Muscular Dystrophy Support Centre

Service User Survey 2025

Survey Report

Prepared by

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Executive Summary

Context

An annual survey of the service users of the Muscular Dystrophy Support Centre (the Charity) has been made since 2016 to gauge service user satisfaction with the facilities, and therapeutic interventions, that are available through the Charity's therapy clinics across the Midlands.

In 2025 we added questions regarding respondents' biographical status (age, gender, employment status and mobility level) to improve the depth of the analysis. Detailed results from this analysis are shown in Part 2.

At the time the survey launched in July 2025 there were 633 registered users from whom 139 responses had been received by the end of September. This represents approximately 22% of the registered user population; slightly up on the 2024 response rate of 21%.

Principal findings

Three things have come to light from the analysis of this years' service user survey. Firstly, satisfaction levels among the respondents remains high, continuing the trend reported on in previous annual surveys. Secondly, the ability to ambulate independently is a factor of some importance in determining the perceived effect that a therapy has on its recipient. And, thirdly, there is evidence to suggest that osteopathy, in conjunction with physiotherapy, enhances the apparent effect of the physiotherapy (see Appendix 3 for detailed discussion).

A brief resumé of the main findings now follows -

- 77% of respondents agreed that the treatments they have received from the Charity have reduced their reliance on the use of NHS services.
- 93% of respondents stated that the professionals who played a primary role in managing their condition were the therapists at the Charity (up from 88% in the 2024 survey).
- 94% of respondents agreed that participating in the Charity's activities and therapies has made them feel more confident and in control.
- 65% of respondents agreed that the Charity's activities and therapies have helped them stay in work.

- 80% of respondents agreed that thanks to the Charity's activities and therapies their condition had improved to some extent.
- 79% of respondents asserted that the Charity's services had worked to prevent or slow deterioration in their general condition.

Part 1 - Introduction and Methods

An annual survey of the service users of the Muscular Dystrophy Support Centre (the Charity) is made to gauge service user satisfaction with the facilities, and therapeutic interventions, that are available through the Charity's therapy clinics across the Midlands.

Results from the survey are shared with service users, staff and donors. Staff discuss each year's results and the comments made by service users with a view to improving service delivery in the coming period.

The survey was launched on the 1st of August 2025 and was terminated on the 30th of September 2025. As of July 2025, there were 633 service users registered with the Charity. Our aim was to engage as many of them as possible in the 2025 survey and, if possible, to improve on the 2024 response rate. In 2024 the survey achieved a 21% response rate from the 586 people registered as service users in August 2024.

A publicity campaign accompanied the launch. Initial notification of the questionnaire was via e-mail and was transmitted to 633 addresses in the Charity's database. On the 2nd of August a text notification was sent to 452 recipients. At the same time posters and leaflets were displayed in the Coventry clinic from the 2nd of August. Satellite clinics received the poster material on the 5th of August. The survey was also highlighted in the newsletter released on the 22nd of August, which was sent to 662 recipients.

By the 30th of September the number of returned surveys totalled 139 (which represents a response rate of approximately 22%, an improvement on the response rate for 2024) although not all of these 139 respondents had completed every question. For each individual question in the survey the number of responses available for analysis varies from 112 to 139[1], with a small drop-off in the number of respondents per question as one moves through the survey.

For the 2025 survey additional questions regarding respondents' biographical status (age, gender, employment status and mobility level) were introduced. The purpose in adding these questions was to improve the range of analytical options available and therefore the depth of the analysis.

In the report is an analysis of respondents' biographical as well as attendance data, e.g., the location where the service user receives therapies. In some places this is compared to

[1] The exception is Section 2 which dealt with the online sessions and where the total number of respondents is 34.

biographical and attendance data from the whole service user population (i.e., the 633 registered service users). This latter data is drawn from the Charity's 'PracticePal' database, which it uses to manage its appointments and bookings. This data is included to provide a contextual backdrop for the data provided by the respondents. The information supplied by the survey respondents is anonymised and cannot be linked to the Charity's records.

The 2025 User Survey introduced a question examining respondents' mobility level: question three in the initial, biography, section of the survey. The question comprised five categories ranging from the ability to walk without the use of mobility aids to being a full-time wheelchair user who lacked the ability to independently transfer from the chair.

The first three categories of this question described levels of independent ambulation with the remaining two covering wheelchair usage. Respondents were able to select one of these options (the question being of the "radio button" format) as being the best description of their abilities.

The decision was taken to break the survey results down by mobility to explore in more detail how respondents with different mobility levels experienced the impact of the four principal therapies that the Charity offers.

Most (71%) of respondents (99 out of a total of 139) fell into one of the three ambulant categories with the remaining forty (29%) split equally between wheelchair users able to transfer independently and those unable to transfer independently.

Due to the small sample sizes across the five categories, the respondents have been split into two groups based on their mobility level – respondents who are wheelchair users and respondents who are not wheelchair users.

The questionnaire was laid out using the QuestionPro[1] survey development package with the answers being stored in their database. Questionnaires were completed without the use of personal identifiers (apart from the biographical variables mentioned above). Question formats were standardised where possible to single choice "radio button" variables (acting as Likert-scaled ordinal variables).

The sections into which the questionnaire was split were as follows:

〉 An opening section that contained the four biographical questions.

〉 Section 1- featuring questions centred around the effect different face to face therapeutic interventions had on aspects of mobility or function such as, for example, joint flexibility or core stability.

- Section 2 - asking for respondents' views regarding the various online therapies available; and,
- Section 3- seeking respondents' general views on the overall impact of the Charity's therapeutic regimes.
- An open text question where respondents could provide comments giving additional detail if they wished (user comments).

For the purposes of the analysis a data dump was taken from the QuestionPro site in the form of an Excel spreadsheet.

In presenting the results, a descriptive mode of analysis has been adopted with results presented in the form of bar graphs and in tabular form. A detailed breakdown of the survey quantitative results (i.e. graphs and tables) can be found in Appendix 1.

Please note that throughout this Report all percentages quoted are figures rounded to whole numbers. For this reason there will be occasions where total percentages do not sum to exactly 100%.

To facilitate the analysis of the qualitative data - i.e., service user comments- in a timely manner, the assistance of the ChatGPT artificial intelligence program was sought. More detail on this process and the resulting output together with service user comments is given in Appendix 2.

Part 2 – Discussion and Key Results

The analysis of the 2025 survey data has been conducted using respondent mobility as the primary unit of analysis. Analysing the responses in this way was not possible in previous years' surveys as this is the first year that such data has been available.

When the results are viewed this way it is apparent that while, overall, both groups are satisfied with the impact of the Charity's work, there are instances where their experiences and assessment of therapeutic impact differ.

To illustrate this disparity of opinion, see figure 1, which show results from questions two to ten of section one of the questionnaire. These questions are focussed on different aspects of physiological function such as joint flexibility, muscle strength, posture, pain control, etc.

The table shows the number of times that either the "strongly agree", "agree" or "neutral" category appeared as the modal[2] category, per therapeutic intervention and then grouped by level of mobility. There were no instances where any other category appeared as the mode, i.e. the categories "disagree" and "strongly disagree" never appeared as the mode for any question. Pictorially, when viewed on the bar graphs, the modal category can be easily identified as the category with the tallest bar. By focusing on the mode, a sense can be gained of the extent to which respondents favour a therapy with respect to a particular outcome.

FIGURE 1 - MODAL CATEGORY COUNT

For section 1 questions 2 to 10, count of number of times the "strongly agree", "agree" or "neutral" categories were the modal categories, by therapy and mobility level.

		Strongly agree	Agree	Neutral
NON-WHEELCHAIR USERS	Physiotherapy	2	7	0
	Osteopathy	9	0	0
	Complementary therapies	8	1	0
	Use of adapted exercise equipment	1	5	3
WHEELCHAIR USERS	Physiotherapy	4	5	2
	Osteopathy	2	3	4
	Complementary therapies	1	4	6
	Use of adapted exercise equipment	4	4	4

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[2] The mode is the most frequently occurring value in a set of data. It represents a form of average used in instances where an arithmetic mean would be either inappropriate or impossible to calculate, such as for a Likert scaled variable. For these variables the category with the largest tally of responses would be considered the modal category. It is possible for more than one mode to exist.

There are nine questions in Section 1. Reading across the table it can be seen that for non-wheelchair users the tally of "strongly agree", "agree", and "neutral" modes adds up to nine across each therapy. This is not the case for wheelchair users. Here the tally equals nine only in the case of osteopathy. With the other three therapies the total ranges from eleven to sixteen. A tally which exceeds nine occurs when there is a multi-modal response, i.e. two or more agreement assessments are equally popular.

Where this happens, it suggests that opinions regarding the impact of a therapy are not uniformly shared. Non-wheelchair users have clear opinions regarding the impact of the therapies they receive; all their answers are uni-modal and the row total adds up to nine. Wheelchair users, by contrast, exhibit greater heterogeneity in their assessments with answers that are frequently multi-modal leading to row totals that exceed nine.

There are two additional points to be borne in mind when reading this table. The first is that the number of wheelchair users who responded is relatively low, being a total of 40 cases. When this number is divided up among the four therapies the number of responses per therapy reduces at times to single figures. The second point concerns the extent to which these 139 respondents represent the wider population of the Charity's service users.

This point regarding the representativeness of the dataset needs further elaboration. The data upon which these findings are based are provided by respondents drawn from the Charity's registered user population. Entry to the survey is open to any user of the Charity's services with no attempt made to select entrants.

The issue here is that no user in this population is *obliged* to respond; all the responses are entirely voluntary. And it is the case that the majority of service users choose not to respond. Thus, there is a relatively large number of the Charity's service users about whose opinions no information is available. Given that the survey respondents are self-selected it is difficult to know how representative they may (or may not) be of the wider service user population. It is possible that the views the survey respondents express are outliers in the user population as a whole and do not reflect the true picture. But, that issue aside, the opinions expressed in the survey obviously represent a current of thinking that needs to be reported and acknowledged.

Returning to the table, while osteopathy scores well among non-wheelchair users (occurring as the mode nine times) it does less well among wheelchair users. Conversely, complementary therapies have a very good rating from non-wheelchair users and a much-reduced rating from the wheelchair users. From this reading of the modal categories, it would appear that non-

wheelchair users are perhaps more inclined to value the manipulative therapies, as delivered through physiotherapy and osteopathy.

This is less the case with the wheelchair users although they do see positive value in the use of the exercise equipment. Wheelchair users also express much greater levels of ambivalence generally (as evidenced by the frequency of the mode as the "neutral" category) across all the therapies. By contrast, it is only with respect to adapted exercise that non-wheelchair users show any degree of ambivalence. Thus, there are clearly wide variations in the perceived impact of these therapies when analysed by ambulatory ability.

A separate matter relating to therapy and its perceived impact can also be touched on here. Further analysis of the data suggests that, for some respondents, being in receipt of osteopathic treatment, leads to a more positive view being taken of physiotherapy treatment. It is not, though, a universal effect. Non-wheelchair users exhibit report higher levels of satisfaction when they receive both osteopathy and physiotherapy whereas wheelchair users do not. This is an issue that is given additional discussion in Appendix 3.

It is not possible to comment on the extent to which function, measured objectively, parallels the subjective impression expressed by respondents in these answers. A respondent may feel that a therapy (or a combination of therapies) assists in maintaining function without this necessarily being demonstrable in any objectively assessable manner. What does matter is that the respondent holds to the opinion that function has been maintained, or that the deterioration has been retarded.

It is therefore important to identify what kind of therapeutic input (or inputs) is seen as being of most benefit by the recipient. The information derived from this level of analysis might eventually be used to further refine and better target the therapies that are offered to both wheelchair users and non-wheelchair users.

In conclusion, there are two major points have become apparent from this year's user survey. Firstly, it would appear that the ability to ambulate independently is a factor of some importance in determining the perceived effect that a therapy has on its recipient. And, secondly, there is also some evidence to suggest that osteopathy, in conjunction with physiotherapy, enhances the apparent effect of the physiotherapy.

Having indicated that these effects appear to exist a note of caution must be sounded. Sub-group analysis, on a sample of this size, can produce sub-groups where the numbers in a sub-group drop into single figures. Random variations in individual responses to a particular

therapy, or even therapist, become magnified and can thus distort the impression given for that therapy. In addition, as discussed earlier, the respondents are a self-selected group which renders generalising these findings problematic.

So, while it would appear to be the case that mobility levels, and the presence or otherwise of any osteopathic input, might affect therapeutic impact it cannot automatically be assumed to be so. Further investigation (i.e. more research of some kind) would be necessary to determine whether these effects are real or simply artefacts caused by small group sizes and self-selection.

That said, the overall results show that the Charity service users continue to greatly value and appreciate the therapeutic and other services that the Charity provides and remain very satisfied with these services.

Key results

- 78% of non-wheelchair respondents and 75% of wheelchair respondents (all respondents combined, 77%) agreed that the treatments they have received from the Charity have reduced their reliance on the use of NHS services.
- 94% of non-wheelchair respondents and 90% of wheelchair respondents (all respondents combined, 93%) stated that the professionals who played a primary role in managing their condition were the therapists at the Charity. In the 2024 survey the corresponding figure was 88%.
- 96% of non-wheelchair users and 87% of wheelchair respondents (all respondents combined, 94%) agreed that participating in the Charity's activities and therapies has made them feel more confident and in control.
- 63% of non-wheelchair respondents and 70% of wheelchair respondents (all respondents combined, 65%) agreed that the Charity's activities and therapies have helped them stay in work.
- 83% of non-wheelchair respondents and 71% of wheelchair respondents (all respondents combined, 80%) agreed that thanks to the Charity's activities and therapies their condition had improved to some extent.

〉 80% of non-wheelchair respondents and 77% of wheelchair respondents (all respondents combined, 79%) asserted that the Charity's services had worked to prevent or slow deterioration in their general condition.

A more detailed breakdown of the main findings follows below.

Face to face therapies

These results concern those therapies that are delivered in person and evaluated by their efficacy in managing or improving the symptoms experienced by service users.

〉 **Pain control:** When considering individual therapies 67% of non-wheelchair users strongly agreed or agreed that physiotherapy had improved their pain control; 77% favoured osteopathy; 70% complementary therapies; and 55% adapted exercise equipment. For wheelchair users the figures are - physiotherapy 79%; 88% Osteopathy; 100% complementary therapies[3], and 55% adapted exercise equipment.

