motor neurone disease by age group (in $000's)



Average annualised committed supports for participants with Multiple sclerosis by age group (in $000's)



Average annualised committed supports for participants with Parkinson's disease by age group (in $000's)



* Total in the charts refers to the average annualised committed supports based on the age distribution of all Scheme participants. This has an effect of reducing the average for each of the five disability types.

The average annualised committed supports are not shown for age groups with 20 or less participants.

Committed supports by
SIL status

Participants with Supported Independent Living (SIL) tend to have much higher committed supports than those without SIL. This is the case for participants across the Scheme and within each neurodegenerative condition.

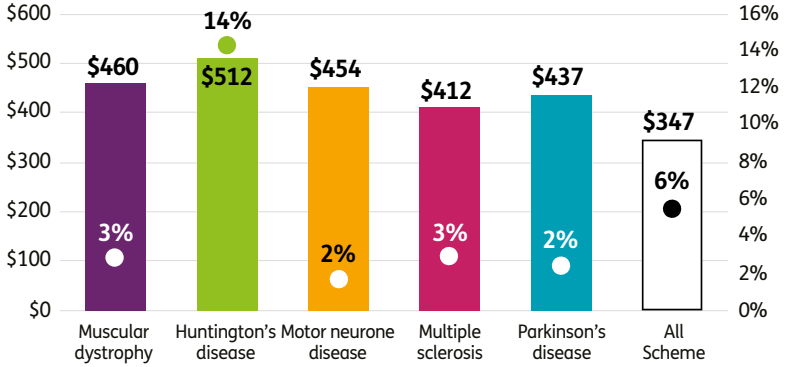
For participants with SIL, the average annualised committed supports for all conditions are higher than the average across the Scheme, notably Huntington's disease with the highest average annualised committed supports for participants with SIL at $512,000 compared with $347,000 for the Scheme as a whole.

Among the five conditions, it is worth noting that 14% of participants with Huntington's disease have SIL supports which is high compared with 6% for the Scheme overall. The proportion for the rest of the conditions are lower than All Scheme, at around 2-3%.

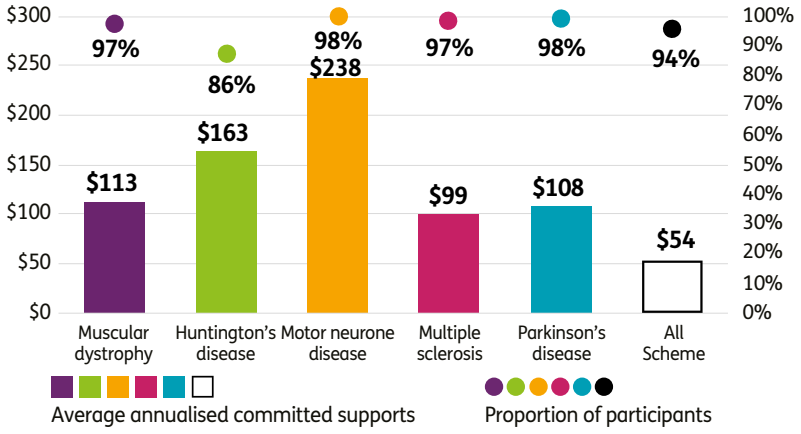
The average annualised committed supports for participants without SIL are also higher than for the Scheme as a whole, and are highest for those with Motor neurone disease at $238,000, followed by Huntington's disease at $163,000, compared with the Scheme average of $54,000.

Note: Since June 2020 there has been an issue with identifying SIL in plans as they are being completed. For these results, the numbers of SIL participants include an estimate of participants who should be identified as having SIL in their plans but do not appear as such on the Agency's system at 31 March 2021.

Average annualised committed supports for participants with SIL and proportions of participants with SIL



Average annualised committed supports for participants without SIL and proportions of participants without SIL



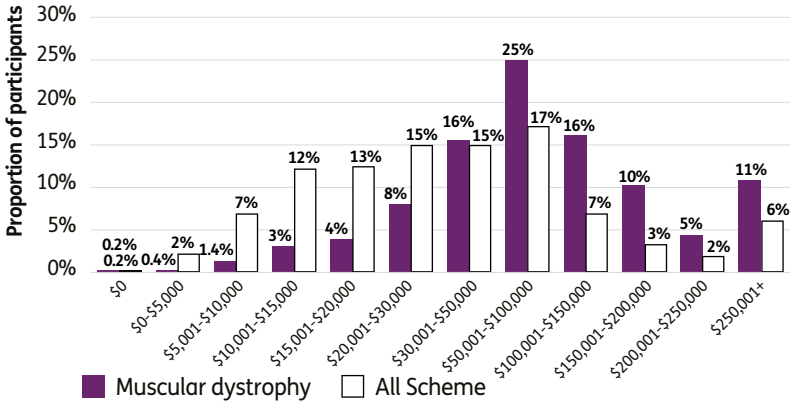
Distribution of committed supports

Compared with the Scheme overall, the distribution of annualised committed supports is more concentrated at the higher cost bands for participants with a neurodegenerative condition.

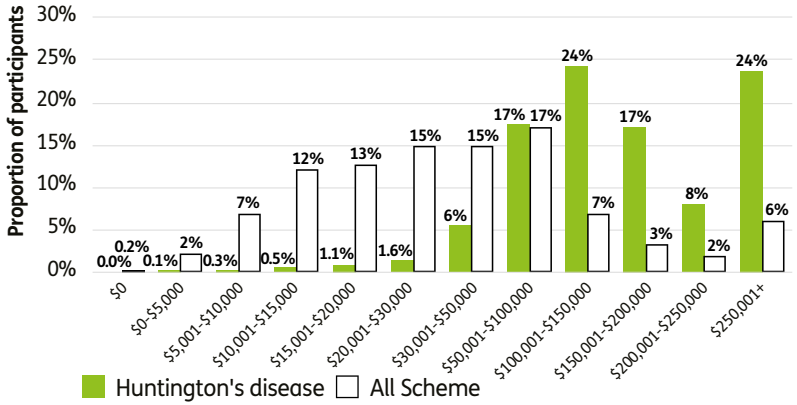
Around one quarter of participants with Muscular dystrophy, Multiple sclerosis, or Parkinson's disease have between $50,000 and $100,000 of annualised committed supports.

For participants with Motor neurone disease, 33% have annualised committed supports greater than $250,000, compared with just 6% for the Scheme overall. The proportion of participants in this group is also high for Huntington's disease at 24%.

Distribution of annualised committed supports for participants with Muscular dystrophy

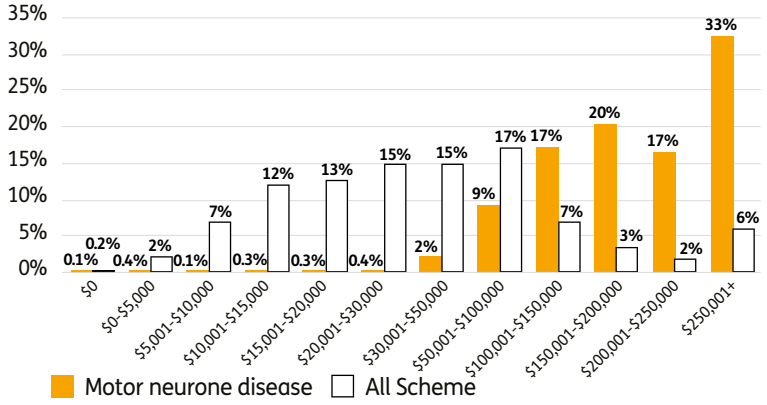


Distribution of annualised committed supports for participants with Huntington's disease

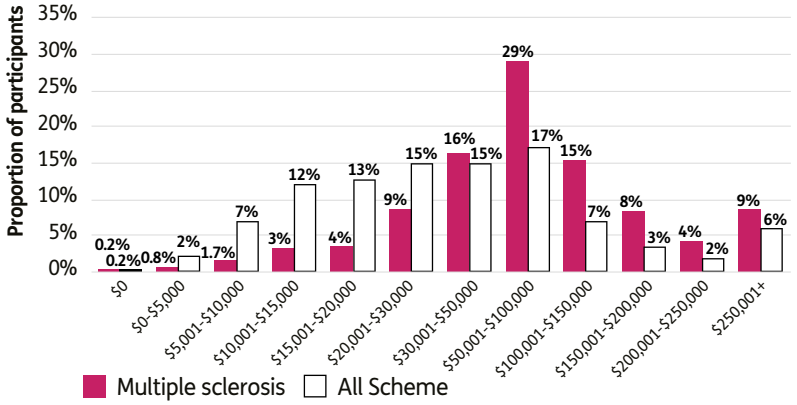


Distribution of committed supports cont.

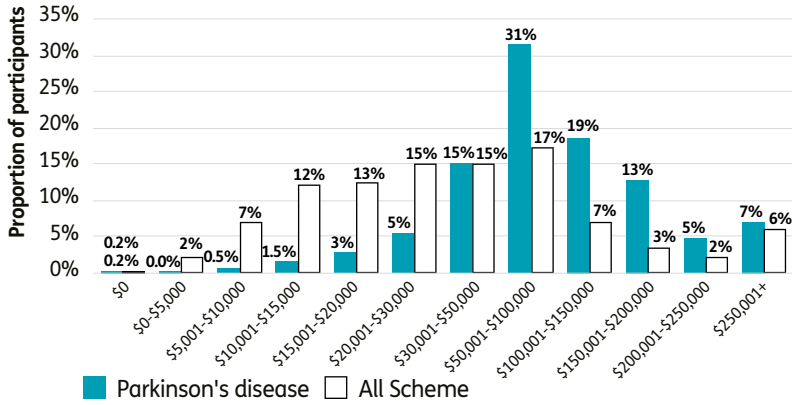
Distribution of annualised committed supports for participants with Motor neurone disease



Distribution of annualised committed supports for participants with Multiple sclerosis



Distribution of annualised committed supports for participants with Parkinson's disease

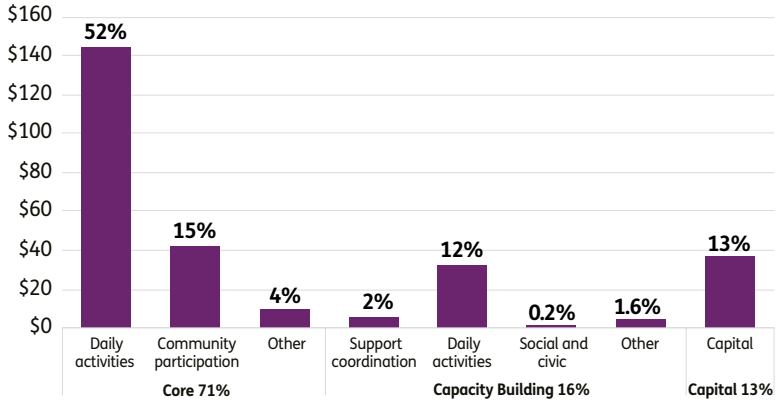


Types of committed supports

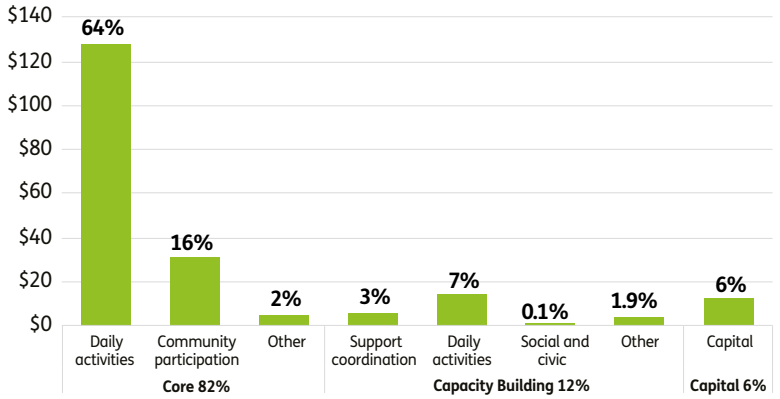
Majority of committed supports in participant plans are for Core supports and over half of all supports are for Core daily activities for all the neurodegenerative conditions. This category makes up 64% of all committed supports for participants with Huntington's disease, 58% of all committed supports for those with Motor neurone disease, 52% of all committed supports for those with Muscular dystrophy and Multiple sclerosis, and 53% of supports for those with Parkinson's disease. The overall Scheme average is lower at 46%.

The second largest category is Core community participation, at up to 20% of all committed supports for participants with a neurodegenerative condition. Capital is a relatively significant component for Muscular dystrophy, Motor neurone disease and Multiple sclerosis, at 11-13%.

Total annualised committed supports by type in active plans for participants with Muscular dystrophy ($ millions)

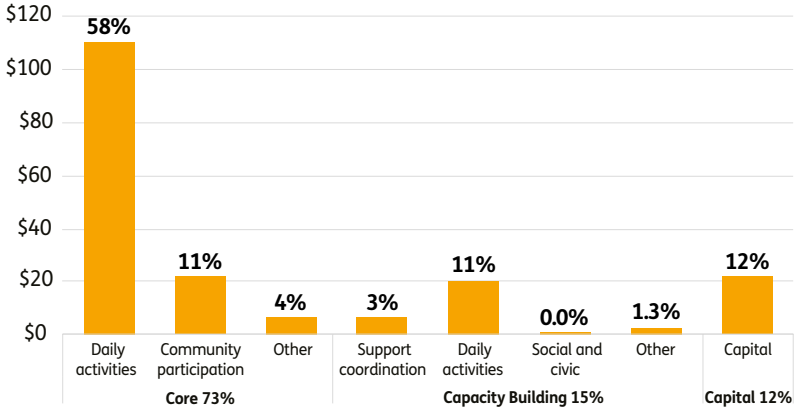


Total annualised committed supports by type in active plans for participants with Huntington's disease ($ millions)

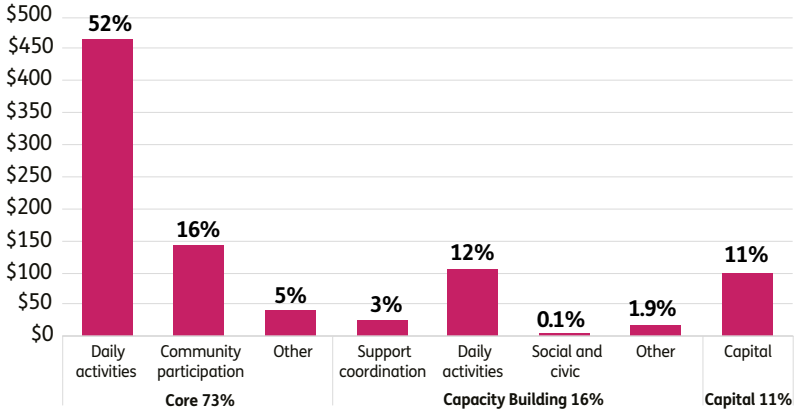


Types of committed supports cont.

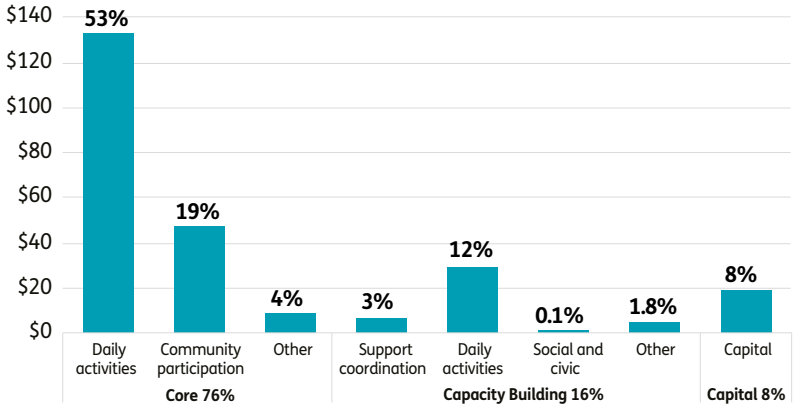
Total annualised committed supports by type in active plans for participants with Motor neurone disease ($ millions)



Total annualised committed supports by type in active plans for participants with Multiple sclerosis ($ millions)



Total annualised committed supports by type in active plans for participants with Parkinson's disease ($ millions)

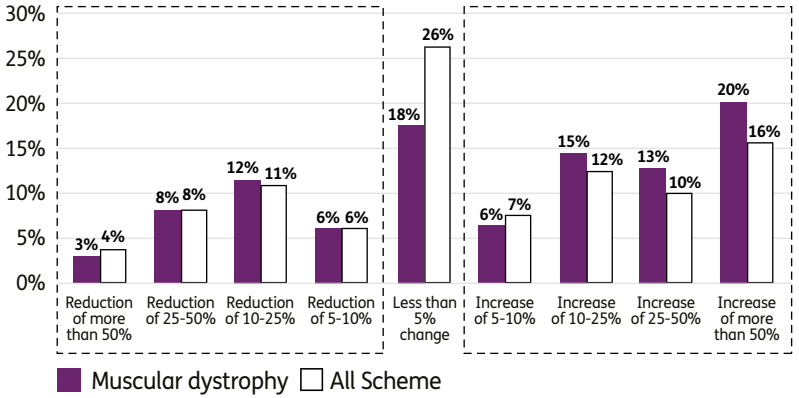


Changes in committed supports

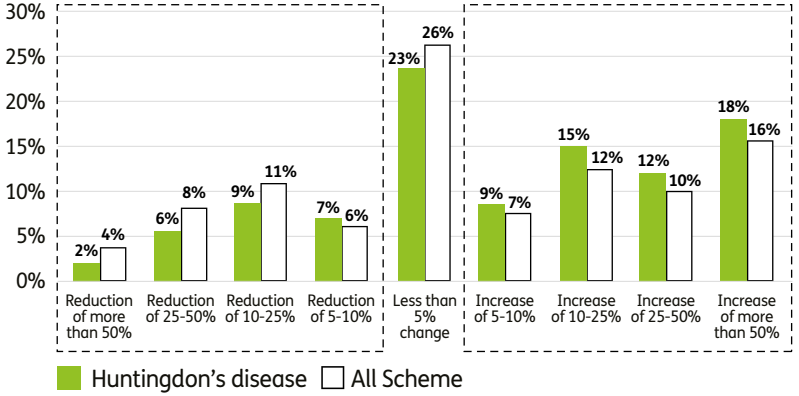
The proportion of participants who have had a change of less than 5% in their annualised plan value compared with their previous plan is lower for each of the five conditions compared to the overall Scheme experience. The proportion is lowest for Muscular dystrophy at 18%, compared to the Scheme experience of 26%.