〉 **Joint flexibility:** 96% of non-wheelchair users strongly agreed or agreed that physiotherapy had improved the flexibility of their joints, 83% favoured osteopathy, 81% complementary therapies and 84% adapted exercise equipment. For wheelchair users the figures are - physiotherapy 89%, osteopathy 74%, complementary therapies 66%, and adapted exercise equipment 88%.

〉 **Muscle strength:** 82% of non-wheelchair users strongly agreed or agreed that physiotherapy had improved their muscle strength, 77% favoured osteopathy, 67% complementary therapies and 80% adapted exercise equipment. For wheelchair users the figures are - physiotherapy 58%, osteopathy 50%, complementary therapies 29%, and adapted exercise equipment 70%.

〉 **Risk of falling over**: 71% of non-wheelchair users strongly agreed or agreed that physiotherapy had reduced their risk of falling over, 79% favoured osteopathy, 64% complementary therapies and 65% adapted exercise equipment. For wheelchair users the figures are - physiotherapy 55%, osteopathy 14%, complementary therapies 20% and adapted exercise equipment 41%.

[3] In some instances the number of respondents is very small. For this question only three respondents had provided answers.

- **Core stability**: 87% of non-wheelchair users strongly agreed or agreed that physiotherapy had improved their core stability, 82% favoured osteopathy, 69% complementary therapies and 77% adapted exercise equipment. For wheelchair users the figures are - physiotherapy 77%, osteopathy 64%, complementary therapies 57% and adapted exercise equipment 81%.
- **Balance:** 80% of non-wheelchair users strongly agreed or agreed that physiotherapy had improved their balance, 80% favoured osteopathy, 73% complementary therapies and 72% adapted exercise equipment. For wheelchair users the figures are - physiotherapy 56%, osteopathy 20%, complementary therapies 25% and adapted exercise equipment 77%.
- **Posture:** 83% of non-wheelchair users strongly agreed or agreed that physiotherapy had improved their posture, 81% favoured osteopathy, 71% complementary therapies and 66% adapted exercise equipment. For wheelchair users the figures are - physiotherapy 77%, osteopathy 69%, complementary therapies 33% and adapted exercise equipment 30%.
- **Mobility:** 87% of non-wheelchair users strongly agreed or agreed that physiotherapy had improved their mobility, 72% favoured osteopathy, 64% complementary therapies and 55% adapted exercise equipment. For wheelchair users the figures are - physiotherapy 57%, osteopathy 50%, complementary therapies 25% and adapted exercise equipment 72%.
- **Ability to do things around the house:** 90% of non-wheelchair users strongly agreed or agreed that physiotherapy had maintained their ability do things around the house, 78% favoured osteopathy, 64% complementary therapies and 63% adapted exercise equipment. For wheelchair users the figures are - physiotherapy 56%, osteopathy 60%, complementary therapies 25% and adapted exercise equipment 54%.

Online exercise

These questions are only concerned with the therapies delivered remotely. When viewing these results, it should be noted that there were only 34 responses received in this section – 24 from non-wheelchair users and 10 from wheelchair users.

- **Core stability:** 87% of non-wheelchair users strongly agreed or agreed that engaging in the online classes had improved their core stability. For wheelchair users the figure is 80%.
- **Muscle strength:** 71% of non-wheelchair users strongly agreed or agreed that engaging in the online classes had improved their muscle strength. For wheelchair users the figure is 80%.

- **Posture:** 59% of non-wheelchair users strongly agreed or agreed that engaging in the online classes had improved their posture. For wheelchair users the figure is 90%.
- **Balance:** 67% of non-wheelchair users strongly agreed or agreed that engaging in the online classes had improved their balance. For wheelchair users the figure is 60%.
- **Mobility:** 71% of non-wheelchair users strongly agreed or agreed that engaging in the online classes had improved their mobility. For wheelchair users the figure is 60%.
- **Pain control:** 54% of non-wheelchair users strongly agreed or agreed that engaging in the online classes had improved their pain control. For wheelchair users the figure is 40%.
- **Emotional wellbeing:** 83% of non-wheelchair users strongly agreed or agreed that engaging in the online classes had improved their emotional well-being. For wheelchair users the figure is 100%.

Wider support

- 62% of non-wheelchair respondents and 81% of wheelchair users agreed that, overall, the Charity's activities and therapies had helped them to **connect with others.**
- 65% of non-wheelchair respondents and 75% of wheelchair users agreed that, overall, the Charity's activities and therapies had given them **a community to feel part of.**
- 65% of non-wheelchair respondents and 75% of wheelchair users agreed that, overall, the Charity's activities and therapies had **helped family and/or carers to feel supported.**
- 88% of non-wheelchair respondents and 85% of wheelchair users agreed that, overall, the Charity's activities and therapies had helped them to **accept and live well with their condition.**

Biographical results

The below analysis includes a comparison of respondents' ages to those of the wider user population using data taken from the Charity's database. Results from the Charity's database as to where users live and which of the Charity's clinics they attend are also included.

Of those who responded:

- **Mobility**: most (71% - 99 out of 139 respondents) fell into one of the three ambulant categories with the remaining forty split equally between the remaining two categories- wheelchair users able to transfer independently and those unable to do so.
- **Gender**: 75 (54%) of the respondents were female, 60 (43%) were male and four (3%) declined to reveal their gender.
- **Employment:** 30 (22%) reported that they are working, 38 (27%) are retired owing to age, 28 (20%) are retired owing to health issues, 23 (17%) are not working owing to health issues, seven (5%) are not working owing to lack of job opportunities, three (2%) are students and ten (7%) declined to comment on their employment status.
- **Age:** the average age for all users as per the Charity's database is 51 years; ranging from 18 years to 93 years. By comparison, the survey respondents are an older cohort than the total population of service users; the mean age for all survey respondents is 58 years.

The below data is taken from the Charity's database, with the results compared against the total number of users (633 registered users in July 2025)

COUNTY OF RESIDENCE

Service users' county of residence

County	Number
West Midlands	284
Leicestershire	83
Warwickshire	75
Worcestershire	53
Staffordshire	29
Northamptonshire	20
Nottinghamshire	20
Others	69

Total = 633

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- **Geography:** most registered users reside in the Midlands (i.e. West Midlands, Warwickshire, Leicestershire, Nottinghamshire, Northamptonshire, Staffordshire). However, there are registered users located as far afield as north Wales, Sussex, the Channel Islands and the north-East of England.

Clinic attendance: Most users access services at the main centre in Coventry and attend the two Birmingham satellites (Movewell and Bournville)

THERAPY CENTRE ATTENDED

User attendances, by location, for the period 1st August 2024 to 31st July 2025.

Coventry	Droitwich	Birmingham Movewell	Bournville	LOROS EM	Murray Hall BC	Daventry
319	9	68	74	33	44	18

Some service users attend more than one centre.

Created with Datawrapper

However, it should be noted that users often attend more than one site for their treatment: 266 users (42%) accessed therapy at a single site; 105 users (17%) accessed two sites; 23 users (4%) attended three sites, and five users (1%) accessed four sites.

Attendance frequency: most users attend at least once per month with a smaller number attending more frequently.

THERAPY CENTRE ATTENDED, FREQUENCY

Users attending more frequently than once per month, by location, for the period 1st August 2024 to 31st July 2025.

Coventry	Droitwich	Birmingham Movewell	Bournville	LOROS EM	Murray Hall BC	Daventry
93	2	0	5	1	12	4

Some service users attend more than one centre.

Created with Datawrapper

The table shows the number of users attending the different centres more than once per month with the largest group being 15% at Coventry.

〉 **Mobility:** 28 (20%) were able to walk without the assistance of mobility aids, 33 (24%) walked with the assistance of mobility aids, 38 (27%) walked with mobility aids and the use of a scooter or wheelchair, 20 (14%) were wheelchair users able to transfer independently from the wheelchair and 20 (14%) were wheelchair users who were unable to transfer independently from the chair.

Appendix 1 – Detailed results

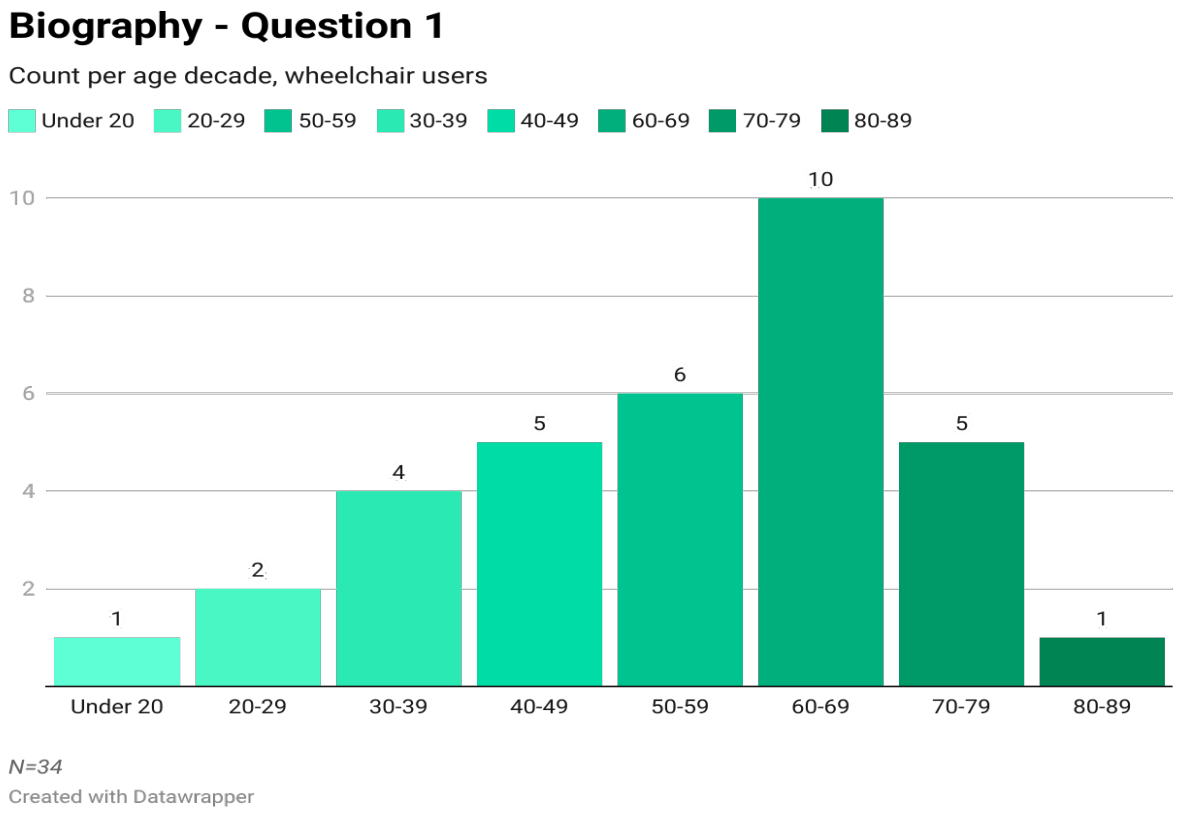
In this appendix will be found graphs and tables giving a full numerical breakdown of the respondents' answers. The data are presented separately for wheelchair users and non-wheelchair users. When interpreting these results and considering any inferences that might be drawn from them, care needs to be exercised. As discussed earlier, the survey respondents form a self-selecting group who may, or may not, reflect the views, experiences and opinions of those who have chosen not to respond.

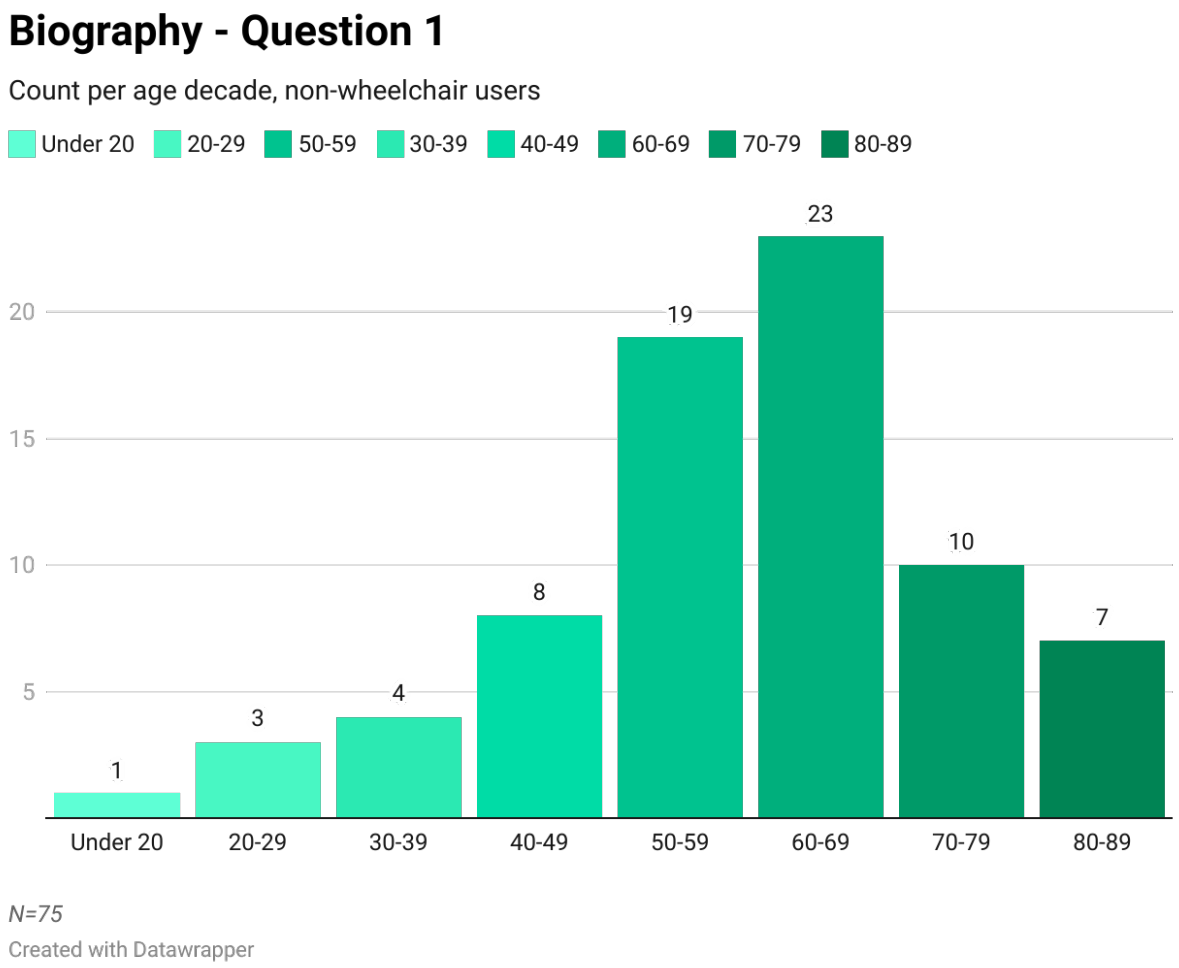
Appendix 1a – Survey respondents' biographical characteristics

The opening part of the survey contained four questions eliciting information on the respondents' age, gender, ambulatory ability and employment status.

The initial question in this section concerned the respondents' age. Each respondent was requested to supply their year of birth from which the current age could be computed. For ease of comparison the ages have been grouped by age decade and displayed using a bar graph format. The modal age band (60-69) is the same for both groups.

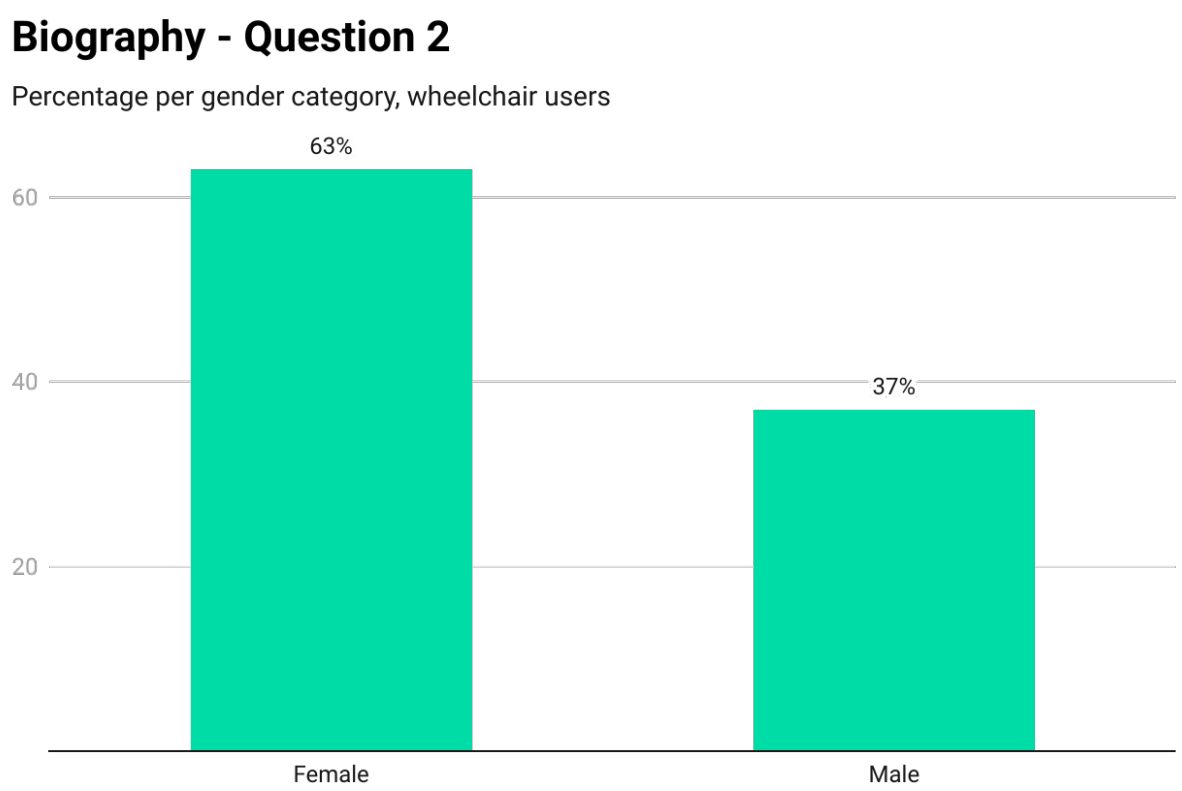
The arithmetic mean age for the wheelchair users is 54 years with a median age of 57.5 years.



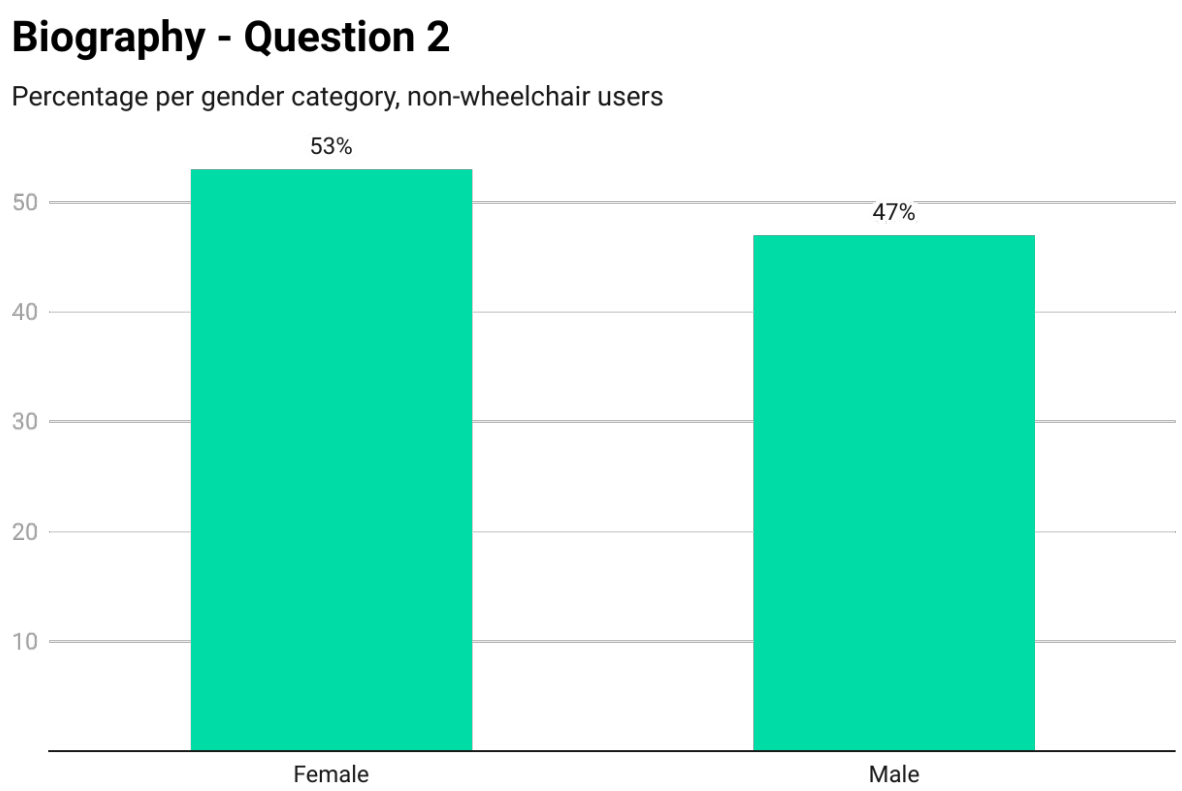


The arithmetic mean age for the non-wheelchair group is 59 years with a median age of 60 years.

The second biographical question concerned the gender breakdown of the respondents. In addition to “female” and “male” choices, an additional option, “would rather not say”, was also included.



There were 40 respondents in the wheelchair user group with two respondents declining to give their gender.

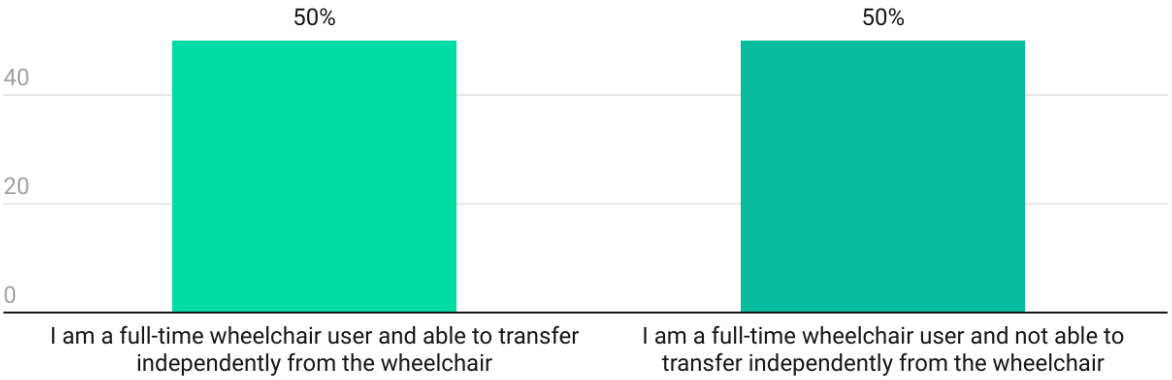


There were 99 respondents in the non-wheelchair user group with two respondents declining to give their gender.

Biography Question 3 - Mobility

I am a full-time wheelchair user and able to transfer independently from the wheelchair I am a full-time wheelchair user and not able to transfer independently from the wheelchair

WHEELCHAIR USER



N=40

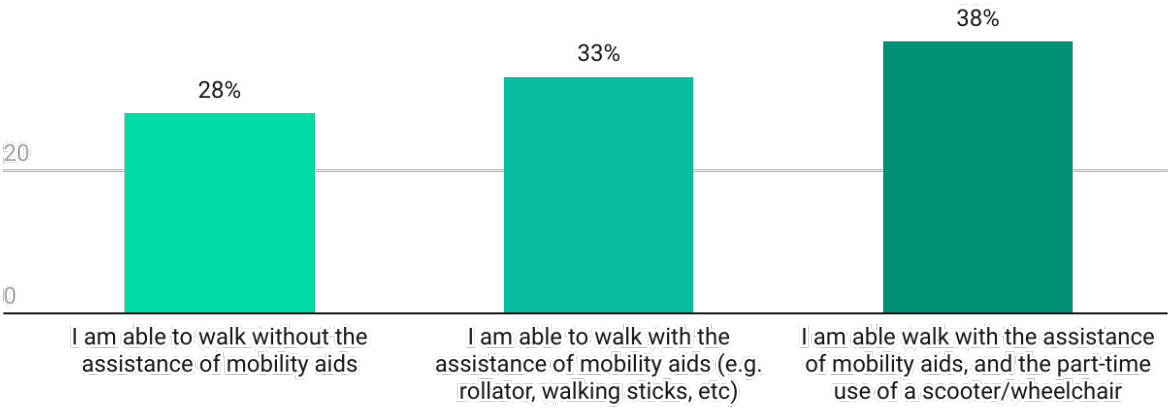
Created with Datawrapper

The 40 wheelchair users were split equally between the two groups.

Biography Question 3 - Mobility

I am able to walk without the assistance of mobility aids I am able to walk with the assistance of mobility aids (e.g. rollator, walking sticks, etc) I am able walk with the assistance of mobility aids, and the part-time use of a scooter/wheelchair