On the other hand, the proportion of participants who have had increases in their annualised plan value is higher for each of the five conditions compared to the overall Scheme experience. Notably, the proportion of participants with an increase of more than 50% in their annualised plan value is 20% for Muscular dystrophy, and 18% for Huntington's disease and Motor neurone disease, compared to 16% for the Scheme overall. This reflects the degenerative nature of the conditions, with the support needs of participants increasing over time.

Change in annualised plan costs, comparing active plan to previous plan for participants with Muscular dystrophy

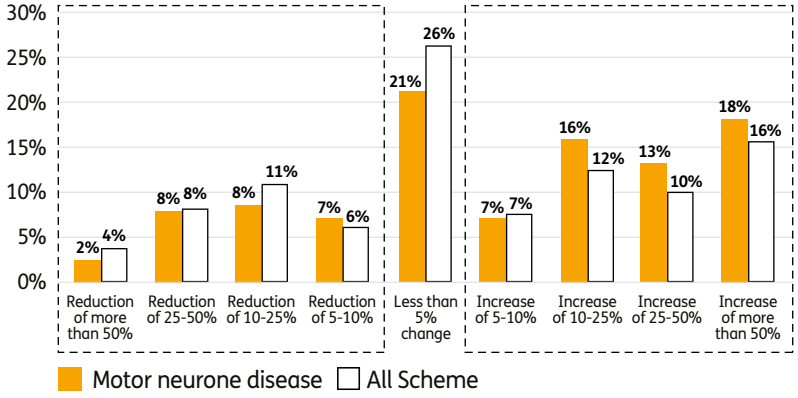


Change in annualised plan costs, comparing active plan to previous plan for participants with Huntington's disease

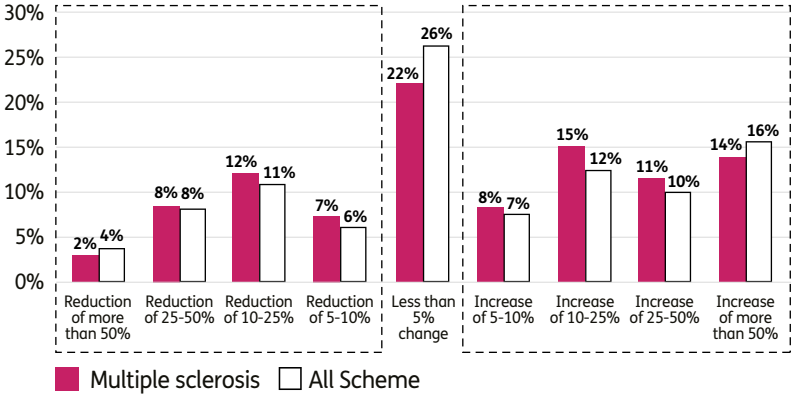


Changes in committed supports cont.

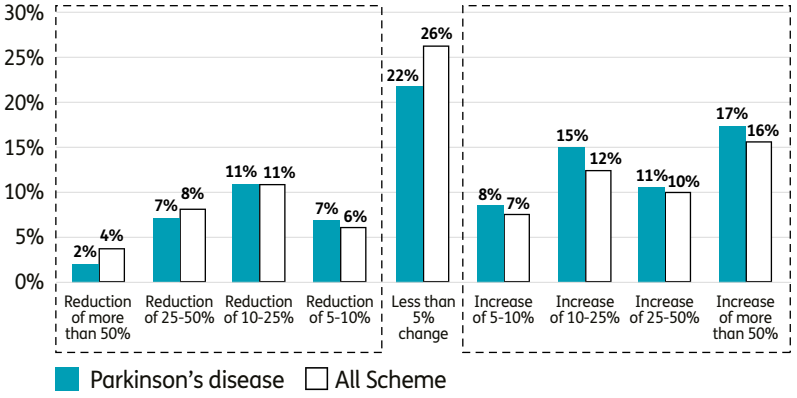
Change in annualised plan costs, comparing active plan to previous plan for participants with Motor neurone disease



Change in annualised plan costs, comparing active plan to previous plan for participants with Multiple sclerosis



Change in annualised plan costs, comparing active plan to previous plan for participants with Parkinson's disease



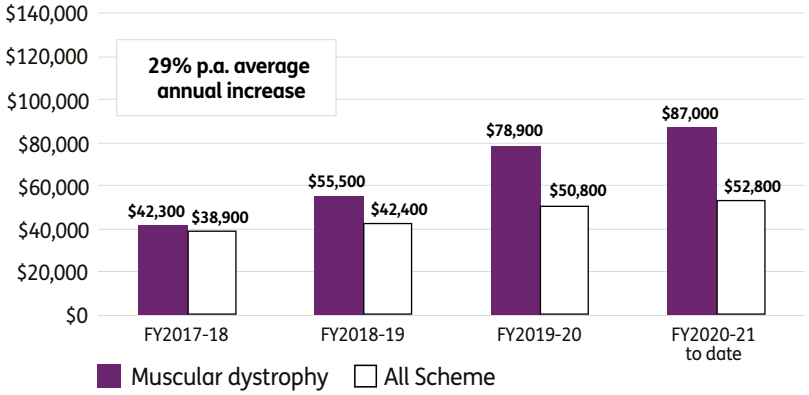
Average annualised payments

Average annualised payments for participants' supports are significantly higher for participants with a neurodegenerative condition than for the Scheme as a whole. This is consistent with the high levels of committed supports for these participants.

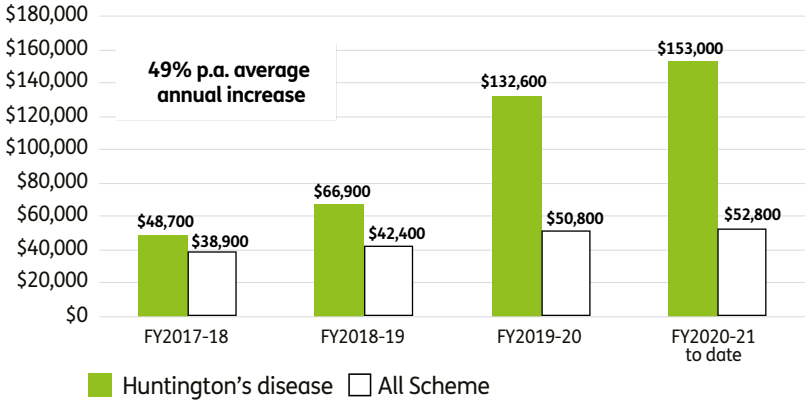
For 2020-21 to date, the average annualised payments for participants with Huntington's disease and Motor neurone disease were remarkably high at around $153,000 compared with the average of $52,800 across the Scheme as a whole. For Muscular dystrophy, Multiple sclerosis, and Parkinson's disease, the amounts were $87,000, $74,200, and $78,000 respectively.

These disability types have seen large increases in payments in each year since 2017-18, with average annual increases of 25% to 49%, compared with the overall Scheme average of 11%.

Average annualised payments for participants with Muscular dystrophy

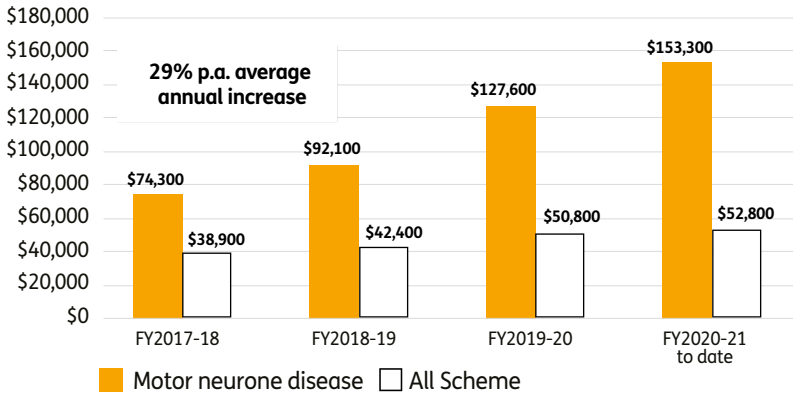


Average annualised payments for participants with Huntington's disease

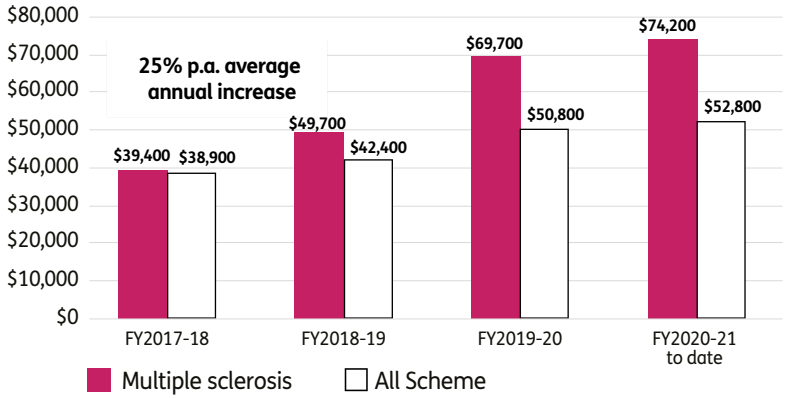


Average annualised payments cont.

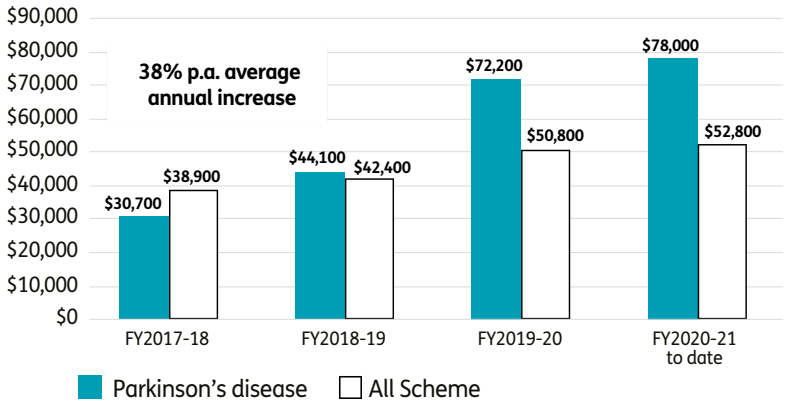
Average annualised payments for participants with Motor neurone disease



Average annualised payments for participants with Multiple sclerosis



Average annualised payments for participants with Parkinson's disease



Utilisation by
time in the Scheme

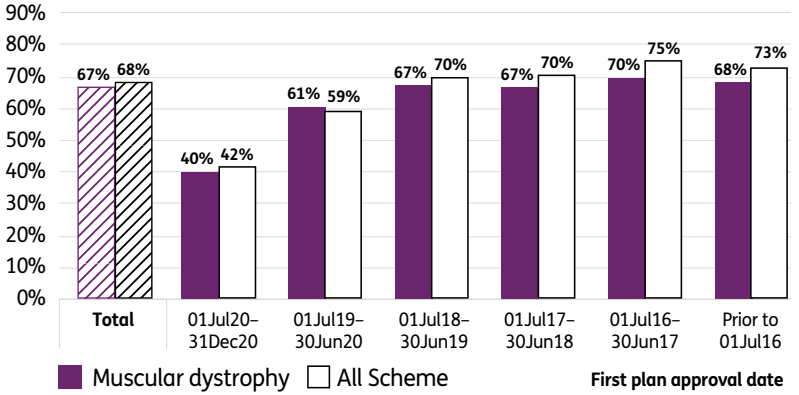
Utilisation rates in this report are based on committed supports for the period 1 July 2020 to 31 December 2020 and including all payments made as at 31 March 2021. This is to allow for lags in payments as experience in the most recent months is still emerging.

The rate of utilisation of committed supports for participants with a neurodegenerative condition is lower than the Scheme average of 68%. The rate of utilisation is lowest for participants with Motor neurone disease at 57%, followed by participants with Parkinson's disease at 61%. Among the five conditions, the rate of utilisation is highest for participants with Muscular dystrophy at 67%.

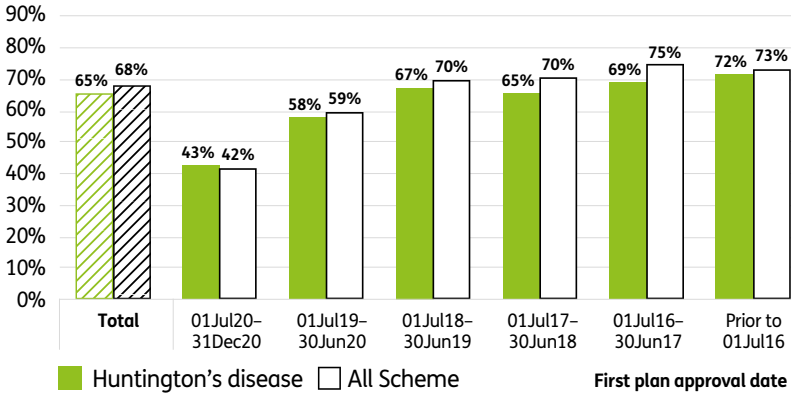
A possible reason for the lower rates of utilisation experienced by participants with a neurodegenerative condition is that in creating an NDIS plan, consideration is given to the progressive nature of neurodegenerative conditions so as to include supports designed to meet the rapidly changing needs of participants, which may not be initially utilised.

Duration in the Scheme is a key driver of utilisation. Participants utilise a greater proportion of committed supports as their time in the Scheme increases. This is evident for each disability type.

Utilisation of committed supports for participants with Muscular dystrophy by time in the Scheme

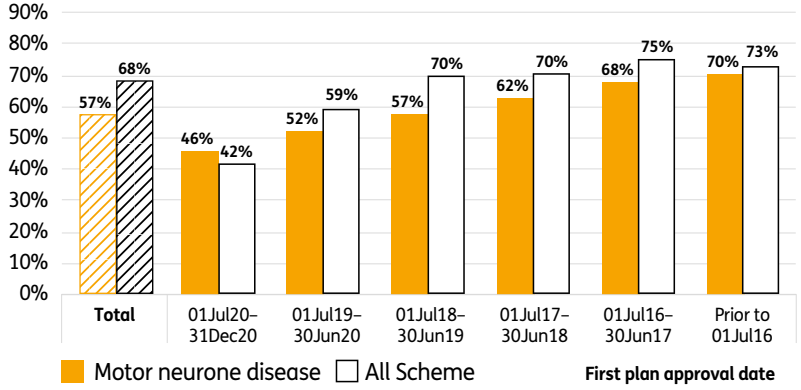


Utilisation of committed supports for participants with Huntington's disease by time in the Scheme

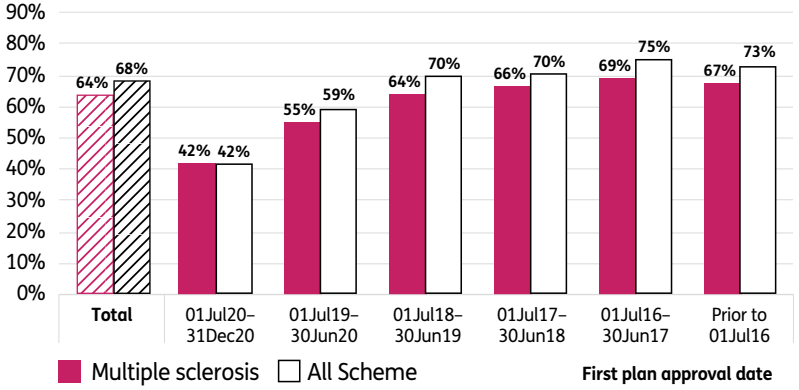


Utilisation by **time in the Scheme** cont.

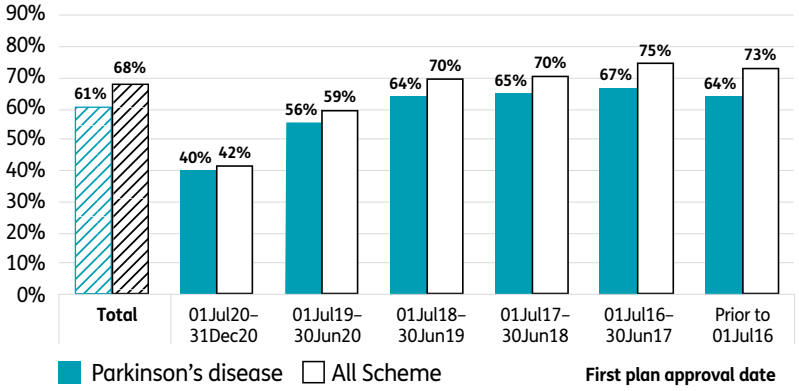
Utilisation of committed supports for participants with Motor neurone disease by time in the Scheme



Utilisation of committed supports for participants with Multiple sclerosis by time in the Scheme



Utilisation of committed supports for participants with Parkinson's disease by time in the Scheme

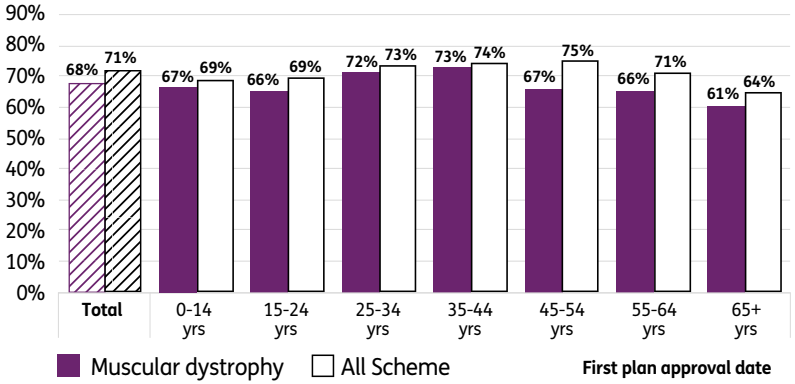


Utilisation by **age group**

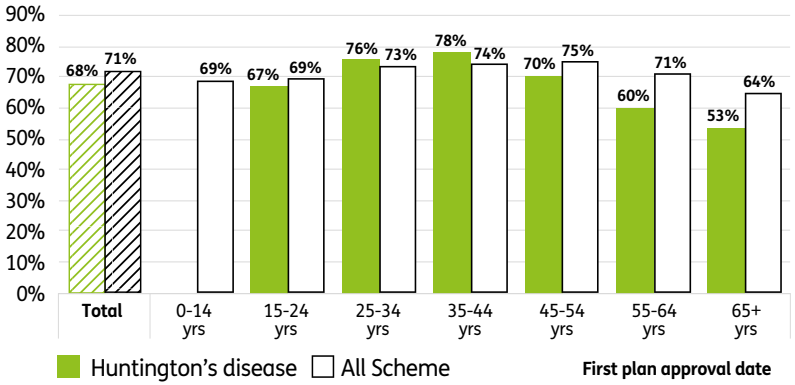
Utilisation by age group is presented based on active participants only, who have been in the Scheme for at least one year. This is to remove the impact of new entrants to the Scheme who tend to have low utilisation.