NON-WHEELCHAIR USER



N=99

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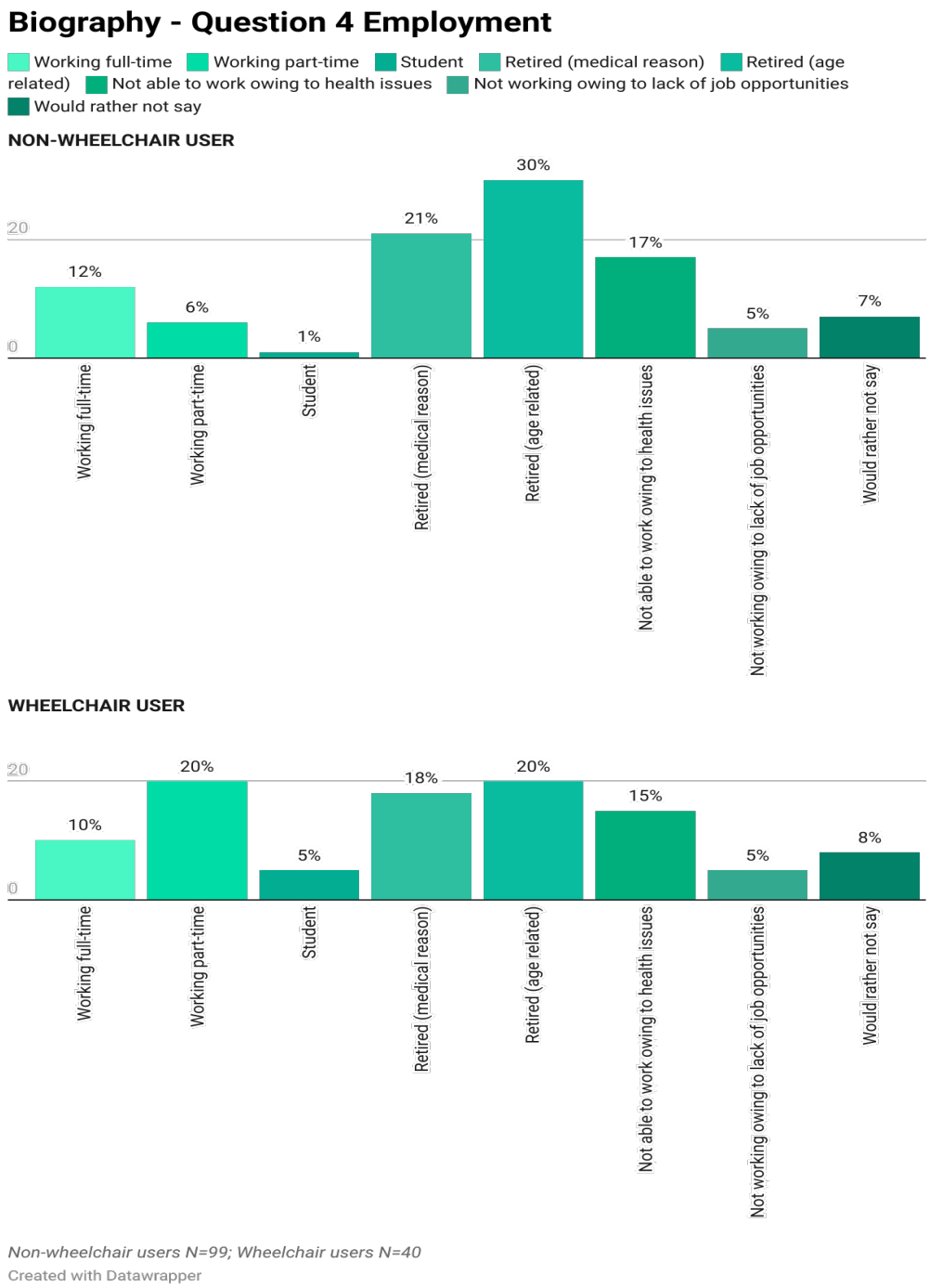
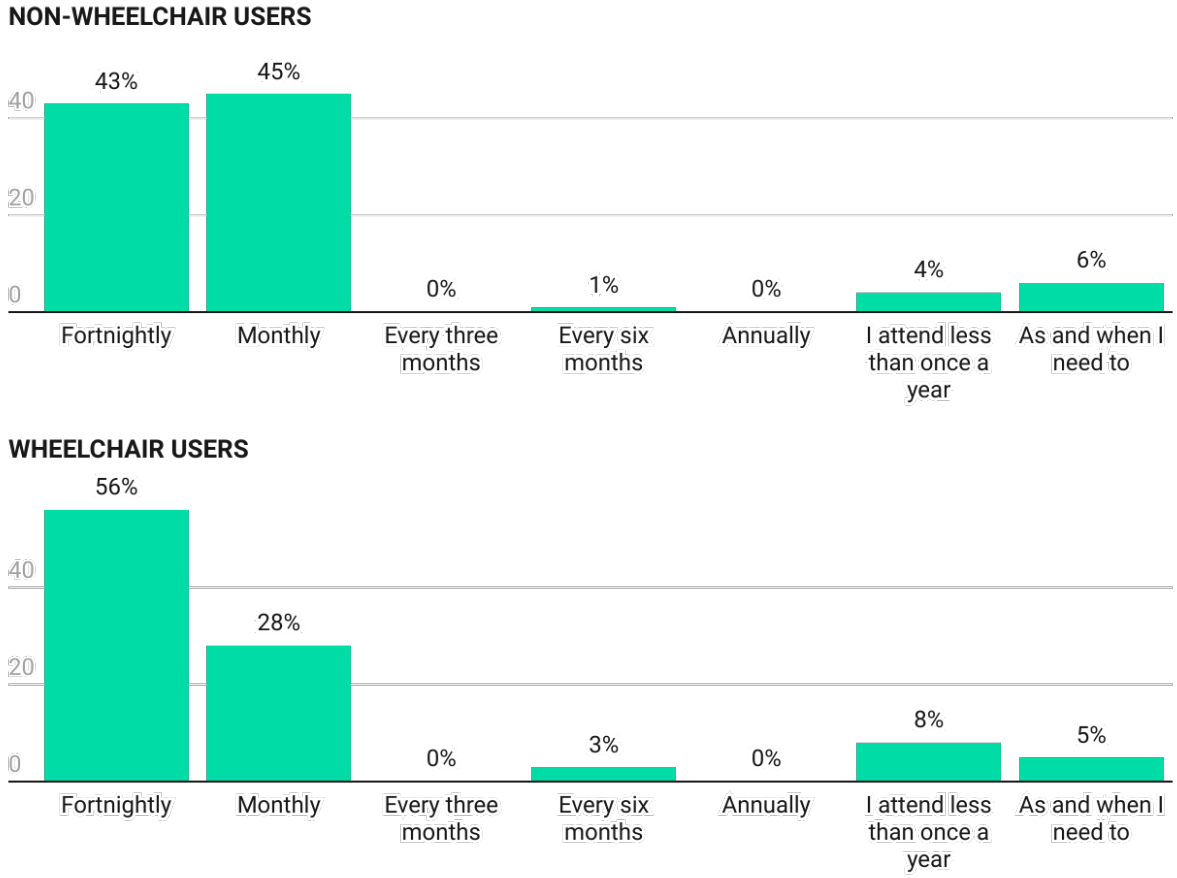
The modal category for the non-wheelchair group is the one for those ambulant with the use of powered mobility devices.



Regarding employment, among non-wheelchair users, the two largest categories are the retired while among wheelchair users it is the age related retired and those working part-time who comprise the largest groups.

Section 1 - Question 1

Can you please indicate how often you usually attend for your therapy?



Non-wheelchair users N=97; Wheelchair users N=39

Created with Datawrapper

Attendance frequency is similar in both groups, being predominantly fortnightly or monthly.

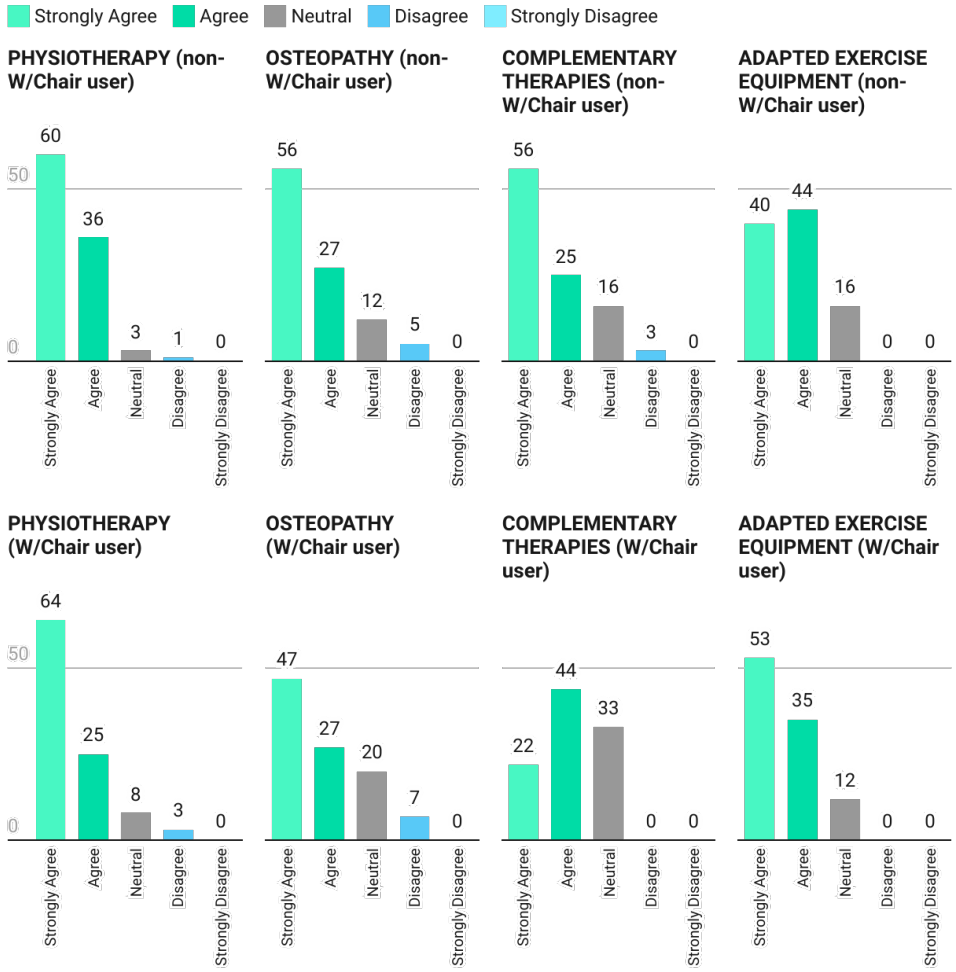
Appendix 1b – User assessed impact on physiology and function

This part of the Appendix presents graphs and tables relating to the remaining sections of the survey. Questions 2 through to question 10 are all of a similar format. A statement is presented relating to some aspect or other of physiological function or ability and then respondents are invited to indicate the strength of their agreement with this statement on a five-point Likert scale. As there are four principal physical therapies deployed at the Charity (physiotherapy, osteopathy, complementary therapies, and the use of adapted exercise equipment) the agreement or otherwise is requested for each therapy. Should the respondent not be receiving or have no experience of a therapy there is, in addition, a "not applicable" option available.

The graphs for these nine questions therefore all follow a matching template. Two rows of bar graphs are shown, the upper row being responses for non-wheelchair users and the lower row being responses for wheelchair users. The numbers at the top of each column or bar indicate the percentage of the responses that fell into each category. These percentages are calculated from the number of respondents who indicated either an agreement or a disagreement with the statement (i.e. all respondents indicating "not applicable" are excluded). The advantage of using bar graphs in this instance, as opposed to, say, pie graphs, lies in the potential to immediately apprehend the pattern of responses and the modal categories (and thus the differences in responses between the wheelchair and the non-wheelchair group).

SECTION 1, QUESTION 2

To what extent would you agree that attending these therapies has improved the flexibility of your joints?



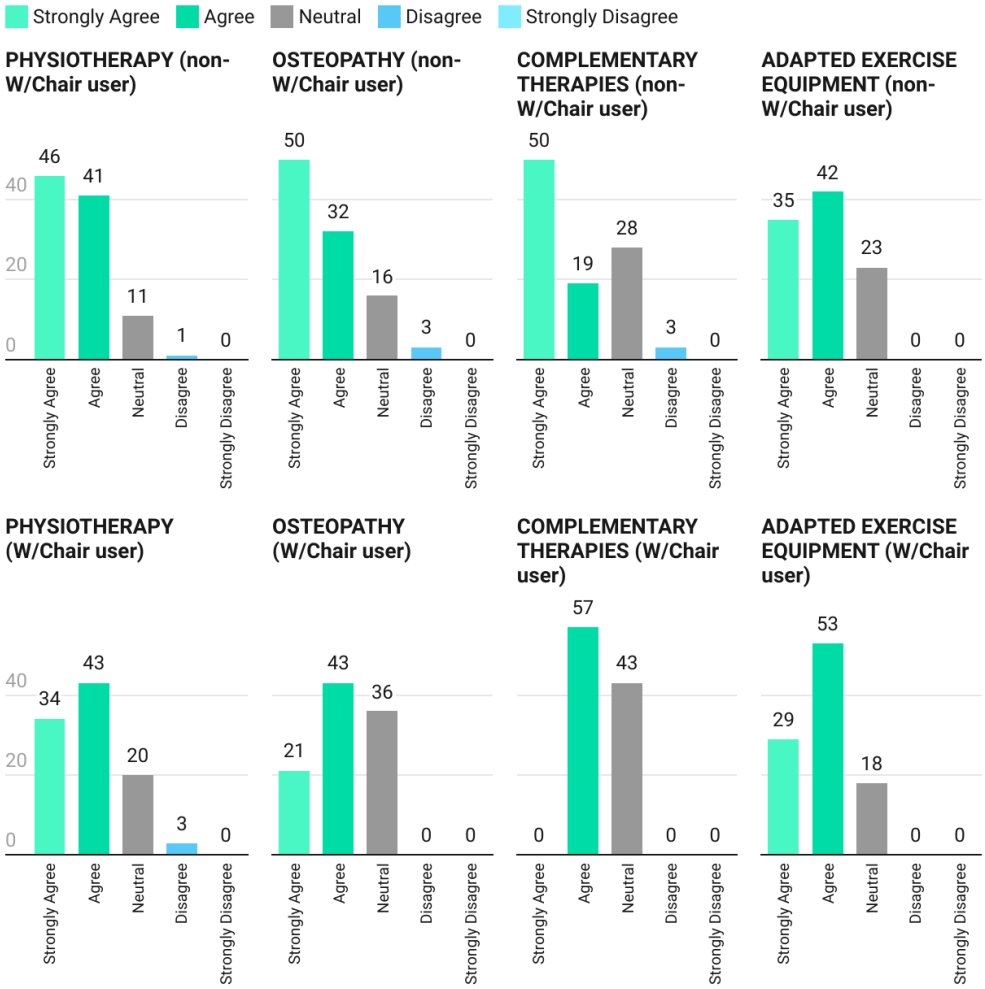
non-Wheelchair user N=97; wheelchair user N=39

Created with Datawrapper

Both groups have similarly positive opinions of physiotherapy and osteopathy regarding joint flexibility. Complementary therapies and adapted exercise equipment are perceived differently with non-wheelchair users being more ambivalent about the adapted exercise equipment and the wheelchair users being less positive about complementary therapies.

SECTION 1, QUESTION 3

To what extent would you agree that attending these therapies has improved your core stability?



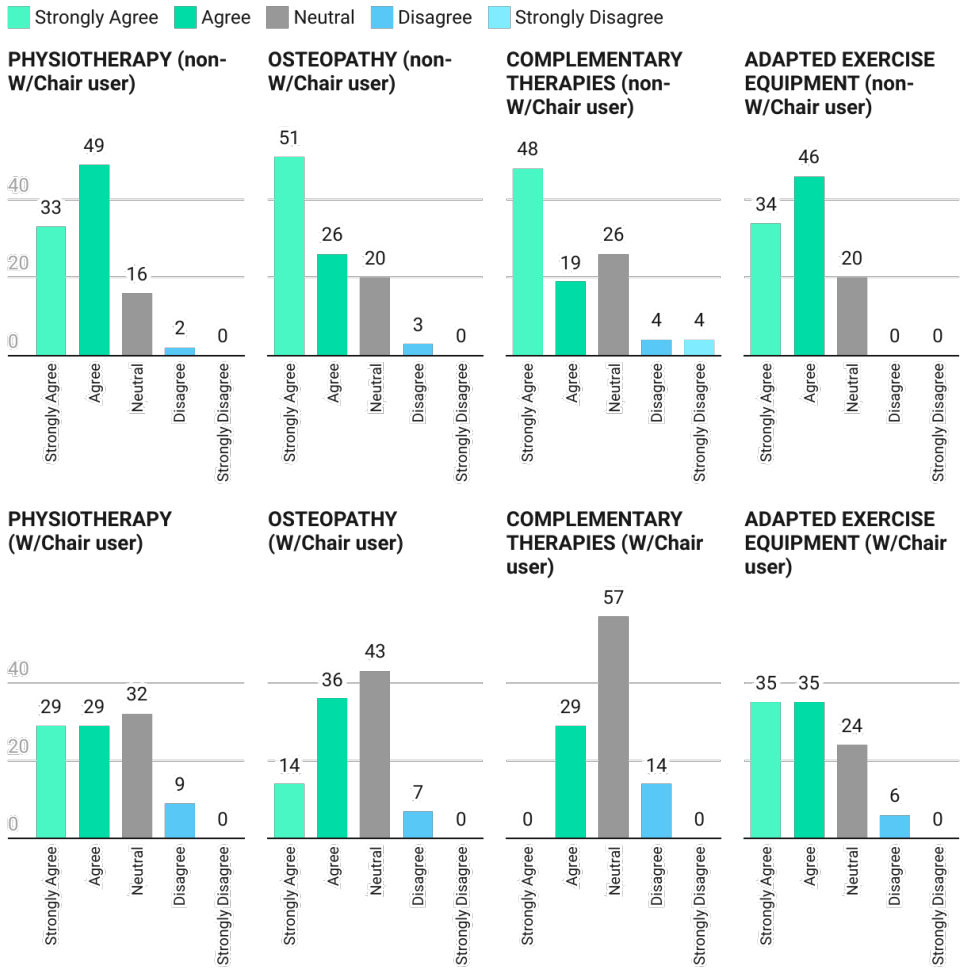
non-Wheelchair user N=91; wheelchair user N=36

Created with Datawrapper

Across all four therapies the wheelchair users express a more ambivalent and less positive response.