For all conditions, utilisation of committed supports is lower than Scheme average in all age groups, except participants with Huntington's disease aged 25 to 44 years where utilisation of supports is higher than Scheme average. The differences in utilisation are generally greater for older participants compared to younger participants.

Utilisation by age for participants with Muscular dystrophy who have been in the Scheme for at least one year



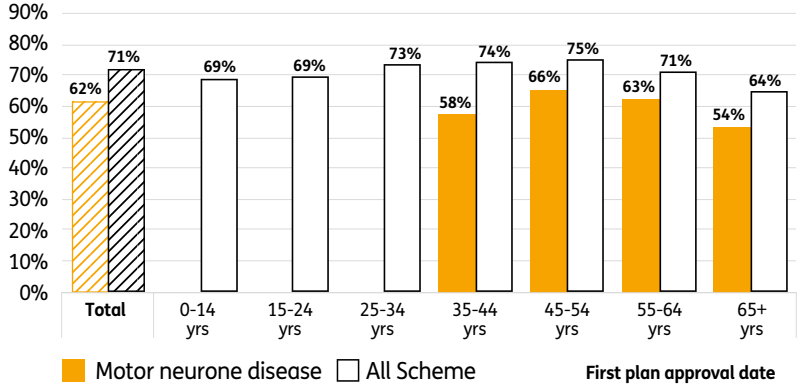
Utilisation by age for participants with Huntington's disease who have been in the Scheme for at least one year



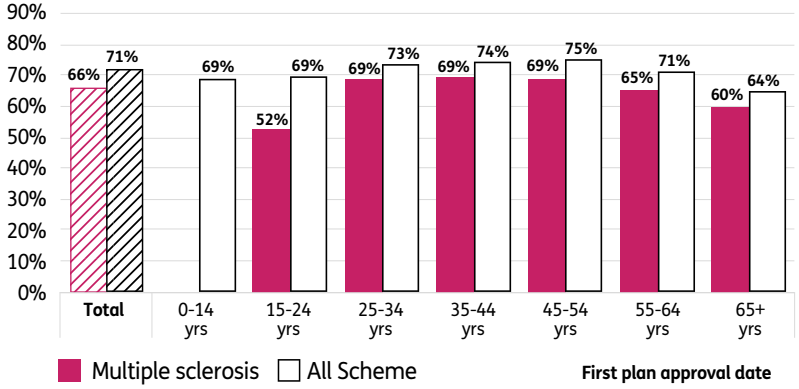
Note: The utilisation of committed supports are not shown for age groups with 20 or less participants.

Utilisation by **age group** cont.

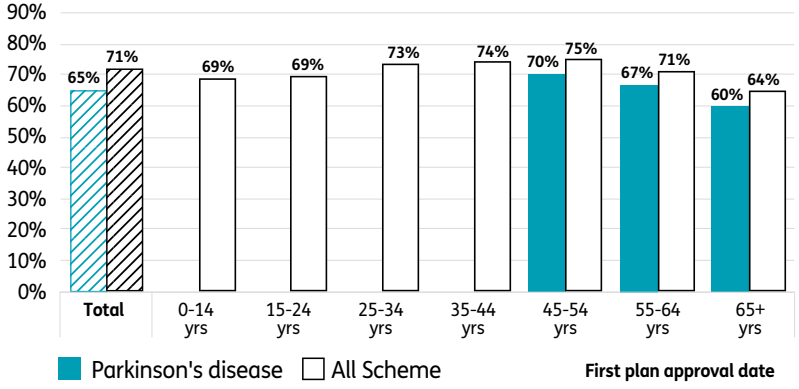
Utilisation by age for participants with Motor neurone disease who have been in the Scheme for at least one year



Utilisation by age for participants with Multiple sclerosis who have been in the Scheme for at least one year



Utilisation by age for participants with Parkinson's disease who have been in the Scheme for at least one year



Note: The utilisation of committed supports are not shown for age groups with 20 or less participants.

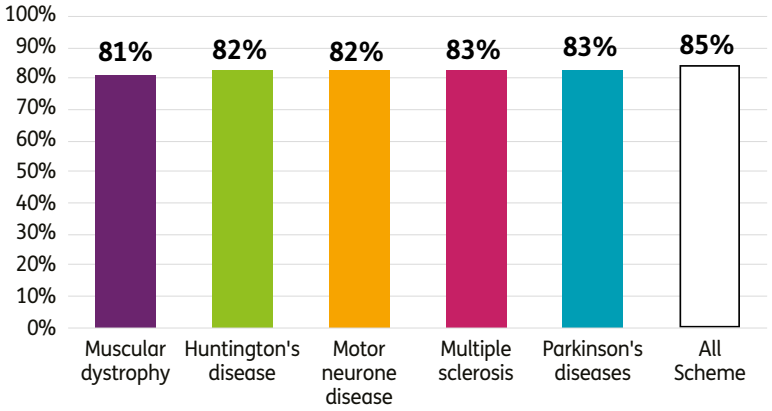
Utilisation by
SIL status

Utilisation of committed supports for participants under Supported Independent Living (SIL) arrangements is consistently higher than for participants without SIL. This is the case across the Scheme and within each neurodegenerative condition.

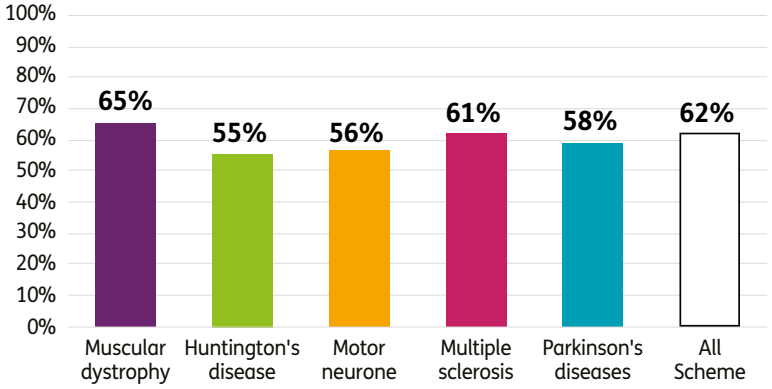
For participants with SIL, utilisation rates for all conditions are slightly lower than the Scheme average of 85%.

For participants without SIL, the utilisation rate for those with Muscular dystrophy is at 65%, which is higher than the Scheme average of 62%. For the remaining conditions, the utilisation rates are lower than the Scheme average, with participants with Huntington's disease having the lowest utilisation at 55%.

Utilisation of committed supports for participants with SIL



Utilisation of committed supports for participants without SIL



Note: Since June 2020 there has been an issue with identifying SIL in plans as they are being completed. For these results, the numbers of SIL participants include an estimate of participants who should be identified as having SIL in their plans but do not appear as such on the Agency's system at 31 March 2021.

PART 4

Participant goals, outcomes and satisfaction

Participants set goals as part of the planning process. Participants with a neurodegenerative condition most often set goals related to daily life, social and community activities, and health and wellbeing.

Information on participant and family and carers outcomes is collected at entry to the Scheme and at subsequent plan reviews. Outcomes for participants with a neurodegenerative condition have improved across most indicators.

A participant satisfaction survey is conducted to gauge the level of satisfaction with Agency processes. It shows that the majority of participants with a neurodegenerative condition rate the Agency's performance as 'good' or 'very good'.

Participant goals, outcomes and satisfaction
Technical notes

A) When comparing the indicators for participants with a neurodegenerative condition with the Scheme as a whole, consider the following:

- In addition to a primary disability group, other participant characteristics (such as age, gender, level of function) can influence experiences and outcomes of a participant and their family and carers. These other factors were not adjusted for in any of the calculations.
- In the "Longitudinal outcomes" section, we report participant and family and carers outcomes at baseline and the latest review, thereby gaining insights into the changes over the period since participants entered the Scheme. Due to phasing and general variability of factors leading to Scheme entry, the average time in the Scheme can be different for participants with a neurodegenerative condition compared to the Scheme as a whole. However, after carrying out analysis, the differences in the average durations were not found to have a material effect on the outcomes.
- In the "Has the NDIS Helped" section, we compare the latest satisfaction rates for participants with a neurodegenerative condition and the Scheme overall. Since the average time in the Scheme for participants with a neurodegenerative condition can be different to the Scheme as a whole, the comparison can be affected by the differences. Similar to the "Longitudinal outcomes" section, based on the analysis, we found that the differences in duration did not have a material effect on the "Has the NDIS Helped?" indicators.

B) Participant level of function has been found to be positively correlated with better outcomes at baseline and longitudinally. For participants with a neurodegenerative condition, level of function tends to decrease over time, and to a greater extent compared to the Scheme as a whole. The differences in level of function between baseline and latest review were significantly different[2] to the rest of the Scheme for participants aged 25 and over with the following disabilities: Motor neurone disease, Parkinson's disease, Muscular dystrophy, and Huntington's disease. Less favourable longitudinal outcomes for these participants compared to the overall Scheme can be partially attributed to decreasing level of function.

1 More information on the association between participant level of function and outcomes can be found in Participant outcomes reports (www.data.ndis.gov.au/reports-and-analyses/outcomes-and-goals/participant-outcomes-report)
2 Based on the t-test, p-value less than 0.05.

Summary

This section presents information on goals, satisfaction, as well as outcomes for participants with a primary neurodegenerative condition and their families and carers across various life domains.

Outcomes are measured when participants enter the Scheme to obtain baseline indicators, as well as at subsequent reviews to monitor longitudinal changes and gauge participant satisfaction via "Has the NDIS Helped?" questions.

Participant satisfaction with the Agency's services is collected using a survey, asking participants to give a rating for each of the four main stages of the participant pathway: access, pre-planning, planning, and plan review.

Key statistics

Participants aged 25 and over

	At Baseline		Longitudinally		Has the NDIS Helped? (Latest Review)	
	% of participants who choose who supports them	% of participants rating their health as excellent, very good or good	Change in the % of participants who participate in social and community activities	Change in the % of participants who are in a paid job	% of participants who said that the NDIS helped them have more choices and control in their life	% of participants who said that the NDIS improved their health and wellbeing
Participants with **Muscular dystrophy**	82%	31%	+9%	-3%	84%	63%
Participants with **Huntington's disease**	54%	27%	+6%	+0%	77%	58%
Participants with **Motor neuron disease**	87%	23%	+7%	-8%	87%	69%
Participants with **Multiple sclerosis**	85%	27%	+5%	-2%	83%	66%
Participants with **Parkinson's disease**	77%	20%	+6%	-3%	84%	67%
The Scheme as a whole	60%	42%	+9%	-2%	77%	58%

Key findings

Participant outcomes

- At Scheme entry, participants with a neurodegenerative condition tend to have more favourable outcomes than the Scheme average in the areas of advocacy, choosing who supports them, and deciding what to do each day. However, they have less favourable outcomes related to self-rated health.
- Community participation among participants with a neurodegenerative condition improved during their time in the Scheme.
- The percentage in paid employment for participants aged 25 and over with Huntington's disease, Motor neurone disease, and Parkinson's disease was lower at baseline compared to the overall Scheme. And, since Scheme entry, the percentages declined further.
- Participants with a neurodegenerative condition are more likely to say the NDIS helped improve their outcomes in choice and control as well as daily living. However, they are less likely to say the NDIS helped with lifelong learning and employment.

Family/Carer outcomes

- The percentage of families and carers of participants with a neurodegenerative condition in paid employment is generally higher compared to the Scheme overall at baseline.
- Longitudinal changes for families and carers of participants with a neurodegenerative conditions are generally in line with the Scheme.

Participant goals

- Participants with a neurodegenerative Scheme overall at baseline.

Participant satisfaction

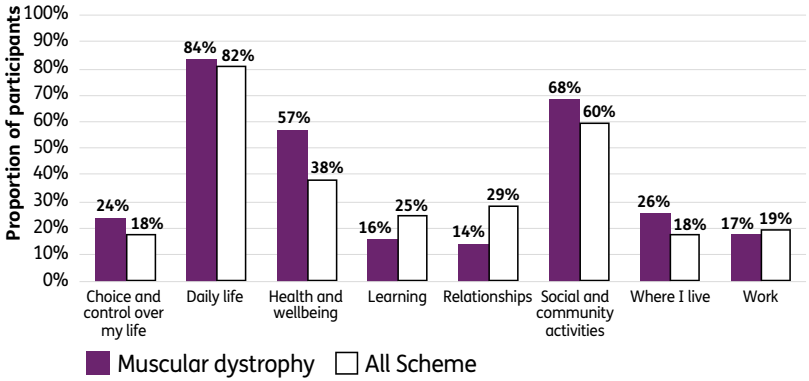
- Participant satisfaction rates with planning and review processes are generally in line with the Scheme overall.

Participant goals

As part of the planning process, participants set goals about what they would like to achieve across various domains. These goals tend to vary by disability type.

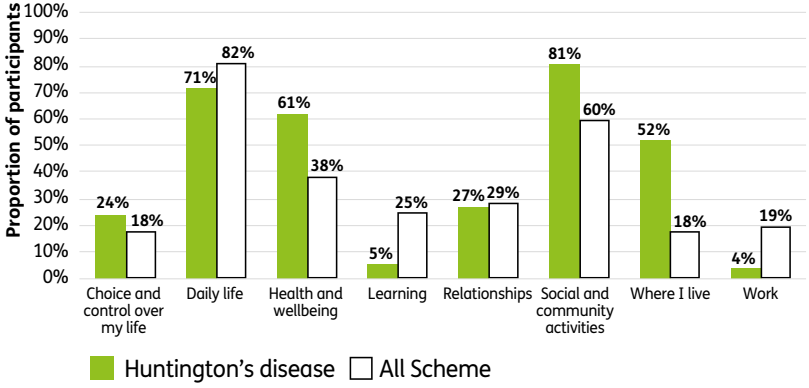
For participants with Muscular dystrophy:
They are the most likely of all neurodegenerative conditions to set goals on daily life (84%). However, they are relatively less likely than other neurodegenerative conditions to set goals on health and wellbeing (57%) or where they live (26%), albeit still considerably more likely than the Scheme averages of 38% and 18% respectively.

Proportion of active participants with goals by domain – Muscular dystrophy



For participants with Huntington's disease:
Results for this disability type are more varied. They are the most likely of all neurodegenerative conditions to set goals on social and community activities (81%), relationships (27%), as well as where they live (52%, almost triple that of the Scheme average). However, they are the least likely to have goals on daily life (71%) and employment (just 4%, well below the the Scheme average of 19%).

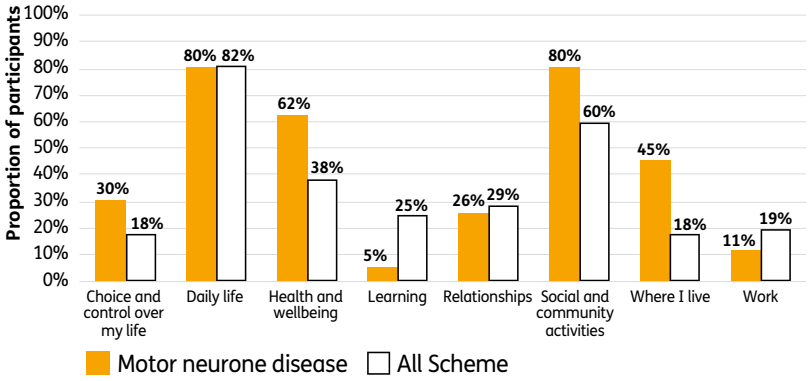
Proportion of active participants with goals by domain – Huntington's disease



Participant goals cont.

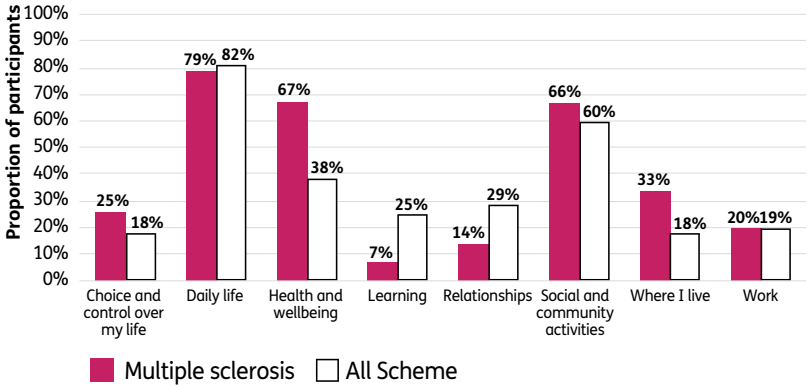
For participants with Motor neurone disease:
While being the most likely of all neurodegenerative conditions to have goals about choice and control over their lives (30%), they are among the least likely (5%, far below the Scheme average of 25%) to set learning-related goals. They are also just 3% less likely than the Scheme as a whole to set relationship goals, one of the highest among all neurodegenerative conditions.

Proportion of active participants with goals by domain – Motor neurone disease



For participants with Multiple sclerosis:
They are 29% more likely than the Scheme average to set health and wellbeing goals, as well as being 1% more likely than the Scheme average to set employment goals, the only neurodegenerative condition where the rate of employment goals is higher than the Scheme average. However, they are the least likely (66%, just 6% above the Scheme average) to have goals for social and community activities.

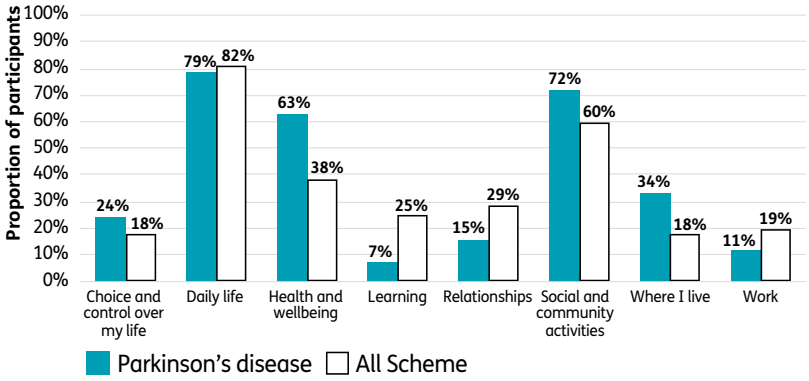
Proportion of active participants with goals by domain – Multiple sclerosis



Participant goals cont.

For participants with Parkinson's disease:
Just 15% of participants with Parkinson's disease have set goals with respect to relationships, compared to 29% for the Scheme as a whole. On the other hand, they are more likely to set goals with respect to social and community participation, with 72% of them doing so compared to the Scheme average of 60%.

Proportion of active participants with goals by domain – Parkinson's disease

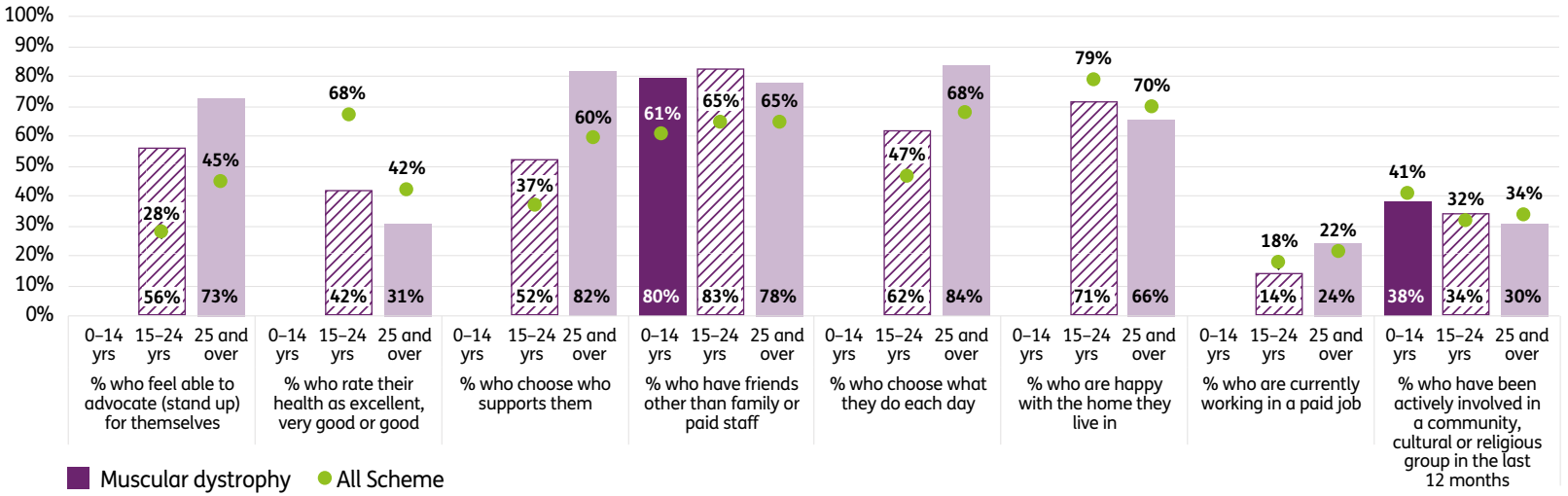


Overall with respect to individual participant goal domains, participants with a neurodegenerative condition, relative to the Scheme as a whole:

- **are slightly more likely to set goals regarding choice and control;**
- **are almost equally likely to set goals to do with daily life;**
- **are substantially more likely to set goals regarding health and wellbeing;**
- **are substantially less likely to set goals with regards to learning;**
- **are slightly less likely to set goals regarding relationships;**
- **are slightly more likely to set goals on social and community activities;**
- **are slightly more likely to set goals to do with where they live;**
- **are slightly less likely to set goals related to employment.**

Participant baseline outcomes
Muscular dystrophy

Selected baseline indicators for participants with Muscular dystrophy compared with the Scheme as a whole



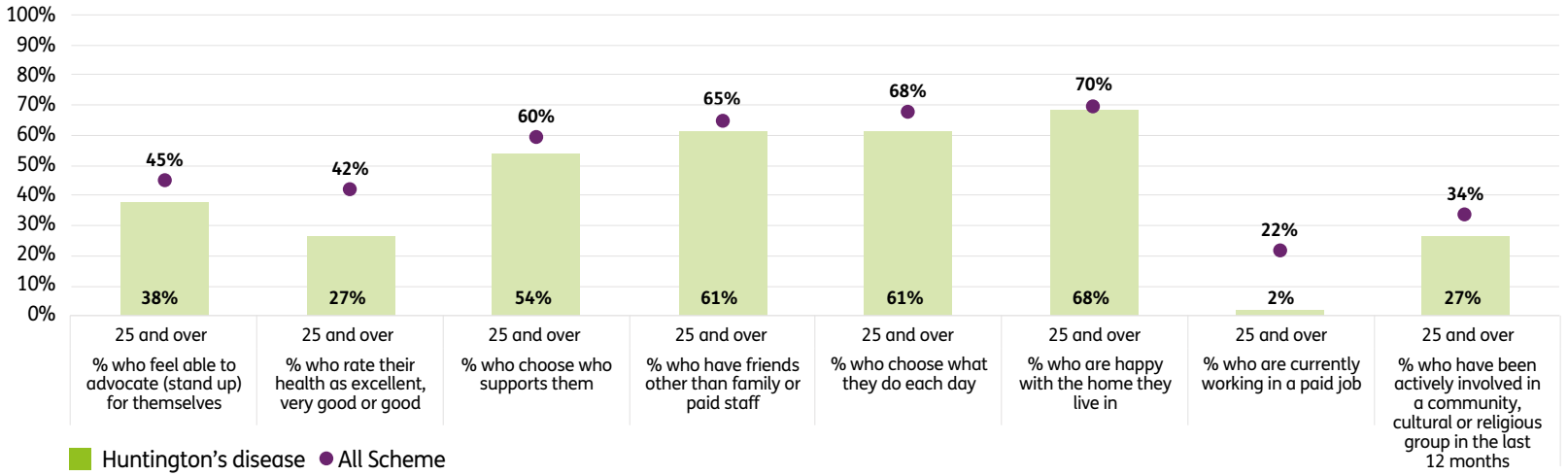
This information on participant baseline indicators has been collected from participants with Muscular dystrophy who received their initial plan since 1 July 2016 (when they entered the Scheme).

Baseline outcomes for participants with Muscular dystrophy relative to the Scheme overall vary by domain.

At Scheme entry, participants with Muscular dystrophy on average fare better in self-advocacy, friendships, choosing who supports them, and choosing what they do each day. However, the percentage of participants who rate their health as good, very good or excellent is lower compared to the Scheme average. The outcomes related to employment, community participation and housing are similar to the Scheme average.

Participant baseline outcomes
Huntington's disease

Selected baseline indicators for participants with Huntington's disease compared with the Scheme as a whole



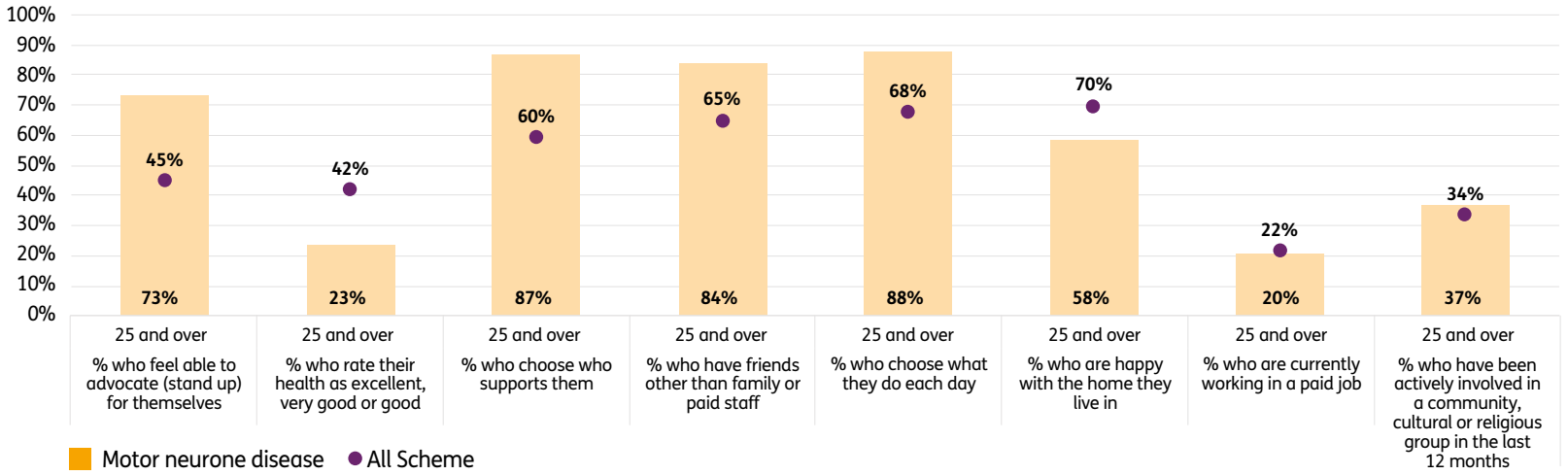
This information on participant baseline indicators has been collected from participants with Huntington's disease who received their initial plan since 1 July 2016 (when they entered the Scheme).

For participants with Huntington's disease, outcomes for the eight indicators shown are generally less positive than for the Scheme as a whole.

In particular, only 27% of participants with Huntington's disease rate their own health positively, compared to 42% of the Scheme as a whole. Although 22% of participants aged 25 and over across the Scheme are working in a paid job, this is true for only 2% of those with Huntington's disease.

Participant baseline outcomes
Motor neurone disease

Selected baseline indicators for participants with Motor neurone disease compared with the Scheme as a whole



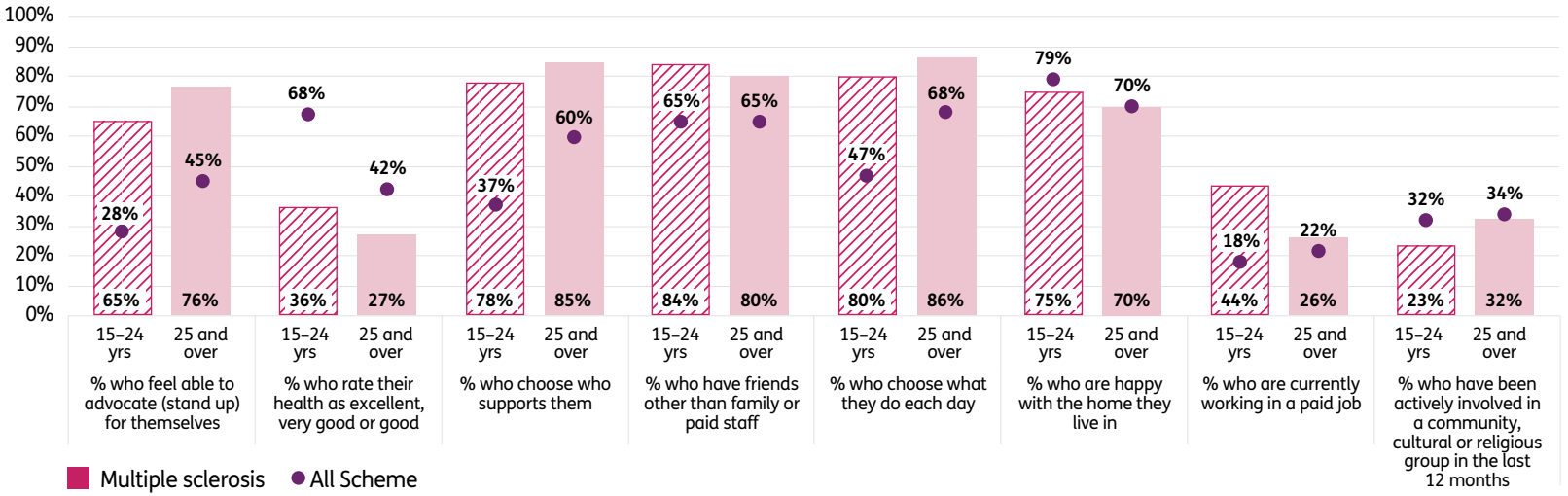
This information on participant baseline indicators has been collected from participants with Motor neurone disease who received their initial plan since 1 July 2016 (when they entered the Scheme).

For participants with Motor neurone disease, outcomes in most domains differ substantially from the Scheme overall. Exceptions are working in a paid job and being actively involved in a community, cultural or religious group, featuring differences of -2% and +3% compared to the Scheme average, respectively.

Participants with Motor neurone disease are 28% more likely than the Scheme average to be able to advocate for themselves, 27% more likely to choose who supports them, 19% more likely to have friends other than family or paid staff and 20% more likely to choose what they do each day. On the other hand, their outcomes are worse than the Scheme as a whole in self-rated health and being happy with the home they live in.

Participant baseline outcomes
Multiple sclerosis

Selected baseline indicators for participants with Multiple sclerosis compared with the Scheme as a whole



This information on participant baseline indicators has been collected from participants with Multiple sclerosis who received their initial plan since 1 July 2016 (when they entered the Scheme).

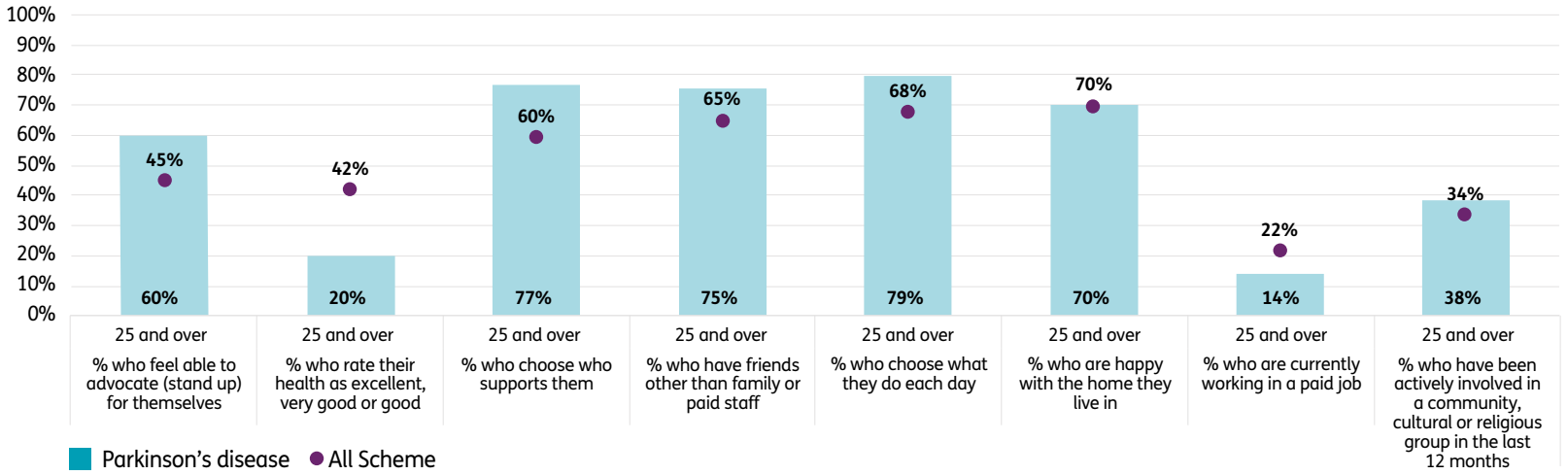
For participants with Multiple sclerosis, outcomes are more favourable than the Scheme as a whole across most indicators, and the difference is more pronounced for the 15 to 24 age group. However, self-rated health is lower than the Scheme overall, and differences are smaller for home.

Highlights in outcomes of participants with Multiple sclerosis include:

- Paid employment rate of 44% for those aged 15 to 24, notably higher than the Scheme average of 18%;
- 65% of those aged 15 to 24 are able to advocate for themselves compared to just 28% for the Scheme overall;
- 78% of those aged 15 to 24 choose who supports them compared to just 37% for the Scheme overall.