SECTION 1, QUESTION 4

To what extent would you agree that attending these therapies has improved your muscle strength?



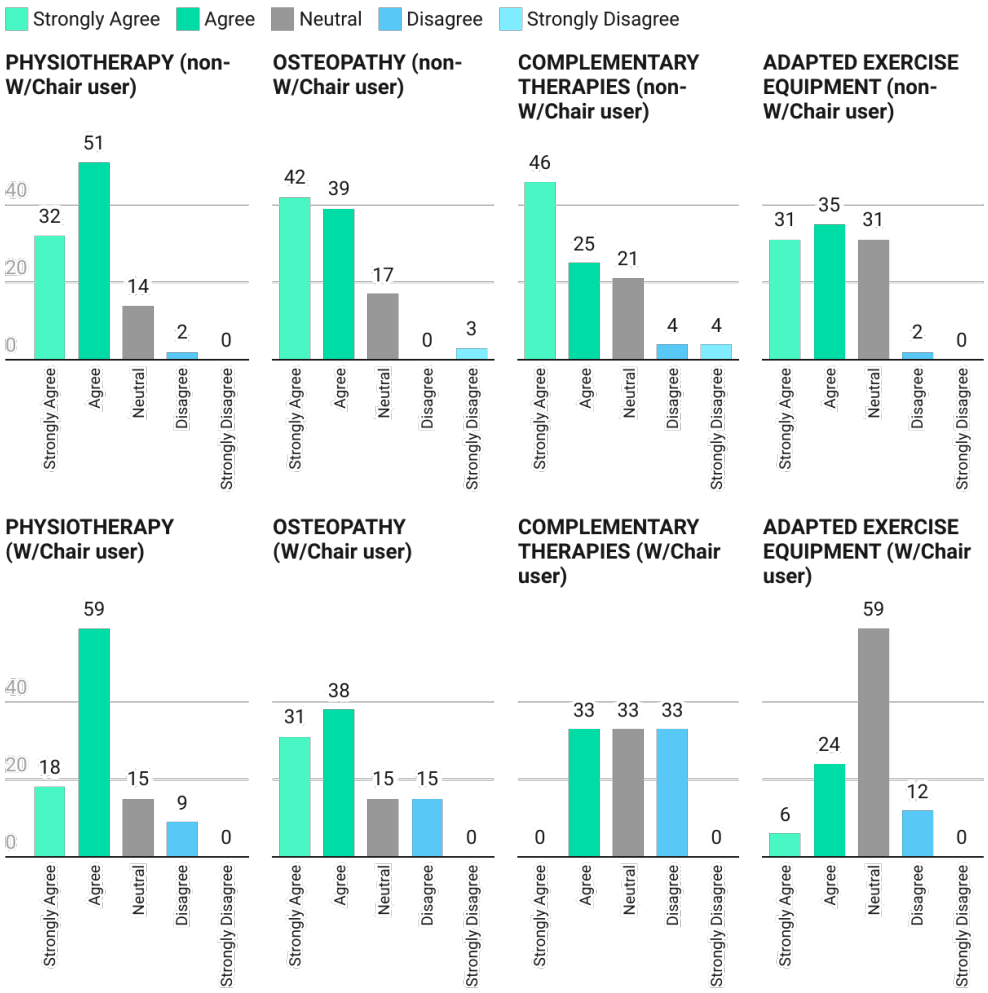
non-Wheelchair user N=90; wheelchair user N=36

Created with Datawrapper

With respect to muscle strength the wheelchair users express markedly less enthusiastic responses for all therapies except the use of adapted exercise equipment. Only here do they see a more positive benefit. Non-wheelchair users find osteopathy and complementary therapies of greatest benefit. It should be borne in mind here that the wheelchair users complementary therapies response set comprises only seven respondents.

SECTION 1, QUESTION 5

To what extent would you agree that attending these therapies has improved your posture?



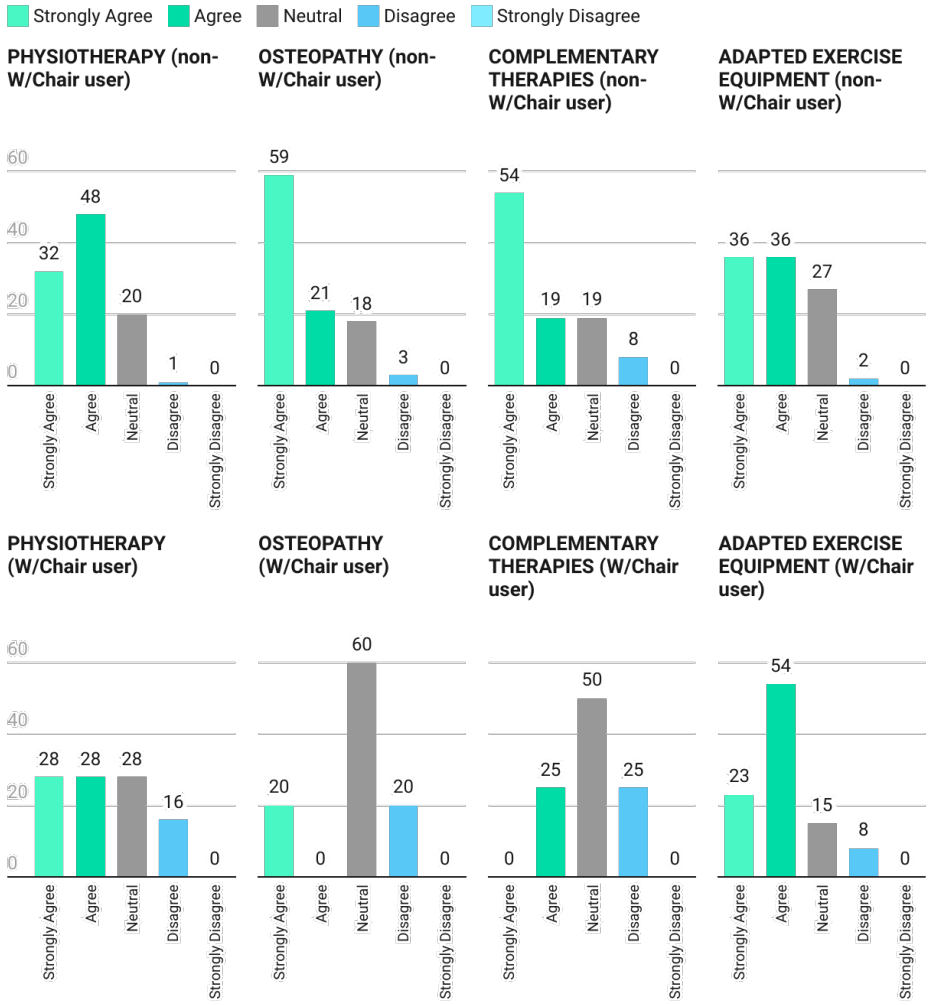
non-Wheelchair user N=88;Wheelchair user N=36

Created with Datawrapper

For the non-wheelchair users here osteopathy and complementary therapies have "strongly agree" as the modal categories whereas with physiotherapy and the use of adapted exercise equipment the modes are "agree". The wheelchair users give both manipulative therapies the better rating, with "agree" as the modes with a less positive view of the other two therapies.

SECTION 1, QUESTION 6

To what extent would you agree that attending these therapies has improved your balance?



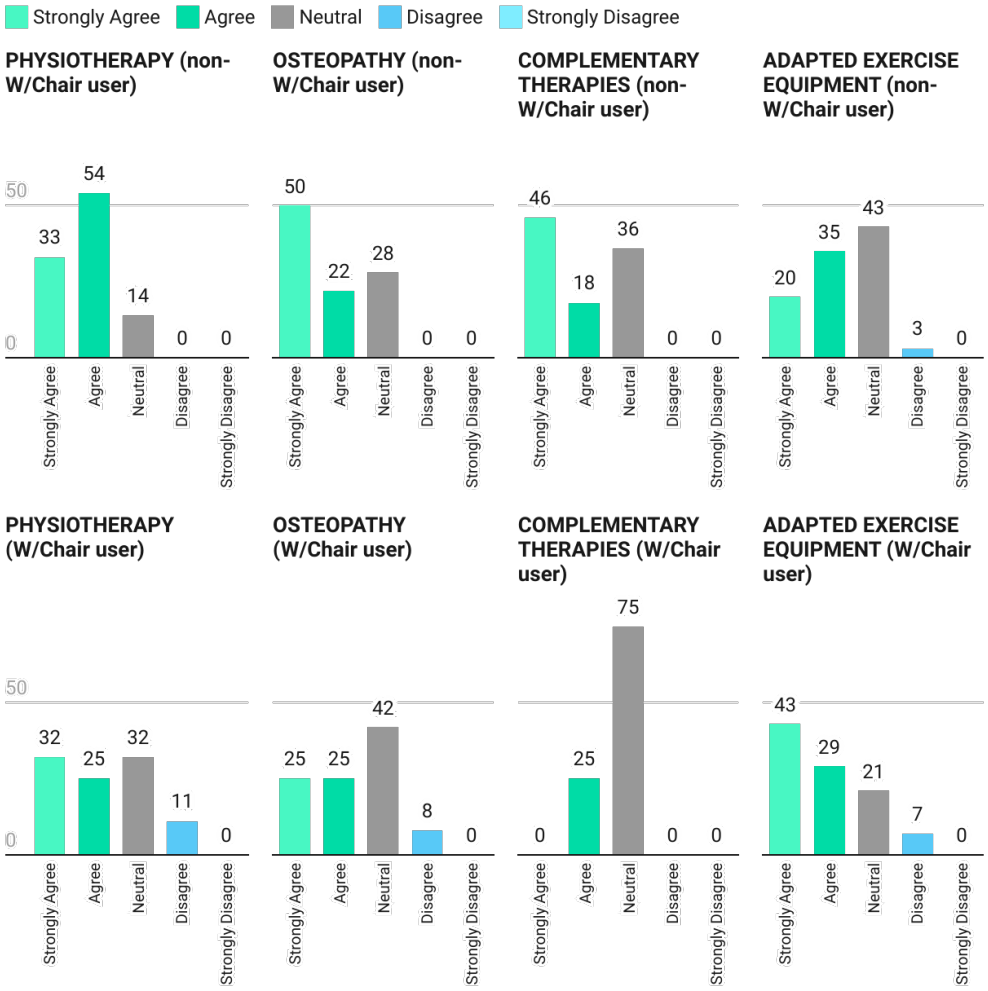
non-Wheelchair user N=86; wheelchair user N=35

Created with Datawrapper

There are clear differences regarding balance improvement between the two groups. Non-wheelchair users place strong emphasis upon osteopathy and complementary therapies in achieving improvement. Wheelchair users, by contrast, value the use of adapted exercise equipment and express less positive opinions about the other therapies.

SECTION 1, QUESTION 7

To what extent would you agree that attending these therapies has improved your mobility?



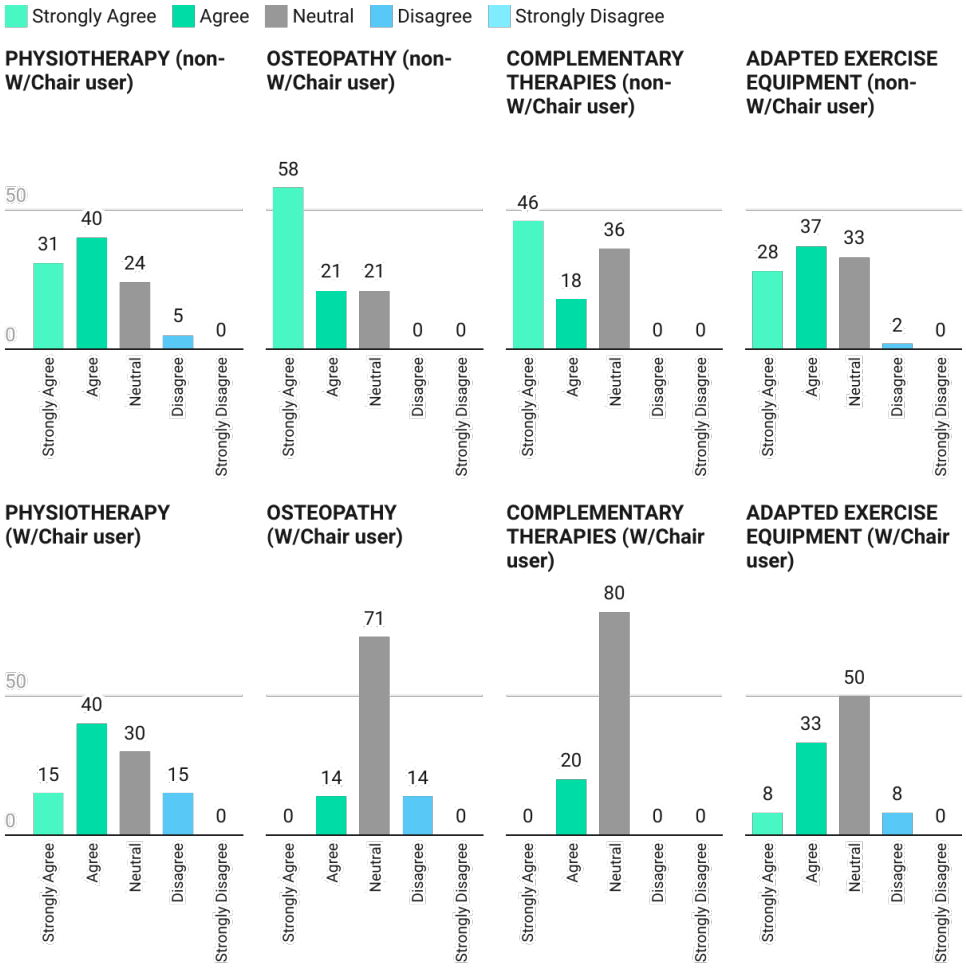
non-Wheelchair user N=84; wheelchair user N=34

Created with Datawrapper

The non-wheelchair users have positive opinions of the impact of the manipulative and complementary therapies regarding improvements to mobility. That said there is also a significant level of ambivalence with respect to both osteopathy and complementary despite this otherwise favourable assessment. The use of adapted exercise equipment is not well regarded by the non-wheelchair group. This is in contrast to the wheelchair users. For them the most valuable therapeutic intervention appears to be the adapted exercise equipment. The other therapies are rated as neutral.