Participant baseline outcomes
Parkinson's disease

Selected baseline indicators for participants with Parkinson's disease compared with the Scheme as a whole



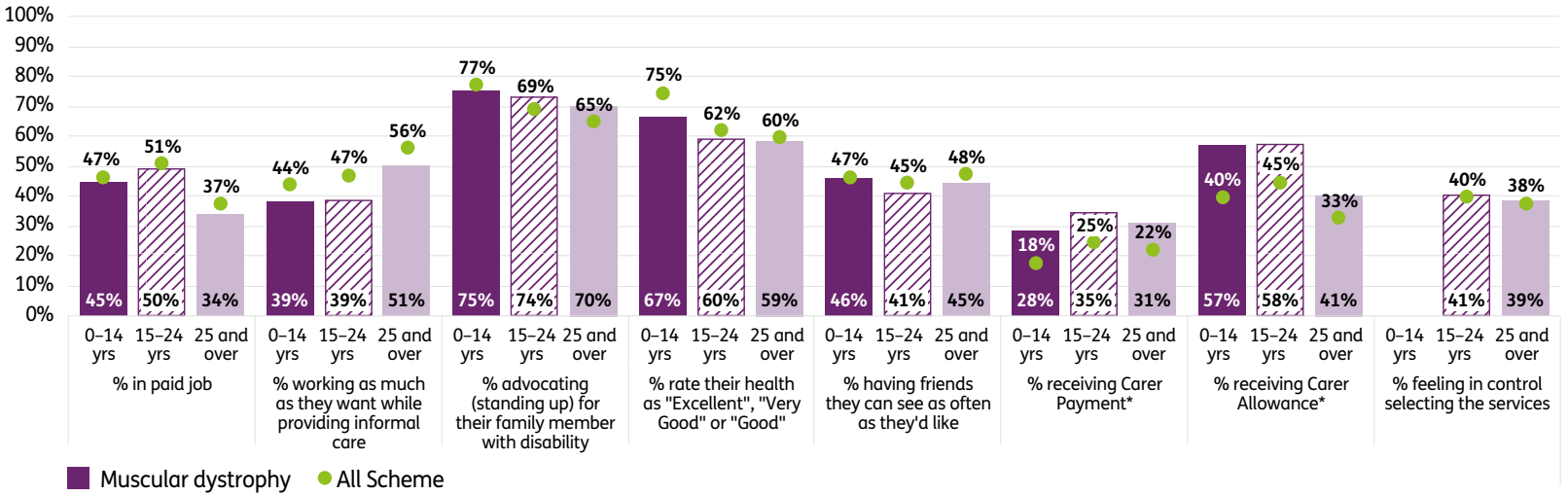
This information on participant baseline indicators has been collected from participants with Parkinson's disease who received their initial plan since 1 July 2016 (when they entered the Scheme).

For participants with Parkinson's disease, outcomes relative to the Scheme average are similar to those with Motor neurone disease for most domains. Their outcomes are higher than the Scheme average in being able to advocate for themselves, choosing who supports them, making friends beyond family and paid staff and choosing what they do each day. On the other hand, they are less than half as likely to rate their health positively, (20% compared to 42% for the Scheme overall). They are also 8% less likely to be working in a paid job compared to the Scheme as a whole.

Family/carer baseline outcomes

Muscular dystrophy

Selected baseline indicators for families/carers of participants with Muscular dystrophy compared with the Scheme as a whole



This information on baseline indicators has been collected from families/carers of participants with Muscular dystrophy where the participant entered the Scheme since 1 July 2016.

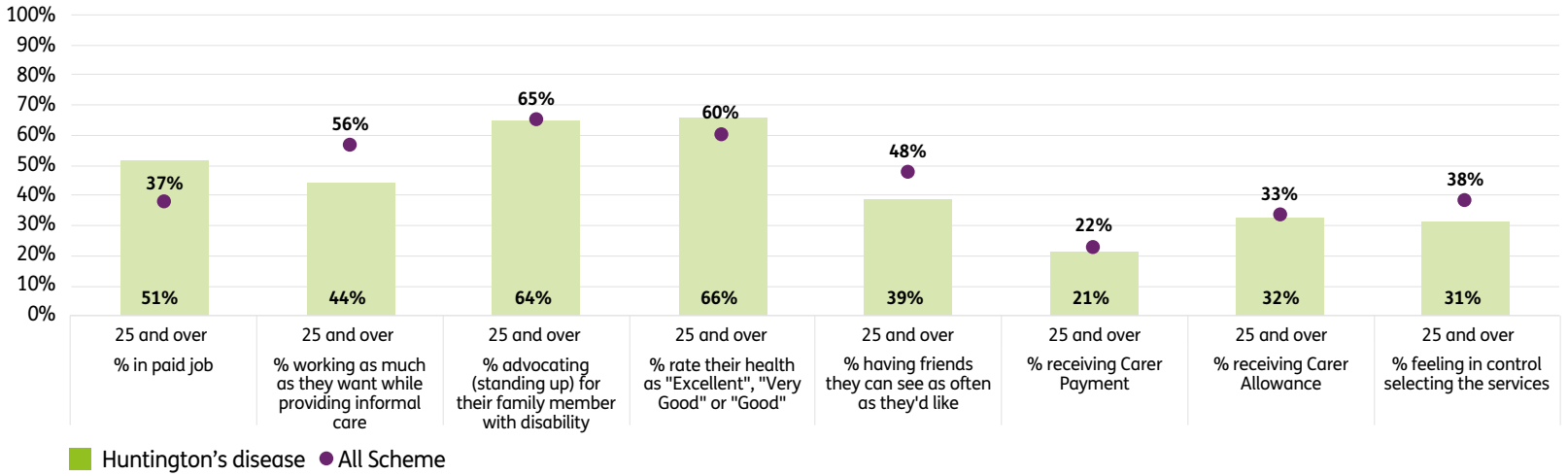
The results for participants with Muscular dystrophy are close to the Scheme average across most domains, with the following exceptions:

- The percentage of families and carers receiving Carer Payment and Carer Allowance for participants with Muscular dystrophy are higher than the Scheme as a whole;
- The percentages who are able to work as much as they want while providing informal carer is lower than the Scheme as a whole;
- The percentage of families and carers of participants with Muscular dystrophy aged 0 to 14 who rated their health as “Excellent”, “Very Good” or “Good” is 67%, 8% lower than 75% for the Scheme as a whole. This gap narrowed for families and carers of participants aged 15 and over.

* Data for Carer Payment and Carer Allowance receipt are based on self-reported information

Family/carer baseline outcomes
Huntington's disease

Selected baseline indicators for families/ carers of participants with Huntington's disease compared with the Scheme as a whole



This information on baseline indicators has been collected from families/carers of participants with Huntington's disease where the participant entered the Scheme since 1 July 2016.

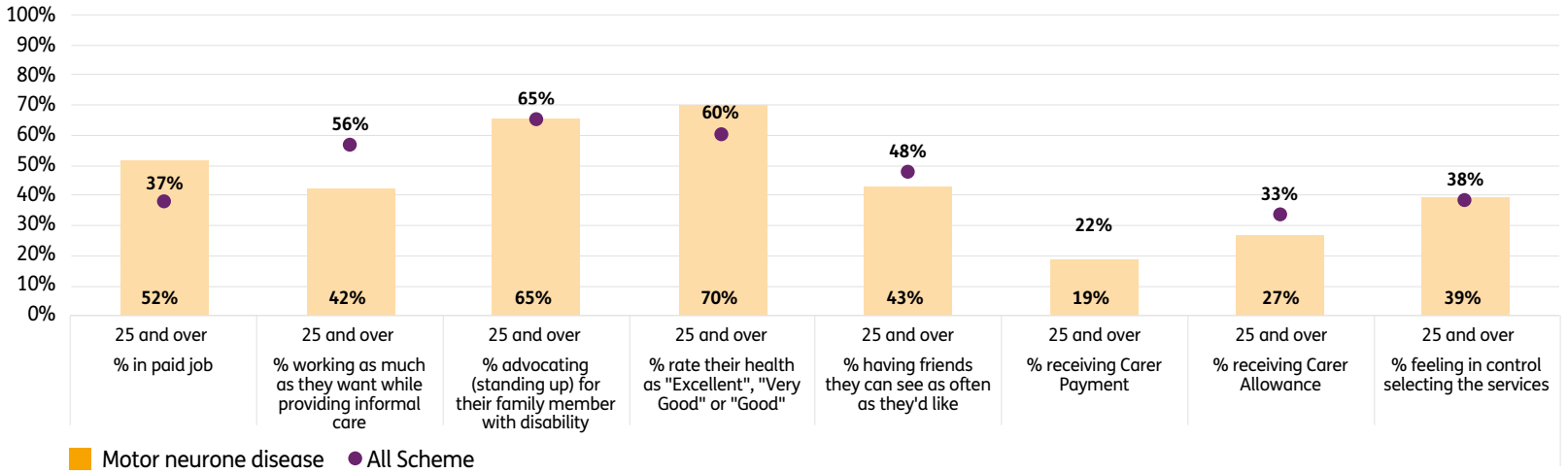
The results for families or carers of participants with Huntington's disease are:

- Similar to the Scheme average for being able to advocate for the participant, as well as Carer Payment and Carer Allowance;
- Lower than overall Scheme results when it comes to being able to work as much as wanted, having friends to see as often as wanted, and feeling in control in selecting services and supports for the participant;
- Higher than the Scheme as a whole for paid employment rate (14% higher) and positive self-rated health.

Family/carer baseline outcomes

Motor neurone disease

Selected baseline indicators for families/ carers of participants with Motor neurone disease compared with the Scheme as a whole



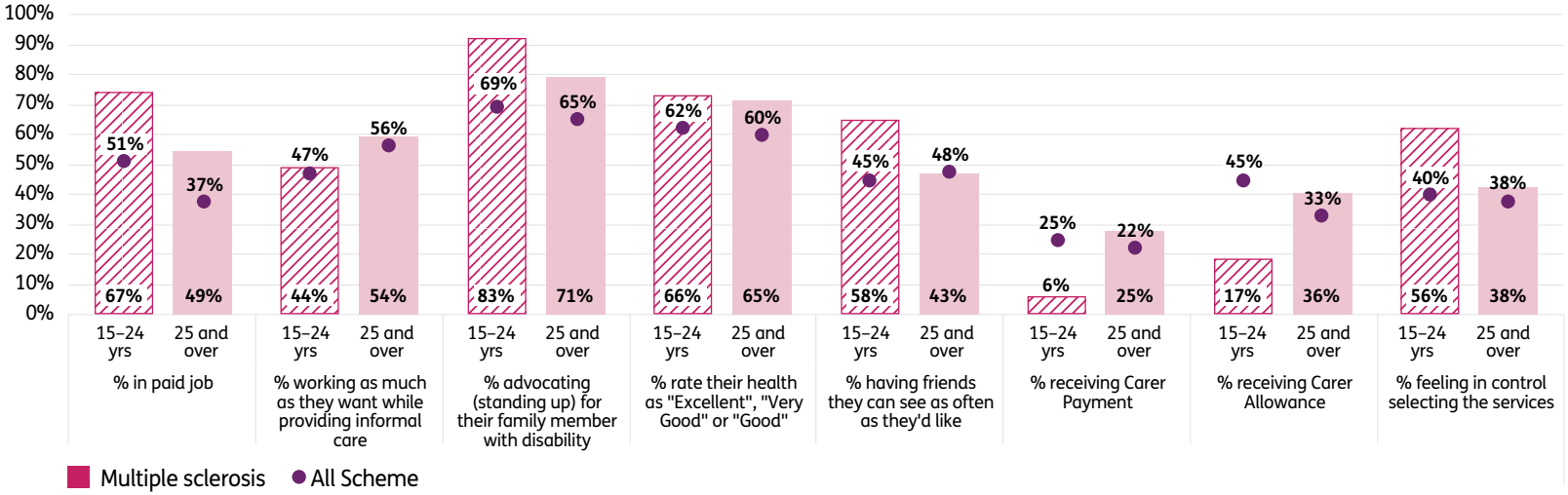
This information on baseline indicators has been collected from families/carers of participants with Motor neurone disease where the participant entered the Scheme since 1 July 2016.

The results for families or carers of participants with Motor neurone disease can be summarised as follows:

- 65% are able to advocate for the participant and 39% feel in control selecting services and supports for the participants, both proportions are very close to the Scheme average;
- Over 10% more likely than the Scheme as a whole to be in paid employment and to rate their health positively;
- However, when it comes to being able to work as much as they want while providing informal care, only 42% responded positively, compared to 56% for the Scheme as a whole.

Family/carer baseline outcomes
Multiple sclerosis

Selected baseline indicators for families/ carers of participants with Multiple sclerosis compared with the Scheme as a whole



This information on baseline indicators has been collected from families/carers of participants with Multiple sclerosis where the participant entered the Scheme since 1 July 2016.

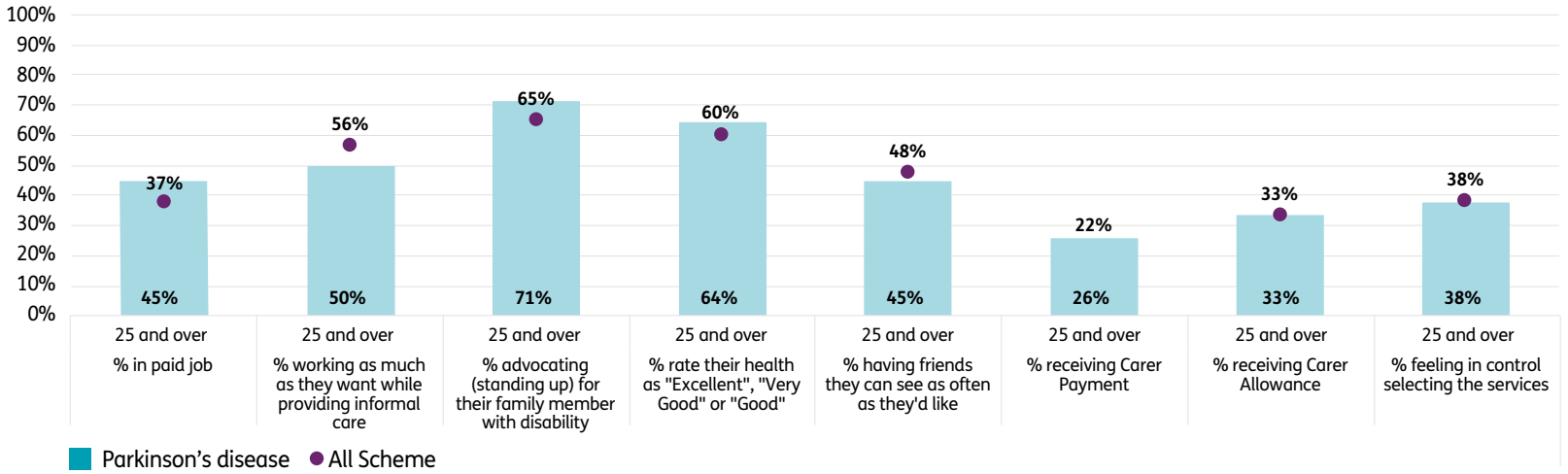
The results for families or carers of participants with Multiple sclerosis relative to the Scheme vary by domain and by participant age group. They are more likely than the Scheme average to be in a paid job, advocate for the participant and self-rate health positively. However, they are less likely to be able to work as much as wanted compared to the Scheme overall.

Families and carers of participants aged 15 to 24 are less likely than the Scheme average to receive Carer Payment and Carer Allowances, and more likely to have friends to see as often as they like. These conclusions are the opposite for families and carers of participants aged 25 and over, namely, being more likely than the Scheme average to receive Carer Payment and Carer Allowance, as well as being less likely to have friends they see as often as they like.

Family/carer baseline outcomes

Parkinson's disease

Selected baseline indicators for families/ carers of participants with Parkinson's disease compared with the Scheme as a whole



This information on baseline indicators has been collected from families/carers of participants with Parkinson's disease where the participant entered the Scheme since 1 July 2016.

The results for families or carers of participants with Parkinson's disease have shown less deviation from the Scheme average compared to other disability types discussed above, with all of them being within 8% of the Scheme average. The largest deviations are for paid employment rate (8% higher than Scheme overall), being able to work as much as they want (6% lower than Scheme overall) and being able to advocate for the participant (6% higher than Scheme overall).

On the other hand, 33% reported that they are receiving Carer Allowance and 38% feel in control selecting services and supports for the participant, both of which are almost identical percentages compared to the Scheme as a whole.

Participant longitudinal outcomes
Muscular dystrophy

Longitudinal outcomes in this section serve the following purposes:

- Outcomes are graphed for participants at Scheme entry (baseline) as well as their latest review to show longitudinal changes over time.

- Trends in indicators for participants with a neurodegenerative condition are contrasted with the Scheme as a whole.

- These results are based on participants who have been in the Scheme for at least two years, measured at baseline and at their latest plan review.

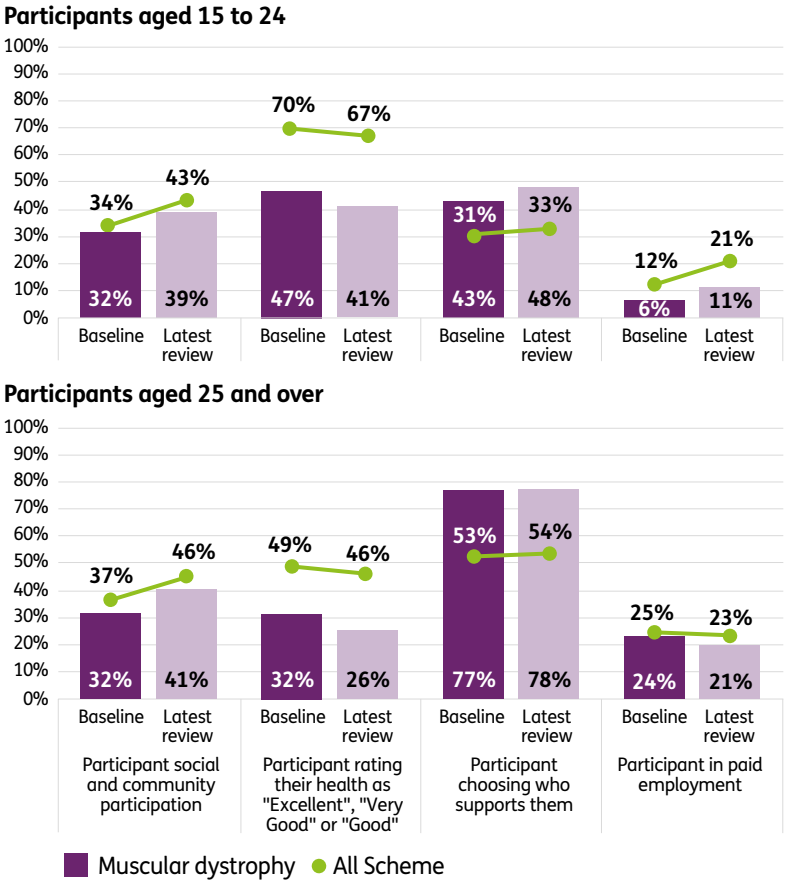
Outcomes in social and community participation for participants with Muscular dystrophy aged 15 and over improved over time, similar to the Scheme overall.

However, the percentage rating their health positively decreased by 6%, more than the Scheme as a whole (a decrease of 3%).

Participants with Muscular dystrophy aged 15 to 24 were more likely than the Scheme average to choose who supports them at baseline, 43% compared to 31% for the Scheme overall. This difference widened to 15 percentage points at latest review.

Compared to the Scheme overall, participants with Muscular dystrophy aged 15 to 24 were less likely to work in a paid job, however, the percentage in paid employment improved over time in the Scheme, from 6% to 11%. Participants aged 25 and over have similar employment outcomes to the Scheme average at both baseline and latest review.

Longitudinal outcomes - Muscular dystrophy compared with the Scheme as a whole



Participant longitudinal outcomes
Huntington's disease

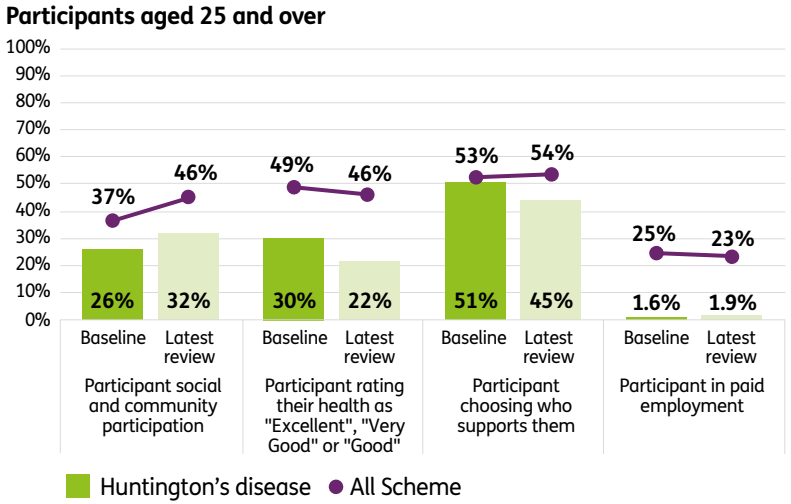
Compared with the Scheme as a whole, participants with Huntington's disease were more likely to experience a decline in the outcome related to self-rated health. The percentage of participants who rate their health as good, very good or excellent decreased from 30% at baseline to 22% at latest review, compared to 49% and 46% for the Scheme as a whole.

The percentage of participants choosing who supports them decreased since baseline by 6 percentage points, from 51% to 45%. At the same time, this indicator remained stable for the Scheme as whole, at 53% at baseline and 54% at latest review.

The outcome for social and community participation improved, from 26% at baseline to 32% at latest review, albeit to a lesser extent than the Scheme average (37% at baseline and 46% at latest review).

The percentage of participants with Huntington's disease in paid employment remained at a lower level compared to the Scheme overall.

Longitudinal outcomes - Huntington's disease compared with the Scheme as a whole



Participant longitudinal outcomes

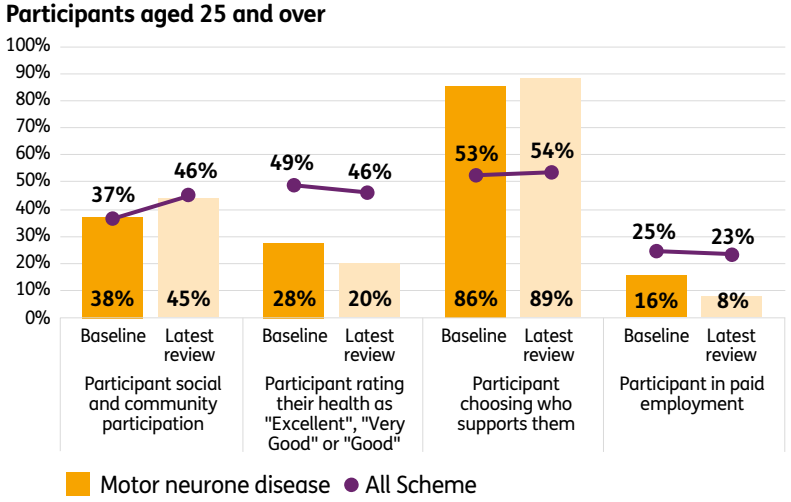
Motor neurone disease

Outcomes in social and community participation for participants with Motor neurone disease improved by 7 percentage points from baseline to latest review, slightly lower compared to 9 percentage points for the Scheme average.

In relation to employment, the percentage of participants with Motor neurone disease with a paid job has decreased considerably, from 16% at baseline to 8% at latest review. The result for the Scheme as whole is less unfavourable, a 2 percentage points decrease.

Similarly, the indicator for self-rated health of participants with Motor neurone disease deteriorated by 8 percentage points, from 28% at baseline to 20% at latest review, a worse outcome compared to a decrease of 3 percentage points for the Scheme as a whole.

Longitudinal outcomes - Motor neurone disease compared with the Scheme as a whole



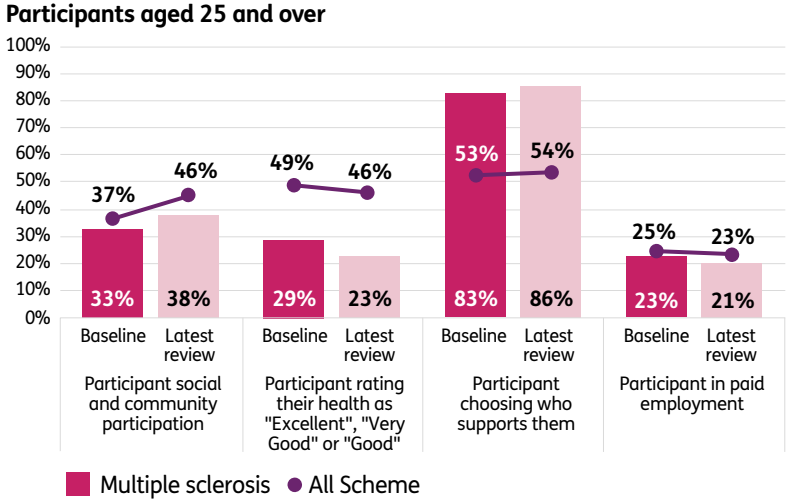
Participant longitudinal outcomes
Multiple sclerosis

The percentage of participants with Multiple sclerosis participating in social and community activities improved by 5% from baseline to latest review, which is a smaller increase compared to the Scheme overall (+9%).

With regards to self-rated health, the percentage of participants with Multiple sclerosis who rated their health positively has decreased by 6 percentage points, from 29% at baseline to 23% at latest review. This is a larger deterioration compared to the Scheme as a whole (-3%).

The percentage of participants in a paid employment decreased by 2 percentage points both for participants with Multiple sclerosis and the Scheme as a whole.

Longitudinal outcomes - Multiple sclerosis compared with the Scheme as a whole



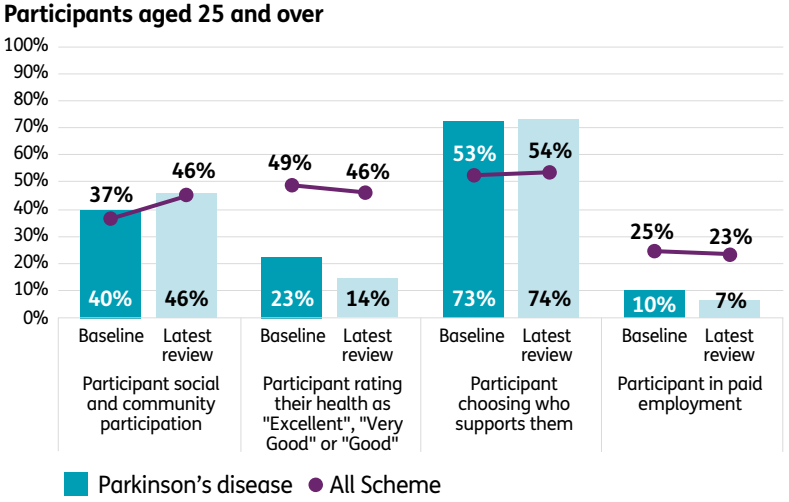
Participant longitudinal outcomes
Parkinson's disease

The percentage of participants with Parkinson's disease who positively rated their health decreased by 9 percentage points, compared to a decrease of only 3 percentage points for the Scheme average.

Outcomes in social and community participation improved (+6%), albeit at a slower rate than the Scheme as a whole (+9%).

The percentage choosing who supports them also increased slightly, similar to the Scheme overall.

Longitudinal outcomes - Parkinson's disease compared with the Scheme as a whole



Family/Carer longitudinal outcomes
Muscular dystrophy

Longitudinal outcomes in this section serve the following purposes:

- Outcomes are graphed for families and carers of participants at Scheme entry (baseline) as well as their latest review to show longitudinal changes over time.

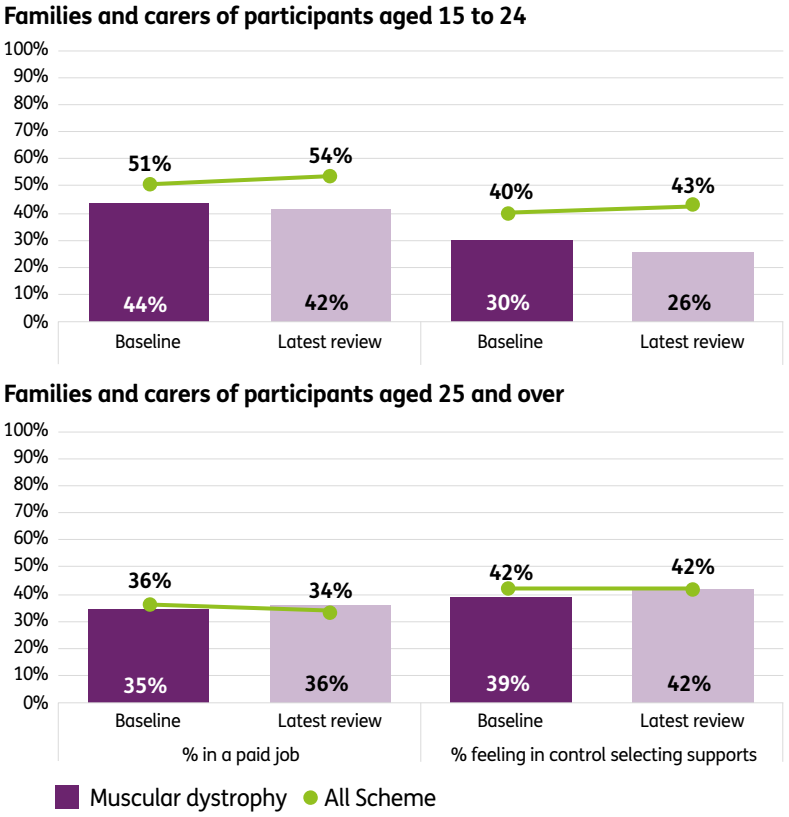
- Trends in indicators for families and carers of participants with a neurodegenerative condition are contrasted with the Scheme as a whole.

- These results are based on families/carers of participants who have been in the Scheme for at least two years, measured at baseline and at their latest plan review.

In terms of employment, the percentage of families and carers of participants with Muscular dystrophy who have a paid job declined slightly for the "age 15 to 24" group and increased for the "age 25 and over" group.

As for feeling in control when selecting services, the indicator for families and carers of participants with Muscular dystrophy aged 15 to 24 declined by 4 percentage points (from 30% to 26%), while it improved for the Scheme as a whole (an increase of 3 percentage points from 40% to 43%). For those aged 25 and over, family/carers of participants reported an improvement of 3 percentage points (from 39% to 42%), while the Scheme average remained constant at 42%.

Longitudinal outcomes - Muscular dystrophy compared with the Scheme as a whole



Family/Carer longitudinal outcomes

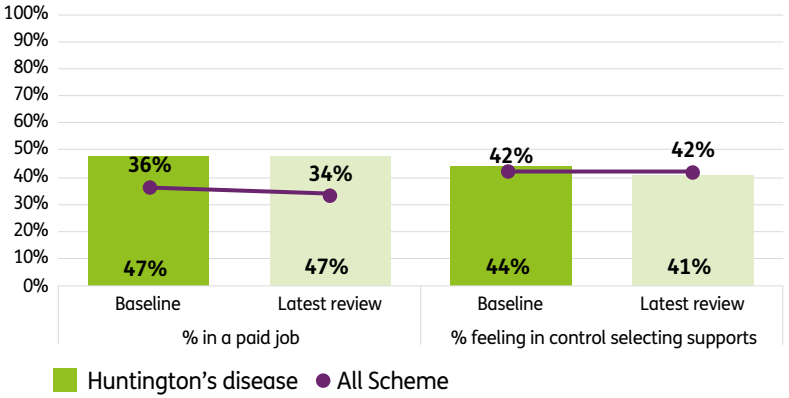
Huntington's disease

Employment outcomes based on the selected indicator remained stable for families and carers of participants with Huntington's disease, compared to a 2 percentage point decrease for the Scheme as a whole.

As for feeling in control selecting supports, the percentage for families and carers with Huntington's disease decreased by 3 percentage points while the Scheme as a whole remained constant.

Longitudinal outcomes - Huntington's disease compared with the Scheme as a whole

Families and carers of participants aged 25 and over



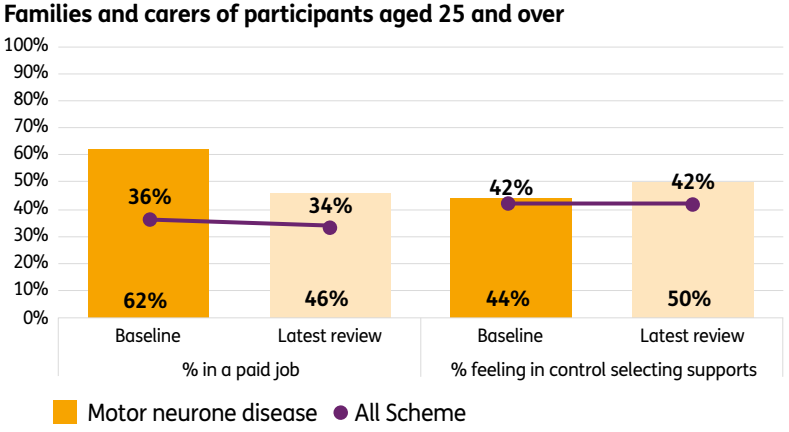
Family/Carer longitudinal outcomes

Motor neurone disease

The percentage of families and carers of participants with Motor neurone disease in a paid job decreased substantially by 16 percentage points, from 62% at baseline to 46% at latest review. In contrast, this indicator decreased by just 2 percentage points, from 36% to 34%, for the Scheme as a whole.

More families and carers of participants with Motor neurone disease feel in control selecting supports compared to baseline (44% and 50% at latest review), a more favourable outcome compared to the Scheme average (constant at 42%).

Longitudinal outcomes - Motor neurone disease compared with the Scheme as a whole



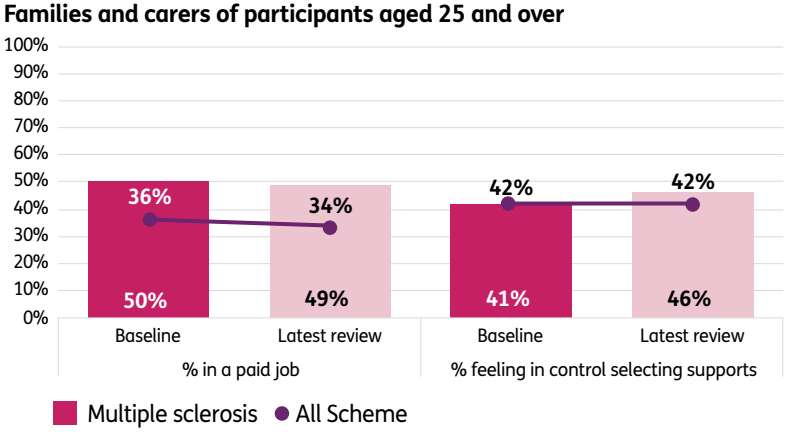
Family/Carer longitudinal outcomes

Multiple sclerosis

The percentage of families and carers of participants with Multiple sclerosis in paid employment decreased by 1 percentage point since baseline, while the Scheme as a whole decreased by 2 percentage points.

Families and carers of participants with Multiple sclerosis on average felt more in control selecting services and supports, with the percentage increasing from 41% at baseline to 46% at latest review, in contrast with the Scheme overall which showed almost no change.

Longitudinal outcomes - Multiple sclerosis compared with the Scheme as a whole



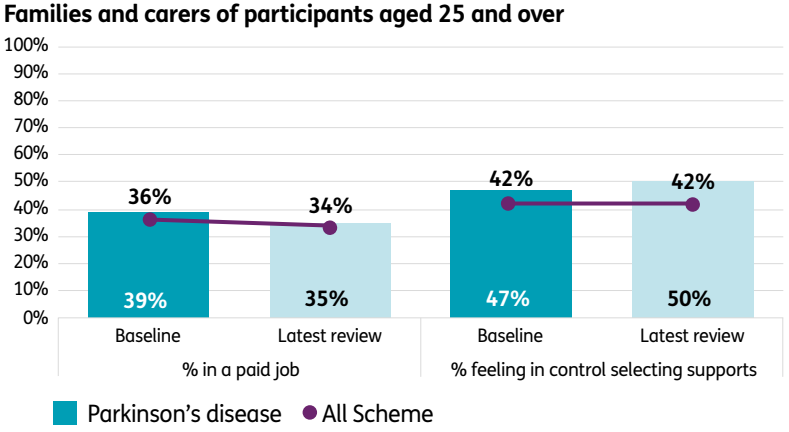
Family/Carer longitudinal outcomes

Parkinson's disease

The percentage of families and carers of participants with Parkinson's disease in a paid job decreased by 4 percentage points from 39% at baseline to 35% at latest review, similar to the Scheme as a whole (a 2 percentage point decrease, from 36% to 34%).