SECTION 1, QUESTION 8

To what extent would you agree that attending these therapies has reduced your risk of falling over?



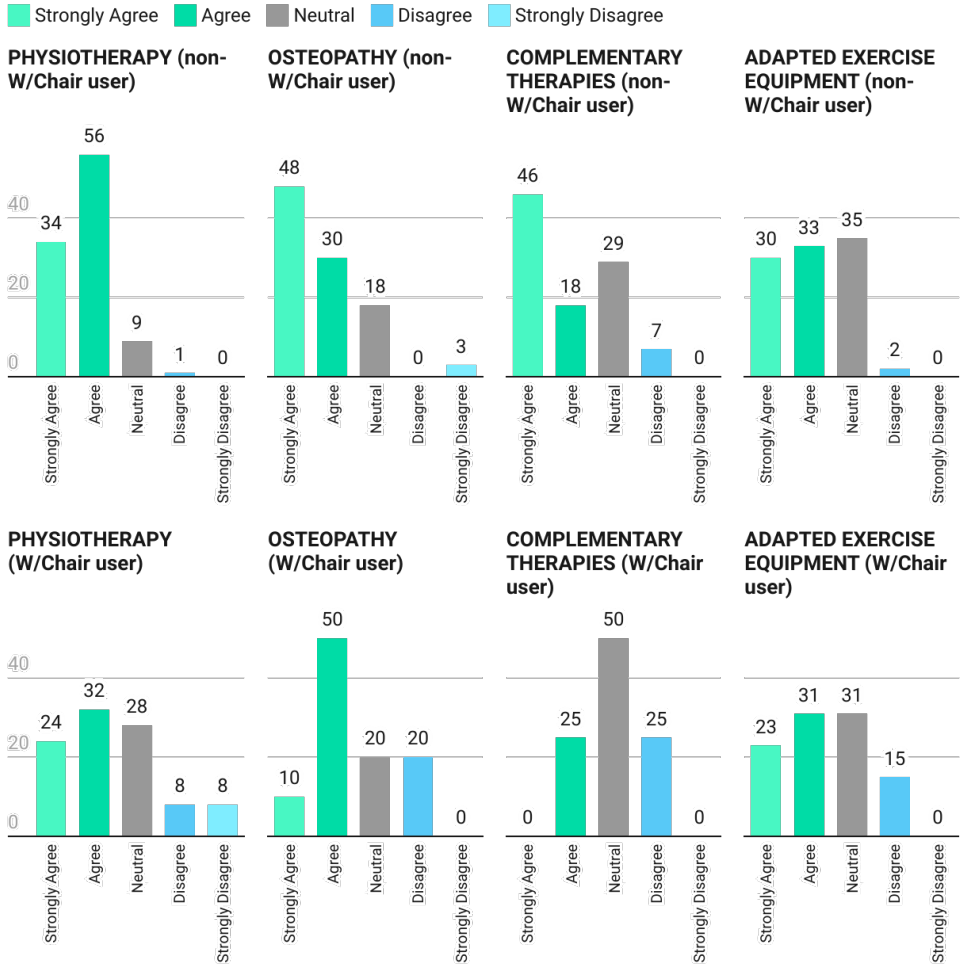
non-Wheelchair user N=83; wheelchair user N=33

Created with Datawrapper

With the exception of physiotherapy, the wheelchair users are markedly ambivalent as to the value of these therapies. Non-wheelchair users do not express very high levels of agreement although the modes for each therapy are either “strongly agree” or “agree”.

SECTION 1, QUESTION 9

To what extent would you agree that attending these therapies has maintained your ability to do things around the house (e.g. washing, dressing, food preparation, housework)?



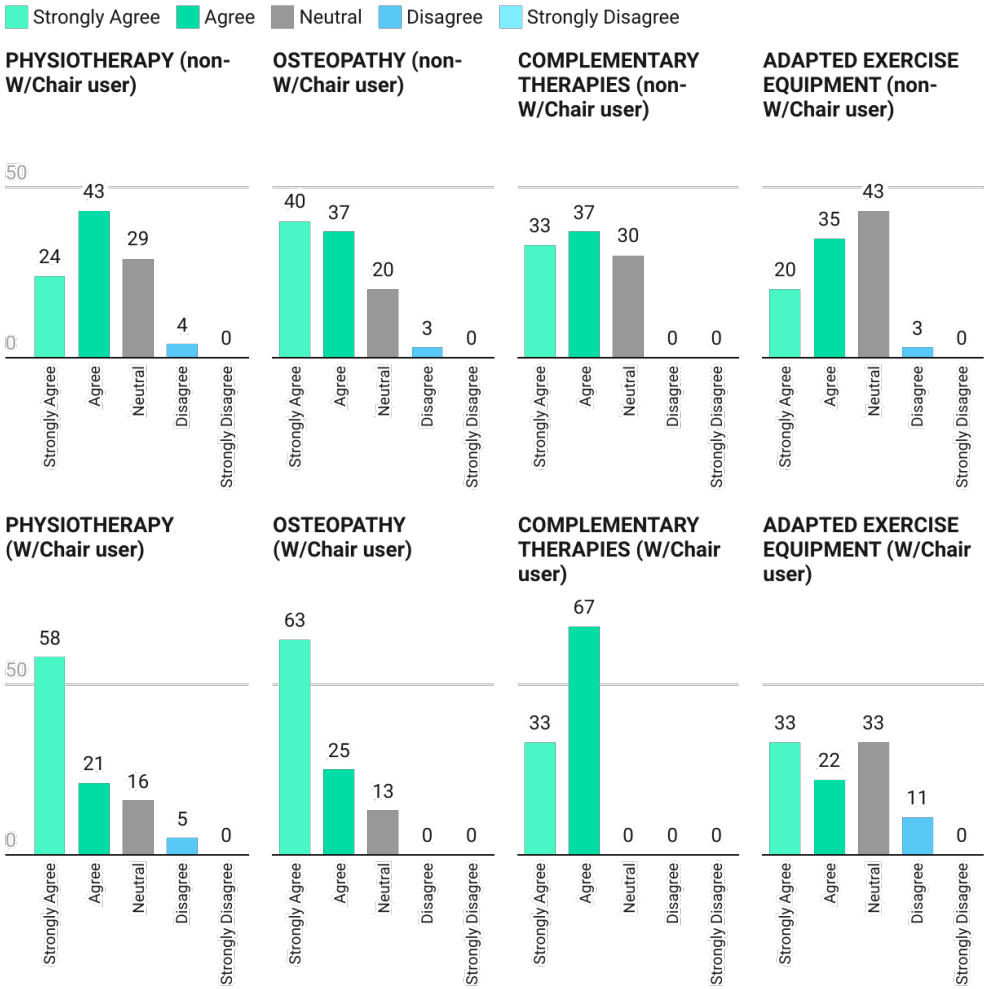
non-Wheelchair user N=83; wheelchair user N=32

Created with Datawrapper

Non-wheelchair users have modes expressing agreement here for all except the adapted exercise equipment. The wheelchair users have positive feelings about the manipulative therapies and the adapted exercise equipment but not complementary therapies.

SECTION 1, QUESTION 10

To what extent would you agree that attending these therapies has improved your pain control?



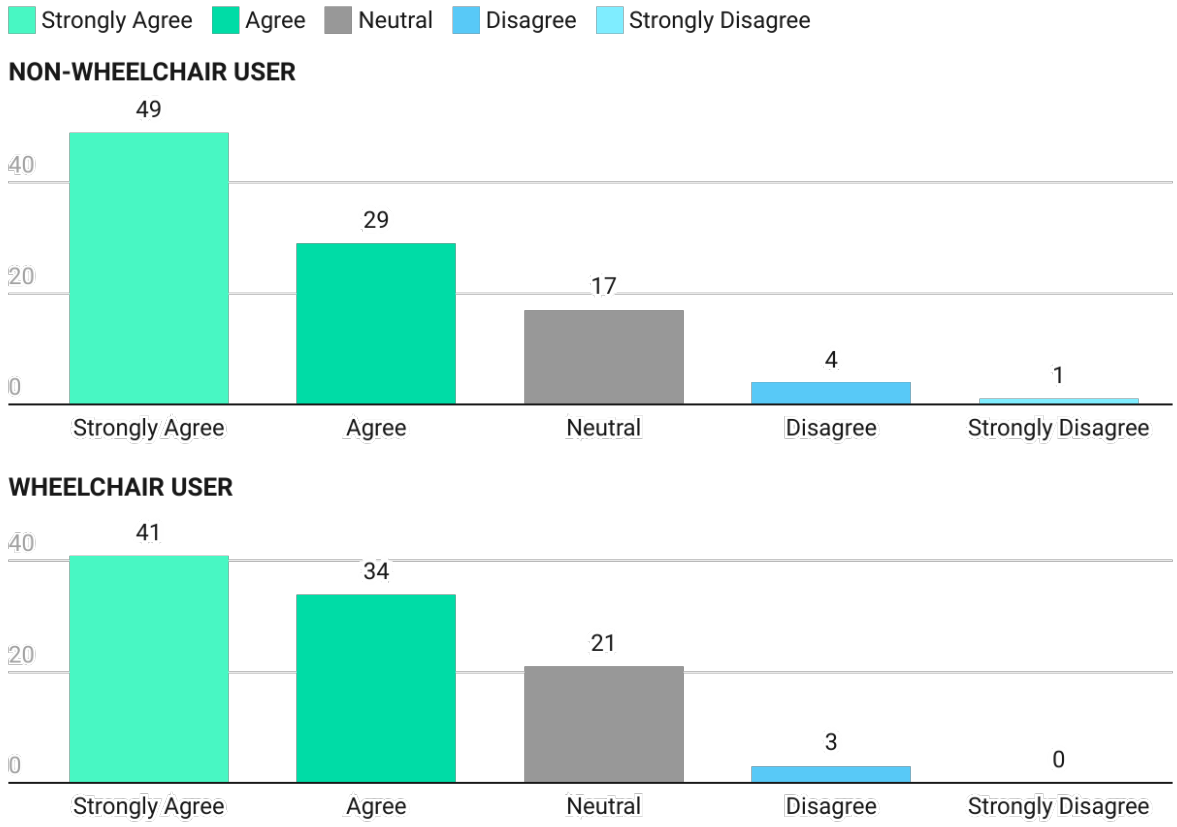
non-Wheelchair user N=83; wheelchair user N=32

Created with Datawrapper

Both groups see the control of pain as having been assisted by the Charity's input, with wheelchair users expressing markedly more positive opinions.

SECTION 1, QUESTION 11

To what extent would you agree that the treatments you have received from the MD Support Centre has reduced your reliance on NHS services, for, by example, reducing the number of falls you experience so you have fewer visits to A&E?



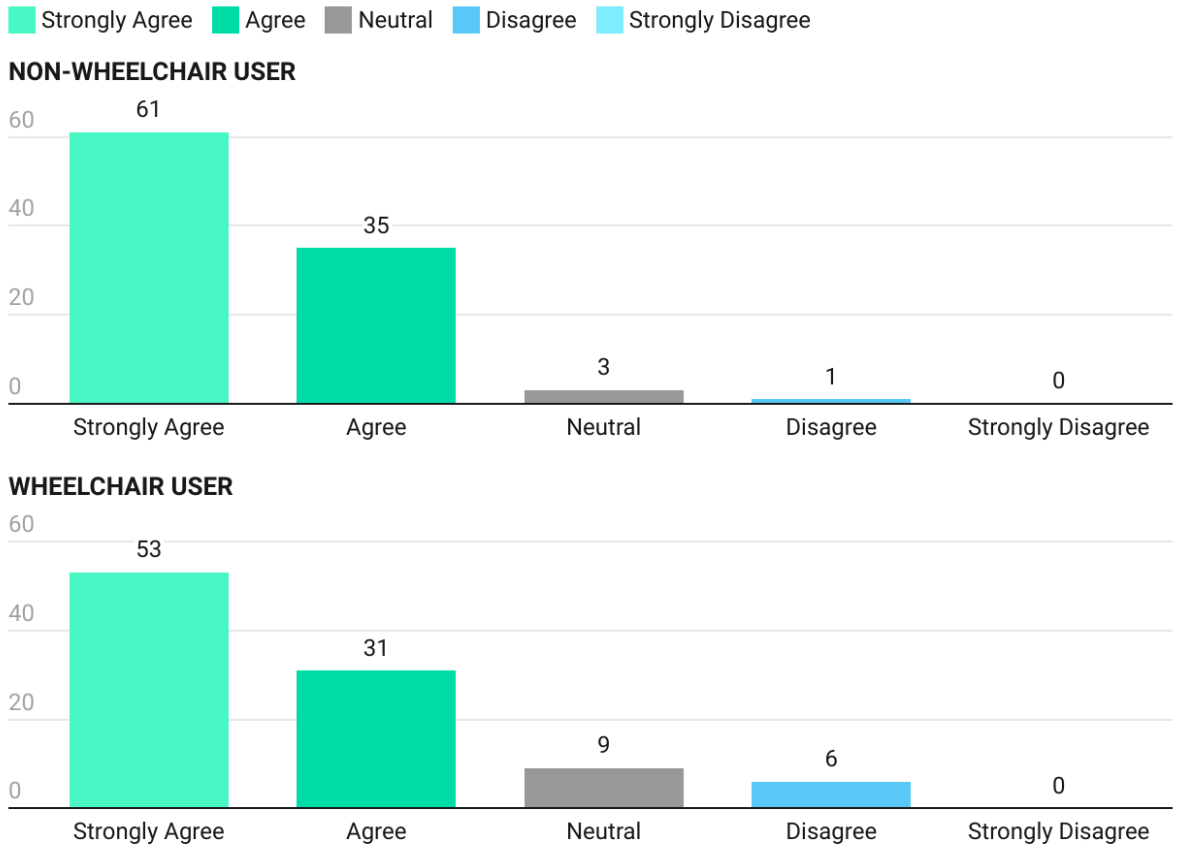
non-Wheelchair user N=83; wheelchair user N=32

Created with Datawrapper

Both groups are in agreement that the Charity has helped in reducing their reliance on NHS services.