The percentage feeling in control selecting services improved by 3 percentage points from 47% at baseline to 50% at latest review, while the Scheme average remained constant at 42%.

Longitudinal outcomes - Parkinson's disease compared with the Scheme as a whole



Has the NDIS helped participants
Muscular dystrophy
(Participants from starting school to age 14)

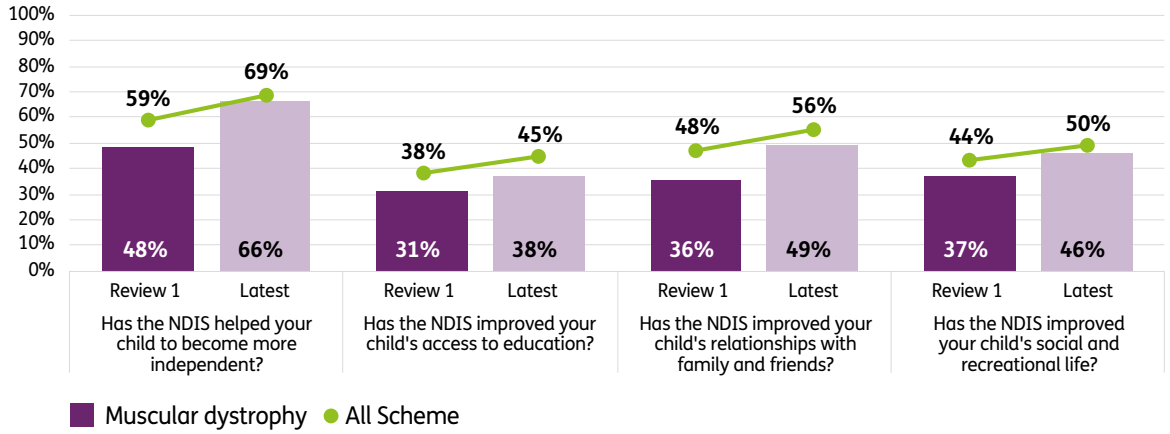
Participants are asked whether the NDIS has helped them at each plan review across various domains. These charts summarise the responses for participants who have been in the Scheme for at least two years and compare the average satisfaction rates at first review (R1) with those at the latest review.

For the starting school to age 14 group, participants with Muscular dystrophy rated the NDIS less favourably than the Scheme average in helping them improve outcomes, across all domains. This is true for both first and latest review.

In particular, 48% of NDIS participants from starting school to age 14 at first review said that the NDIS improved their relationships with family and friends, compared to just 36% of those with Muscular dystrophy. However, this 12% gap narrowed to 7% at the latest review.

Proportion of participants with Muscular dystrophy who had two or more plan reviews and responded 'yes' to the "Has the NDIS helped?" questions

Participants from starting school to age 14



Has the NDIS helped participants
Muscular dystrophy
(participants aged 15 and over)

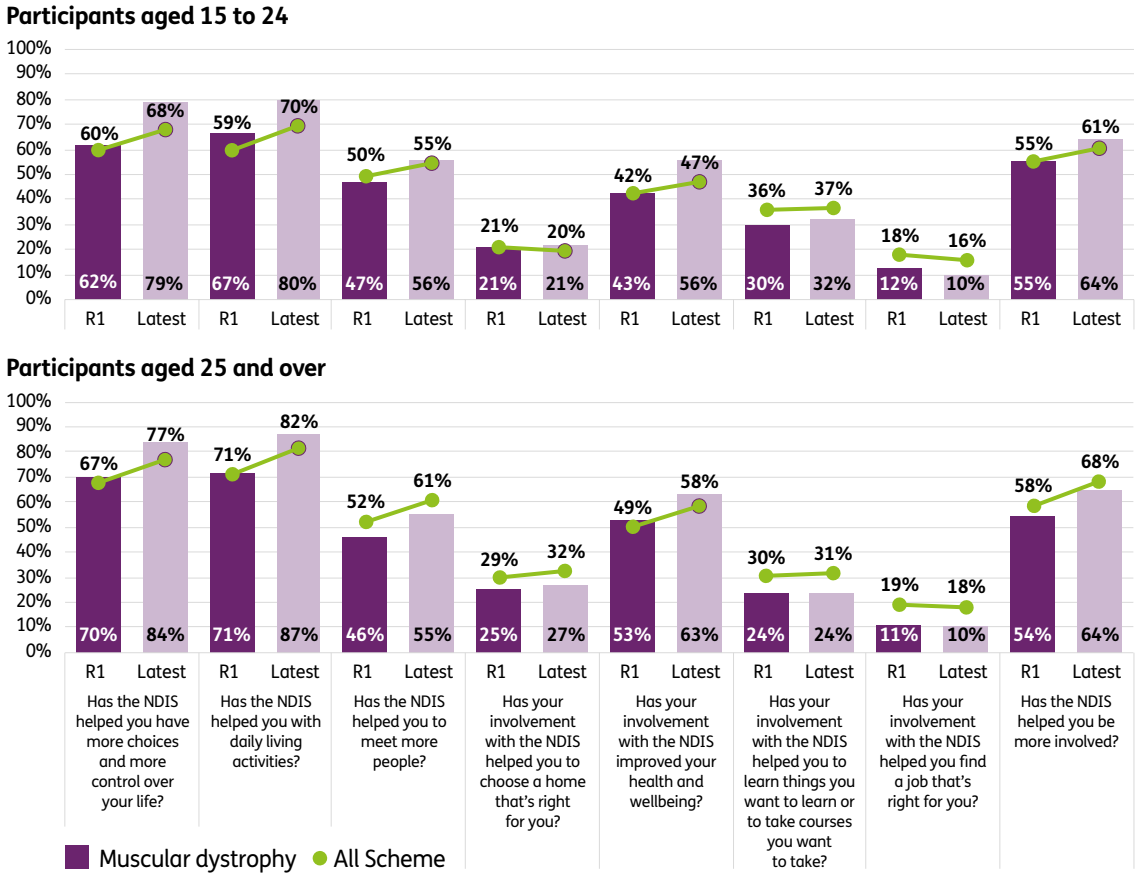
By contrast with the starting school to age 14 group, the percentage saying the NDIS helped has exceeded the Scheme average in some domains among participants aged 15 and over.

67% of participants with Muscular dystrophy aged 15 to 24 said that the NDIS helped them with daily living activities, compared to the Scheme average of 59%. This 8% difference increased to 10% at the latest review.

For choice and control, 70% of participants with Muscular dystrophy aged 25 and over said the NDIS helped, slightly higher than the Scheme average of 67%. At the latest review, these percentages increased considerably to 84% and 77%, representing a 7% difference from the Scheme average.

However, participants with Muscular dystrophy in both age groups are 5% to 8% less likely than participants overall to think that the NDIS has helped in the domains of lifelong learning and employment.

Proportion of participants with Muscular dystrophy who had two or more plan reviews and responded 'yes' to the "Has the NDIS helped?" questions



Has the NDIS helped participants
Huntington's disease

Whether the NDIS has helped among participants with Huntington's disease relative to the Scheme as a whole varies substantially by domain.

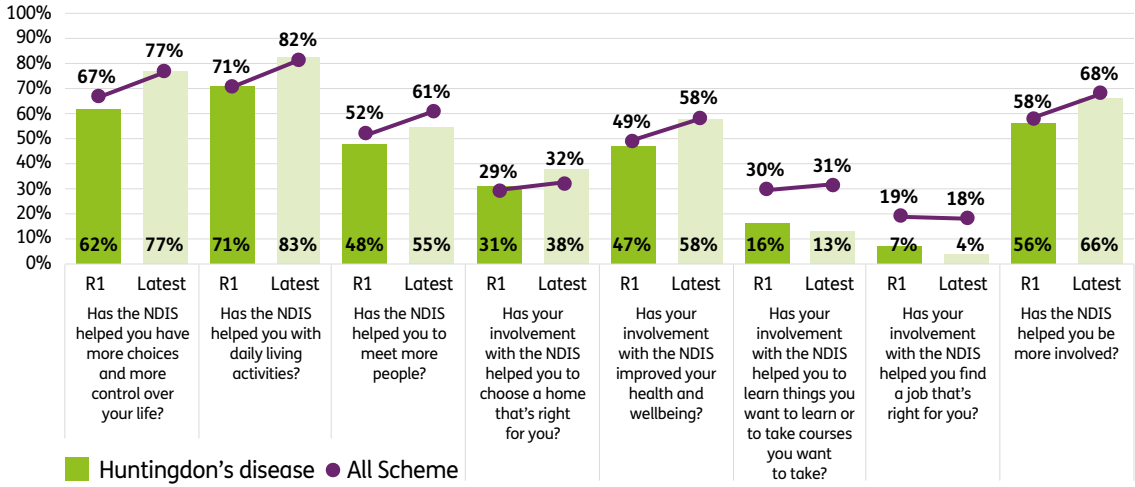
In daily living, health and wellbeing, as well as social and community participation, the percentage of participants with Huntington's disease saying the NDIS helped are within 2% of the Scheme average at both first review and latest review.

Participants with Huntington's disease are 2% and 6% more likely than the Scheme average to say the NDIS helped them choose the right home at first and latest review, respectively.

However, the percentages responding positively are notably lower than the Scheme average, in lifelong learning and employment. This may reflect the low percentage of participants setting goals in these domains (see Participant Goals section).

Proportion of participants with Huntington's disease who had two or more plan reviews and responded 'yes' to the "Has the NDIS helped?" questions

Participants aged 25 and over



Has the NDIS helped participants
Motor neurone disease

Participants with Motor neurone disease are more likely than the Scheme average at both first and latest review in five domains to say the NDIS helped. Less improvement is seen in participants with Motor neurone disease relative to the Scheme overall.

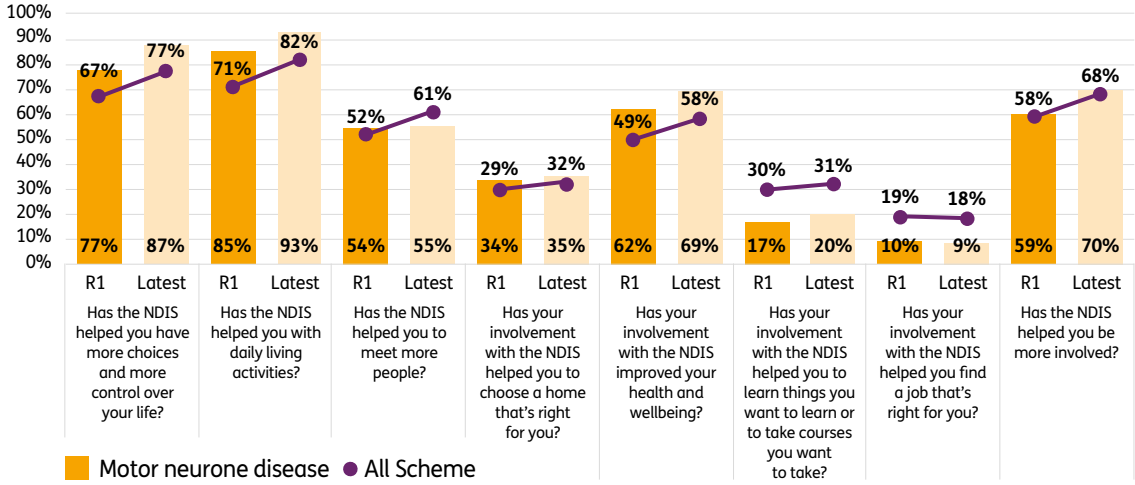
In choice and control as well as daily living, percentages thinking the NDIS has helped for participants with Motor neurone disease exceed the Scheme average by 10% or more.

Nevertheless, similar to Huntington's disease, participants with Motor neurone disease remained remarkably below the Scheme average in the domains of lifelong learning and employment.

Despite being 2% above the Scheme average at first review in terms of meeting more people, participants with Motor neurone disease were 6% below the Scheme average at latest review (55% compared to 61%).

Proportion of participants with Motor neurone disease who had two or more plan reviews and responded 'yes' to the "Has the NDIS helped?" questions

Participants aged 25 and over



Has the NDIS helped participants
Multiple sclerosis

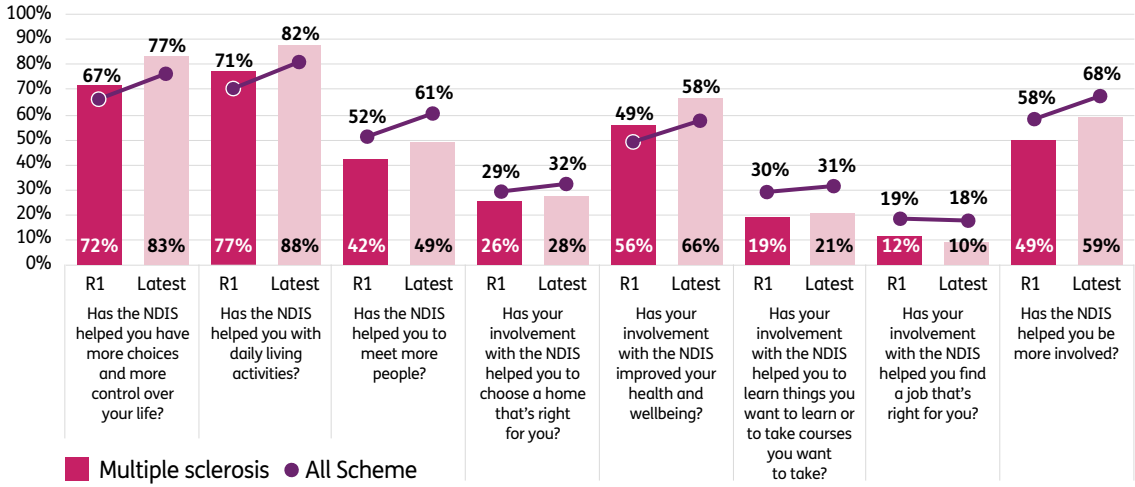
In three out of eight domains, participants with Multiple sclerosis were more likely to say the NDIS helped than the Scheme overall at both first and latest reviews. The opposite is true for the other five domains.

In the domains of choice and control, daily living, and health and wellbeing, participants with Multiple sclerosis consistently remained above the Scheme average by 5% to 8%.

By contrast, in regards to meeting more people and lifelong learning, participants with Multiple sclerosis were at least 10% less likely to think the NDIS has helped than the Scheme as a whole.

Proportion of participants with Multiple sclerosis who had two or more plan reviews and responded 'yes' to the "Has the NDIS helped?" questions

Participants aged 25 and over



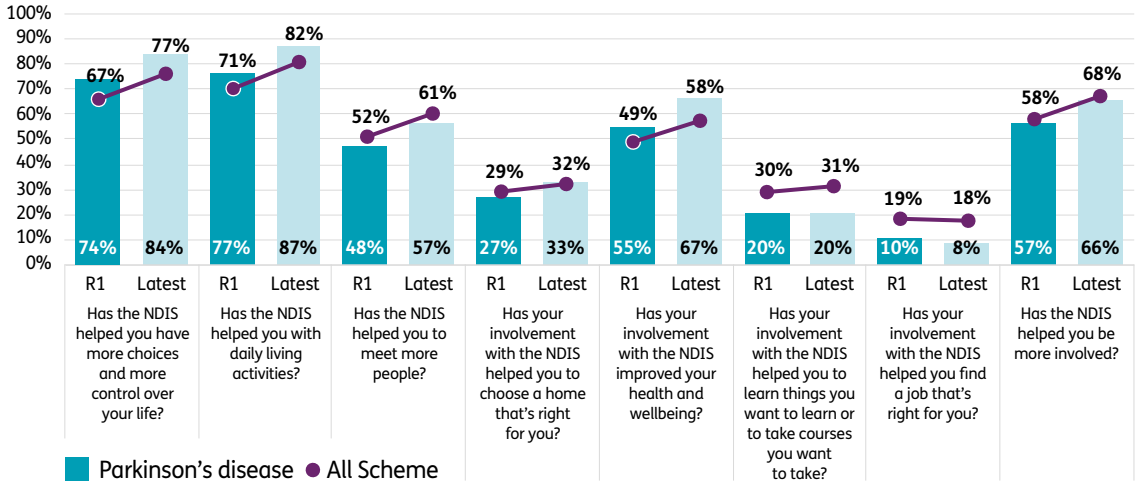
Has the NDIS helped participants
Parkinson's disease

Opinions on whether the NDIS helped among participants with Parkinson's disease follow a similar trend as other neurodegenerative conditions, relative to the Scheme overall. Namely, exceeding the Scheme average in daily living, but falling short in lifelong learning and finding a suitable job.

For participants with Parkinson's disease, changes in the percentage saying the NDIS helped from first to latest review closely track the Scheme average. The exception is health and wellbeing, where participants with Parkinson's disease improved by 12% over time, greater than the 9% improvement for the Scheme as a whole.

Proportion of participants with Parkinson's disease who had two or more plan reviews and responded 'yes' to the "Has the NDIS helped?" questions

Participants aged 25 and over



Has the NDIS helped families/carers

Muscular dystrophy

(Families/carers of participants aged 0 to 14)

Families and carers of participants are asked whether the NDIS has helped them at each plan review across various domains. These charts summarise the responses for participants who have been in the Scheme for at least two years and compare the average satisfaction rates at first review (R1) with those at the latest review.