SECTION 1, QUESTION 12

To what extent would you agree that your participation in the MD Support Centre activities and therapies, by helping you understand and better manage your condition, has made you feel more confident and in control?



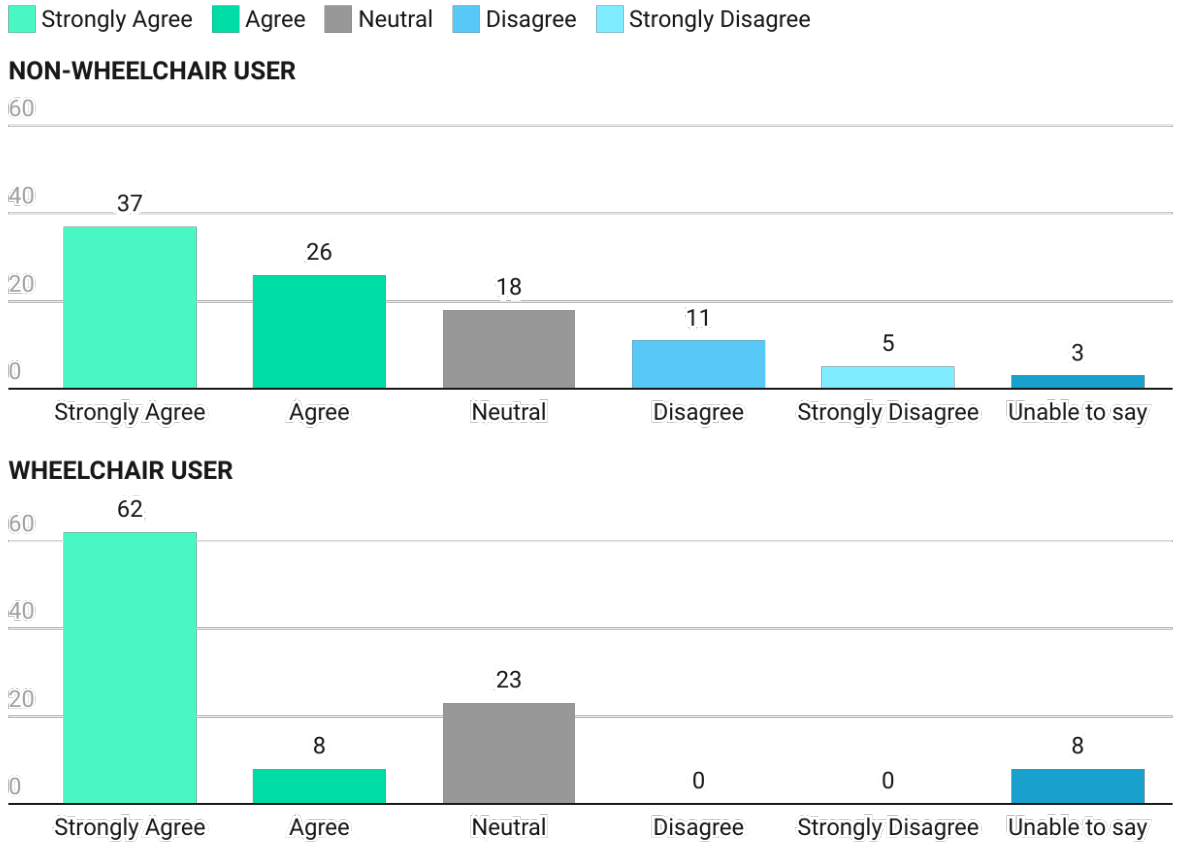
non-Wheelchair user N=83; wheelchair user N=33

Created with Datawrapper

Both groups are of the majority opinion that the Charity, through its activities and therapies, has helped them to maintain their confidence and feel in control.

SECTION 1, QUESTION 13

Viewed overall, would you agree or disagree that the MD Support Centre activities and therapies you have benefited from has helped you to stay in work?



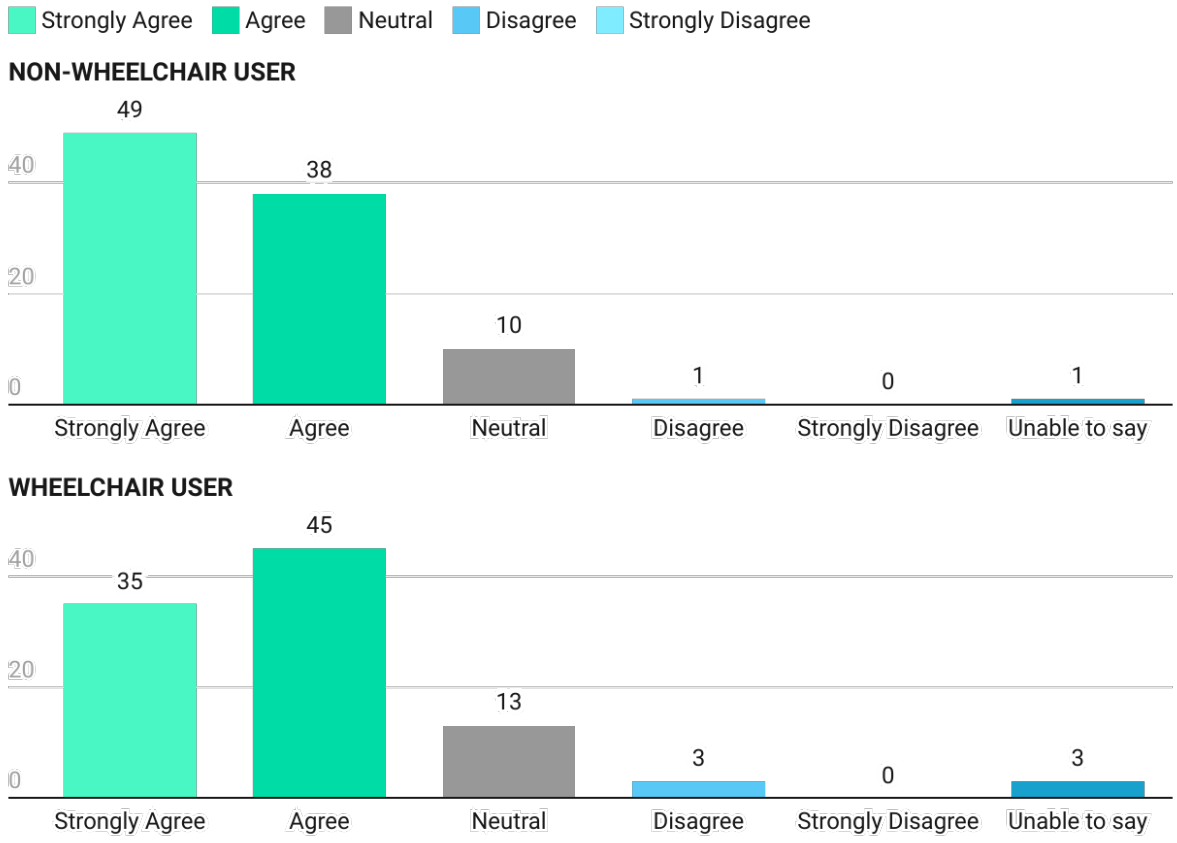
non-Wheelchair user N=83; wheelchair user N=32

Created with Datawrapper

Wheelchair users appear more inclined to see the Charity as having helped them to stay in work.

SECTION 1, QUESTION 14

Viewed overall, would you agree or disagree that the MD Support Centre activities and therapies you have benefited from has helped you to maintain your independence and do more with your family and friends?



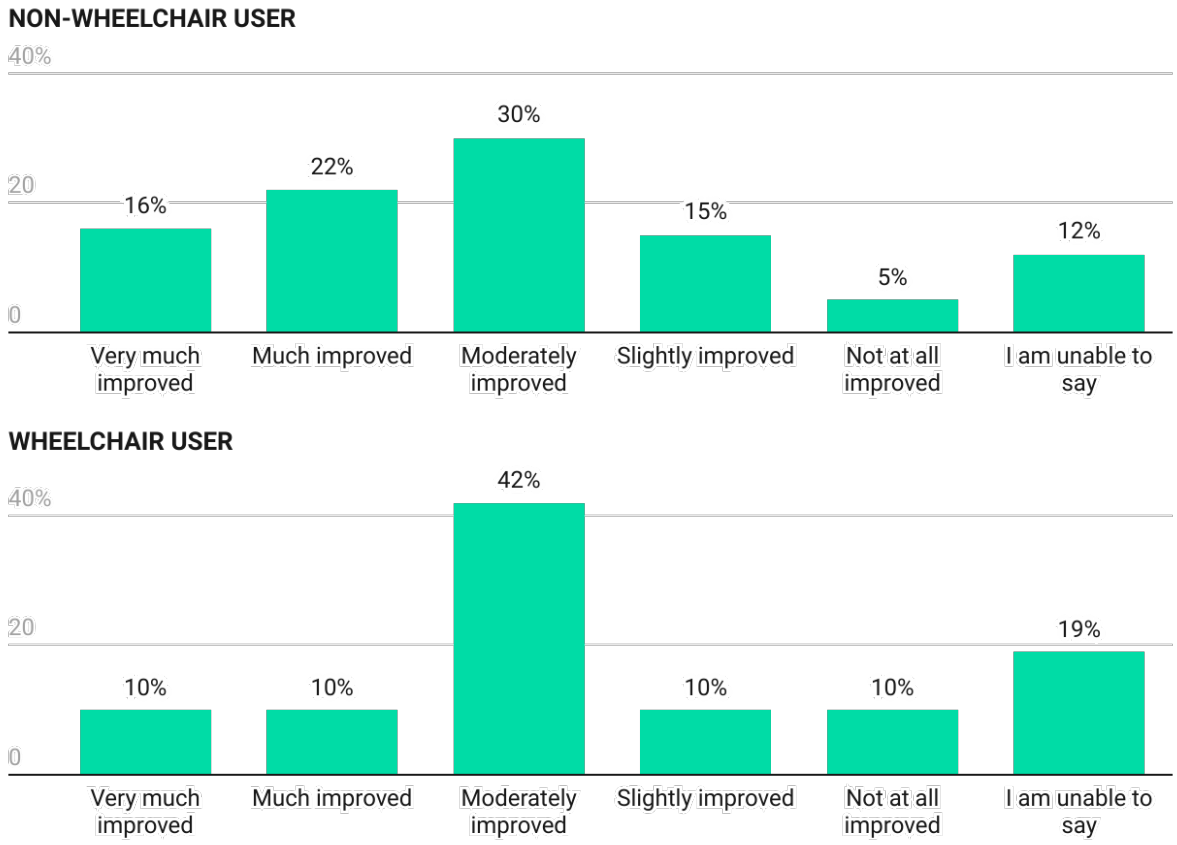
non-Wheelchair user N=83; wheelchair user N=32

Created with Datawrapper

Both groups are of the majority opinion that the Charity's input has helped them to maintain their independence and their ability to engage with their family and friends.

SECTION 1, QUESTION 15

Viewed overall, would you say that with the MD Support Centre activities and therapies your condition is ...



non-Wheelchair user N=82; wheelchair user N=31

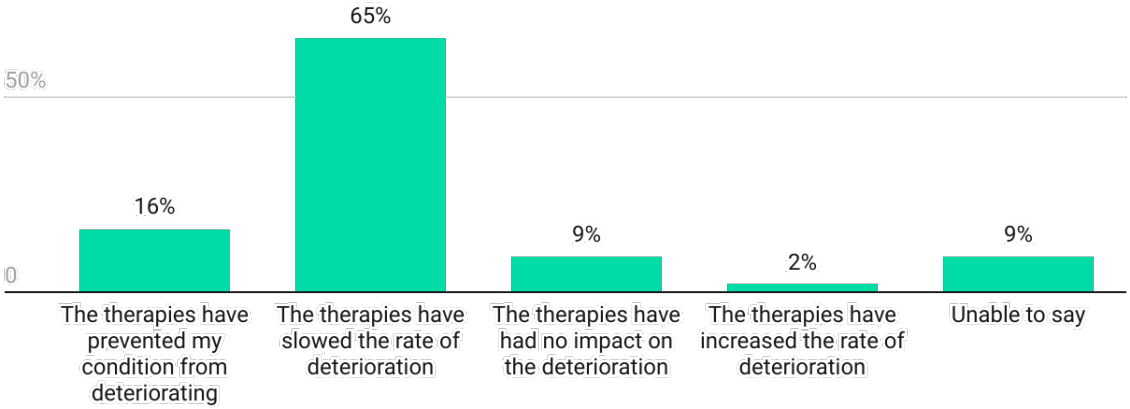
Created with Datawrapper

Both groups see their condition as having at least moderately improved, and in some cases have seen even greater improvement.

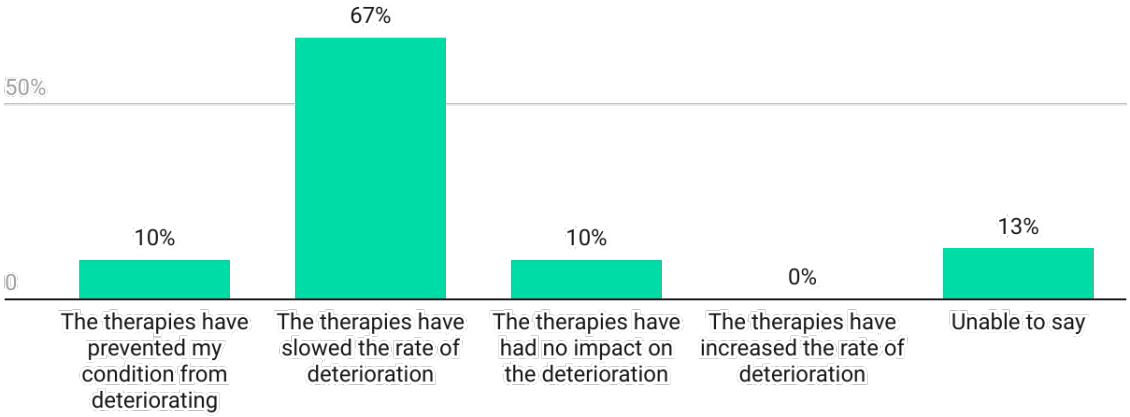
SECTION 1, QUESTION 16

Which statement do you think would best describe the general impact the MD Support Centre activities and therapies have had on your general condition?