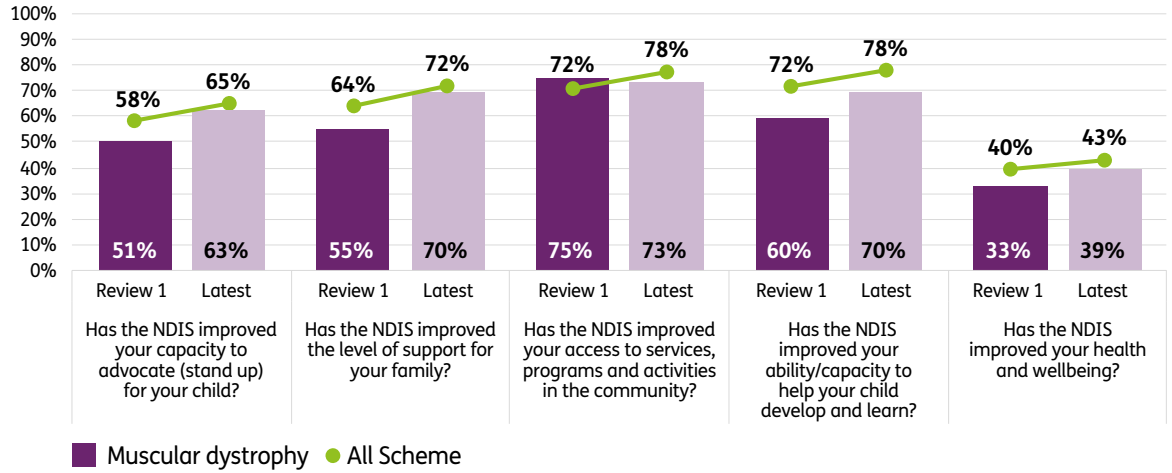
For families and carers of those aged 0 to 14, results have been mostly below the Scheme average at both first and latest review except for access to services at first review.

In all domains except access to services, the percentage of families and carers of participants with Muscular dystrophy responding positively improved at a higher rate than the Scheme as a whole.

For access to services, the proportion of families and carers of participants with Muscular dystrophy saying the NDIS helped deteriorated while the Scheme overall improved.

Proportion of families/carers of participants with Muscular dystrophy who had two or more plan reviews and responded 'yes' to the "Has the NDIS helped?" questions

Families and carers of participants aged 0 to 14



Has the NDIS helped families/carers

Muscular dystrophy

(Families/carers of participants aged 15 and over)

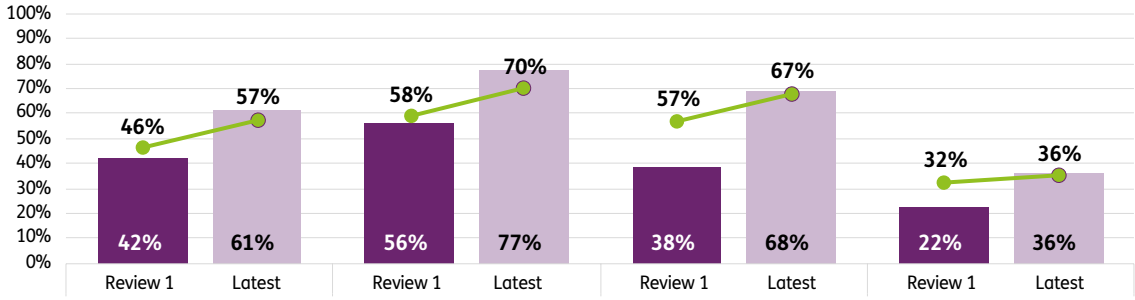
For families and carers of participants with Muscular dystrophy aged 15 and over, the proportion saying the NDIS helped tend to improve to a greater extent than the Scheme as a whole. For the age group 15 to 24, in particular, positive response rates are below the Scheme as a whole but catch up with or even surpass the Scheme average at the latest review.

In the domain of access to services, just 38% of families and carers of participants with Muscular dystrophy aged 15 to 24 said the NDIS helped them in this regard, 19% lower than the Scheme as a whole. However, they improved by 30% over time and exceeded the Scheme average, which improved by 10%.

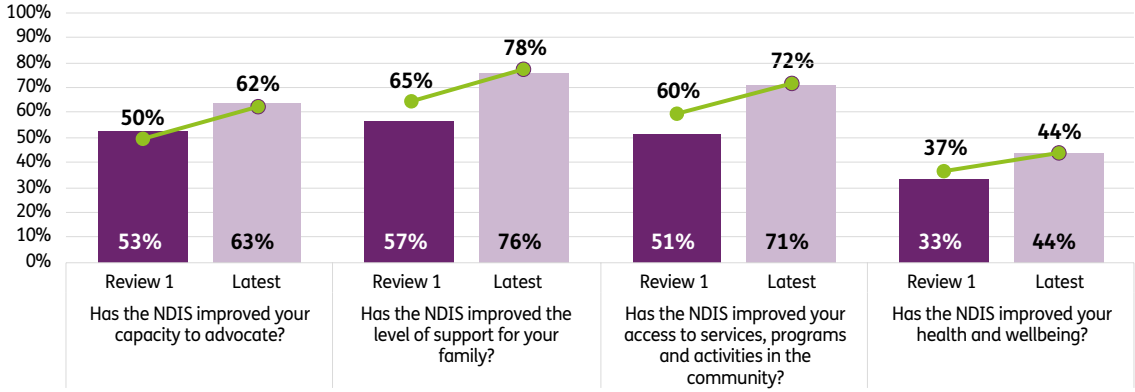
For families and carers of participants aged 25 and over, the greatest improvements are in the domains of level of support for family and access to services, by 19% and 20% respectively.

Proportion of families/carers of participants with Muscular dystrophy who had two or more plan reviews and responded 'yes' to the "Has the NDIS helped?" questions

Families and carers of participants aged 15 to 24



Families and carers of participants aged 25 and over

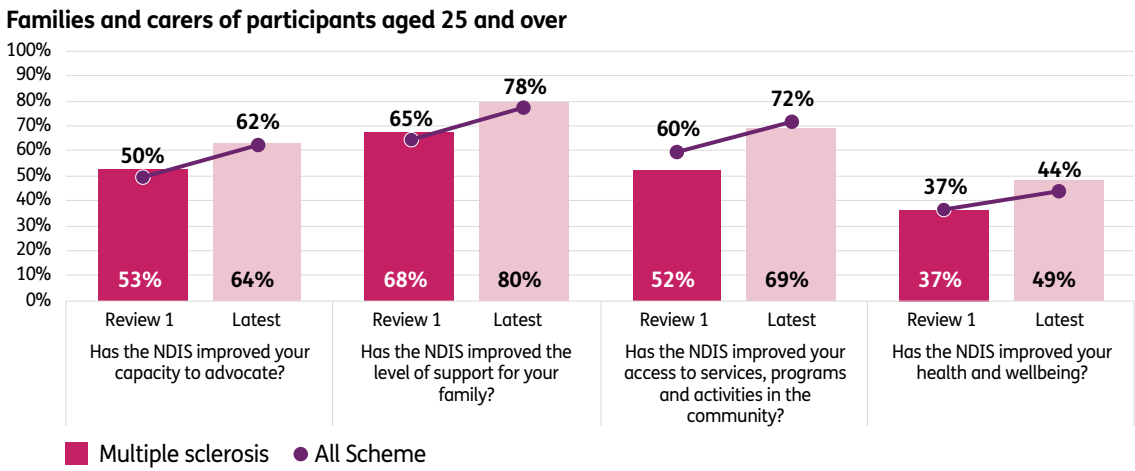


Has the NDIS helped families/carers
Multiple sclerosis

Compared to other neurodegenerative conditions, families and carers of participants with Multiple sclerosis are similar to the Scheme as a whole in the likelihood of saying the NDIS helped, especially for the domains of rights and advocacy, families feeling supported as well as health and wellbeing.

At first review, 52% of Multiple sclerosis families and carers said that the NDIS improved their access to services, programs and activities in the community, 8% lower than the 60% for the Scheme as a whole. However, the difference narrowed to 3% by the latest review (69% for Multiple sclerosis and 72% for the Scheme as a whole).

Proportion of families/carers of participants with Multiple sclerosis who had two or more plan reviews and responded 'yes' to the "Has the NDIS helped?" questions

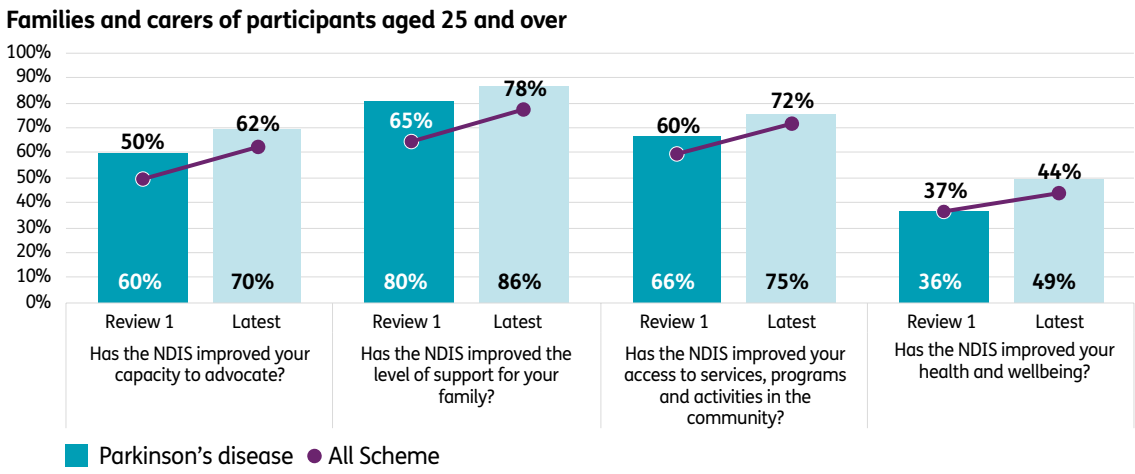


Has the NDIS helped families/carers
Parkinson's disease

The percentage of families and carers for participants with Parkinson's disease saying the NDIS helped are higher than the Scheme as a whole in most cases. They are more likely than the Scheme as a whole to say that the NDIS improved their outcomes in rights and advocacy, level of support for family, as well as access to services.

Improvement is lower in most domains for participants with Parkinson's disease as compared to the Scheme average. However, there was a 13% improvement in saying the NDIS improved their health and wellbeing from first review to latest (36% to 49%), as compared to a 7% improvement for the Scheme as a whole (37% to 44%).

Proportion of families/carers of participants with Parkinson's disease who had two or more plan reviews and responded 'yes' to the "Has the NDIS helped?" questions

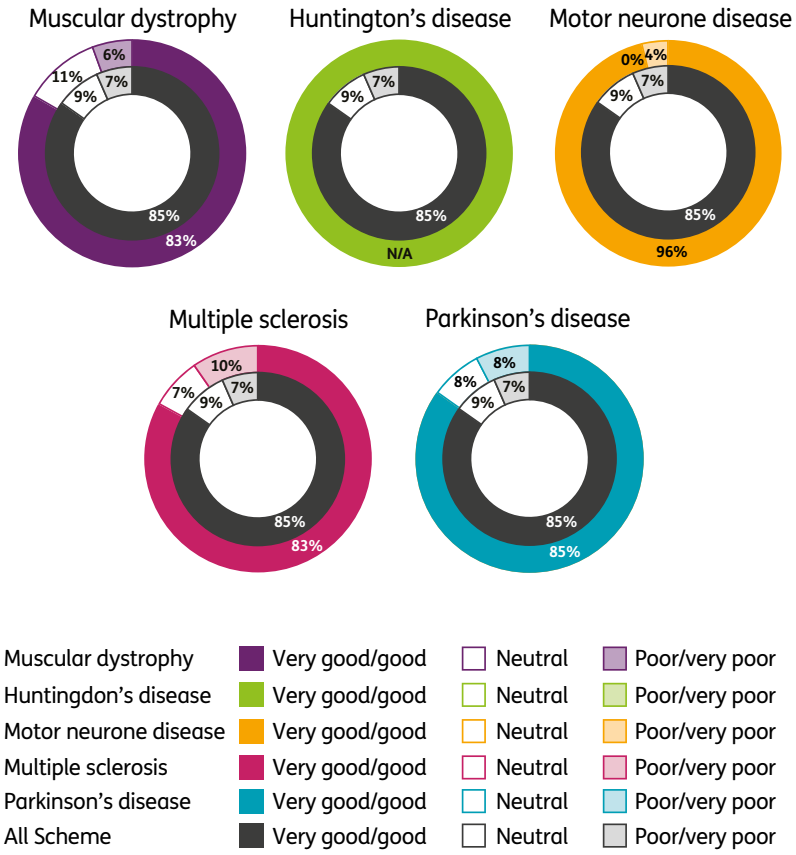


Participant satisfaction
The Planning stage

At the planning stage, 85% of participants in the Scheme as a whole were satisfied with their experience with the NDIA and rated the experience as "Very Good" or "Good". 9% rated their experience as neutral and 7% were dissatisfied with their experience. By comparison, among participants with a degenerative condition:

- The satisfaction rates for participants with Muscular dystrophy, Multiple sclerosis and Parkinson's disease are similar with the average Scheme ratings
- Those with Motor neurone disease are more likely to be satisfied than the Scheme average.
- The number of responses for Huntington's disease are too small to be reported.

Rating of experience with the NDIA in Q2-Q3 2020-21 at the Planning stage



A new participant satisfaction survey was implemented from September 2018 to better record the experience of NDIS participants and their families and carers at different stages of the participant pathway.The survey gathers responses at four primary stages of the participant pathway: Access, Pre-planning, Planning and Plan Review.

Since October 2020, the survey has been administered by an independent third party. This has resulted in a 'break' in the time series, meaning the previous quarterly results do not compare well with those for prior quarters.

Hence, participant satisfaction results are shown for the December 2020 and March 2021 quarters only.

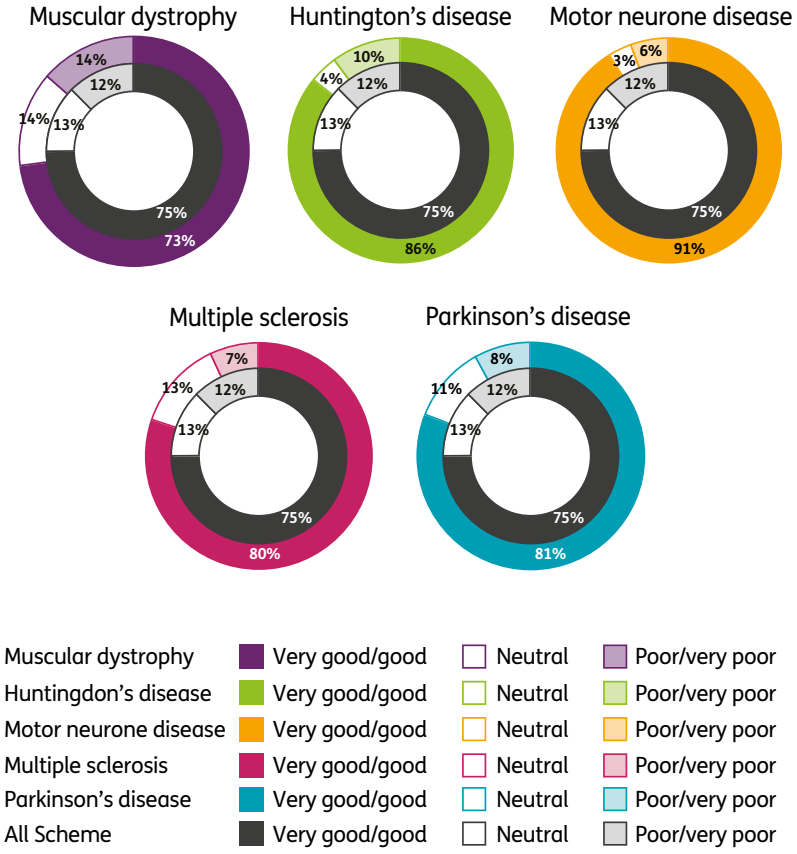
At the Access and Pre-planning stages, there is insufficient data for these disability types to show results separately. Results are only shown for the Planning and Plan Review pathway stages.

The Review stage

At the Plan Review stage, 75% of Scheme participants are satisfied with their experience with the NDIA, 13% felt neutral and 12% were dissatisfied. By comparison:

- Participants with Muscular dystrophy have similar satisfaction rates compared to the Scheme overall, albeit slightly less likely to be satisfied.
- Participants with Huntington's disease, Motor neurone disease, Multiple sclerosis or Parkinson's disease are more likely than the Scheme average to say their experience was "Very Good" or "Good". Participants with Huntington's disease or Motor neurone disease, in particular, rated the review process at least 10% higher than the Scheme as a whole.

Rating of experience with the NDIA in Q2-Q3 2020-21 at the Review stage



Exclusions

Due to insufficient data, the following participant groups were excluded from the report:

- In the **baseline outcomes** section:
  - Participants with Huntington's disease, Motor neurone disease and Parkinson's disease aged 0 to 24;
  - Participants with Multiple sclerosis aged 0 to 14;
  - Families and carers of participants with Huntington's disease, Motor neurone disease and Parkinson's disease aged 0 to 24;
  - Families and carers of participants with Multiple sclerosis aged 0 to 14.

- In the **longitudinal outcomes** section:
  - Participants with Muscular dystrophy aged 0 to 14;
  - Participants with Huntington's disease, Motor neurone disease, Multiple sclerosis and Parkinson's disease aged 0 to 24;
  - Families and carers of participants with Muscular dystrophy aged 0 to 14;
  - Families and carers of participants with Huntington's disease, Motor neurone disease, Multiple sclerosis and Parkinson's disease aged 0 to 24.

- In the **"Has the NDIS Helped?"** section:
  - Participants with Muscular dystrophy from birth to starting school;
  - Participants with Huntington's disease, Motor neurone disease, Multiple sclerosis and Parkinson's disease aged 0 to 24;
  - Families and carers of participants with Multiple sclerosis and Parkinson's disease aged 0 to 24;
  - Families and carers of participants with Huntington's disease and Motor neurone disease, all age groups.

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