NON-WHEELCHAIR USER



WHEELCHAIR USER



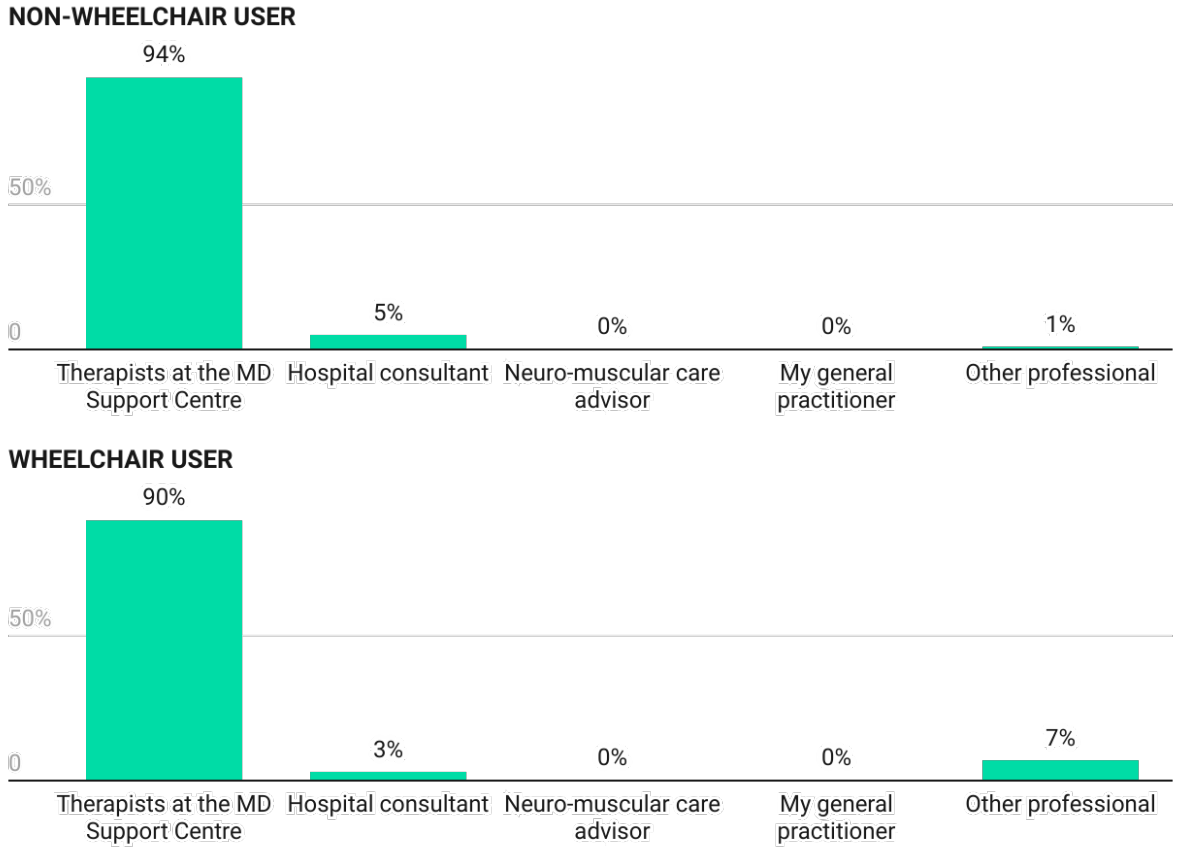
non-Wheelchair user N=82; wheelchair user N=30

Created with Datawrapper

For both groups the majority impression is that the Charity's therapeutic input has slowed the rate of deterioration.

SECTION 1, QUESTION 17

Which professional do you feel plays the primary role in helping you manage your condition?



non-Wheelchair user N=82; wheelchair user N=30

Created with Datawrapper

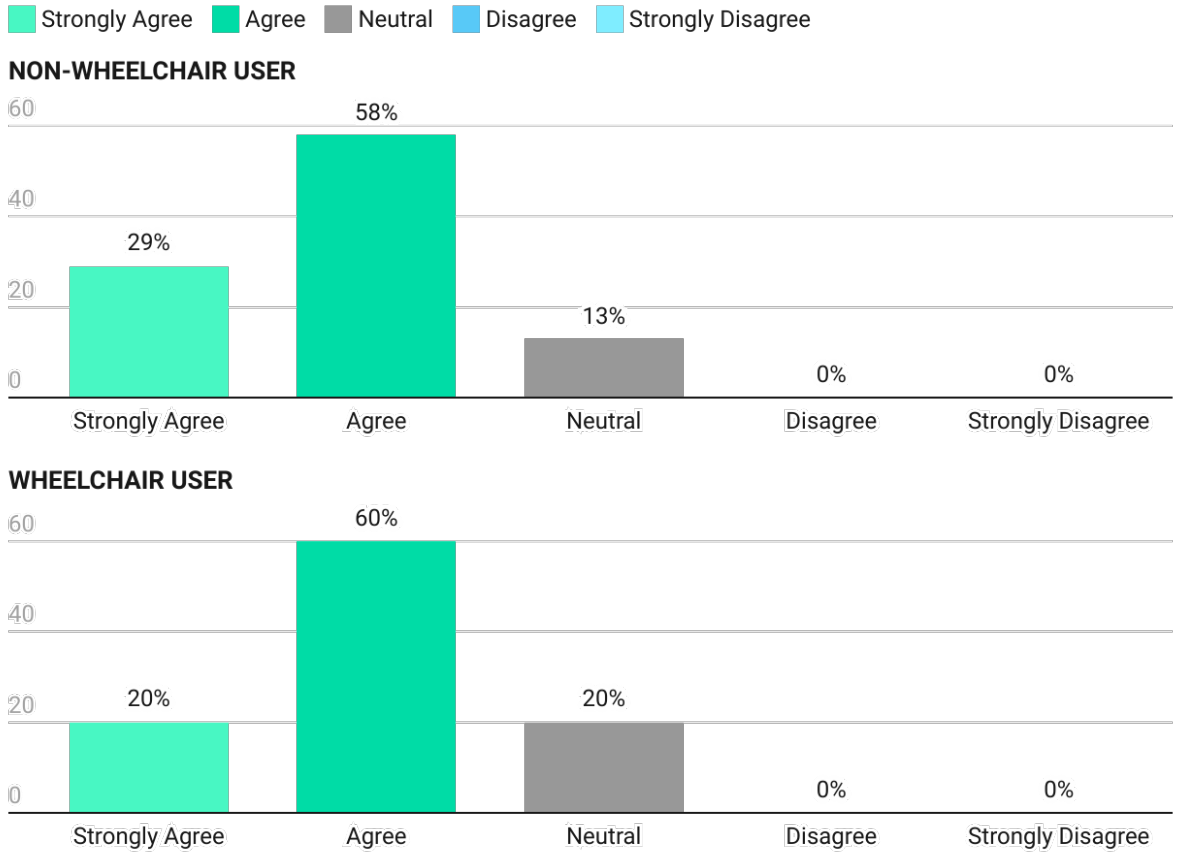
Overwhelmingly, both groups see the Charity therapists as being the most important professionals involved in the management of their condition.

Appendix 1c User assessment of online classes

The focus now moves to the online classes provided by the Charity. There are seven questions asking respondents for their opinions regarding the impact the online classes have had on physiology and function. These questions are contained in Section 2 of the questionnaire. Responding to questions in this section were ten wheelchair users and twenty-four non-wheelchair users. As the number of respondents in this section is low (34 out of 139 respondents in total) the number of responses in any individual category of these answers may be in single figures. Overall, respondents view the impact of the online classes as very favourable.

SECTION 2, QUESTION 1

To what extent would you agree that engaging in online classes led by MD Support Centre therapists has improved your core stability?



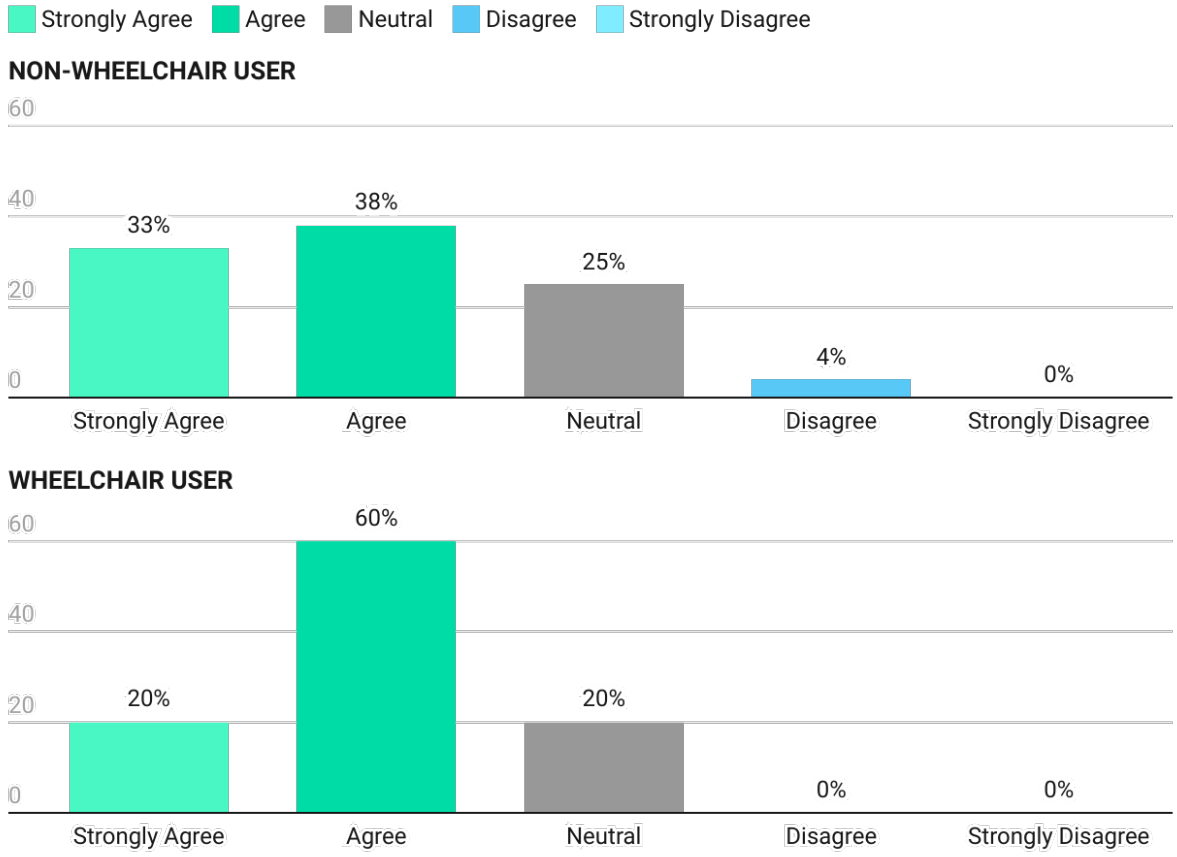
non-Wheelchair user N=24; wheelchair user N=10

Created with Datawrapper

Both groups express high levels of agreement that their core stability had been improved by the online classes.

SECTION 2, QUESTION 2

To what extent would you agree that engaging in online classes led by MD Support Centre therapists has improved your muscle strength?



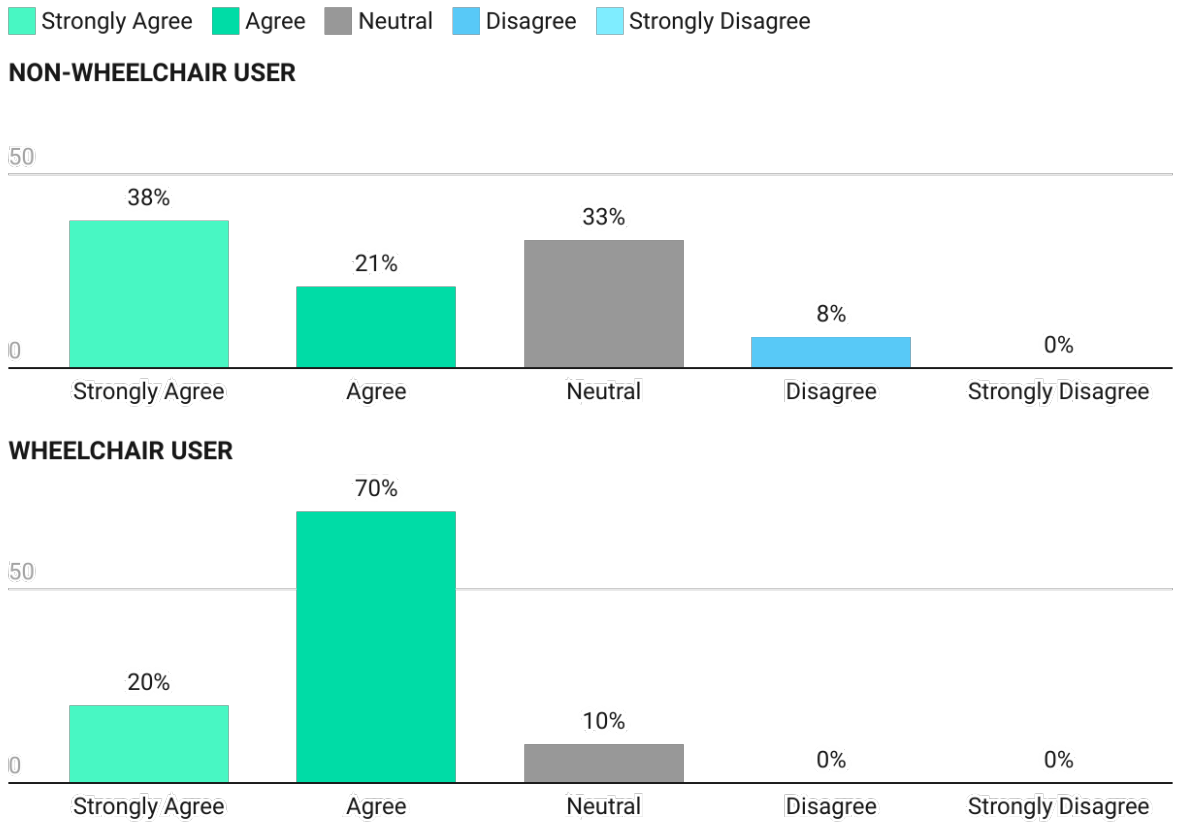
non-Wheelchair user N=24; wheelchair user N=10

Created with Datawrapper

Wheelchair users are more inclined to see an improvement in their muscle strength than the non-wheelchair users. Both groups though do see this as having improved by online participation.

SECTION 2, QUESTION 3

To what extent would you agree that engaging in online classes led by MD Support Centre therapists has improved your posture?



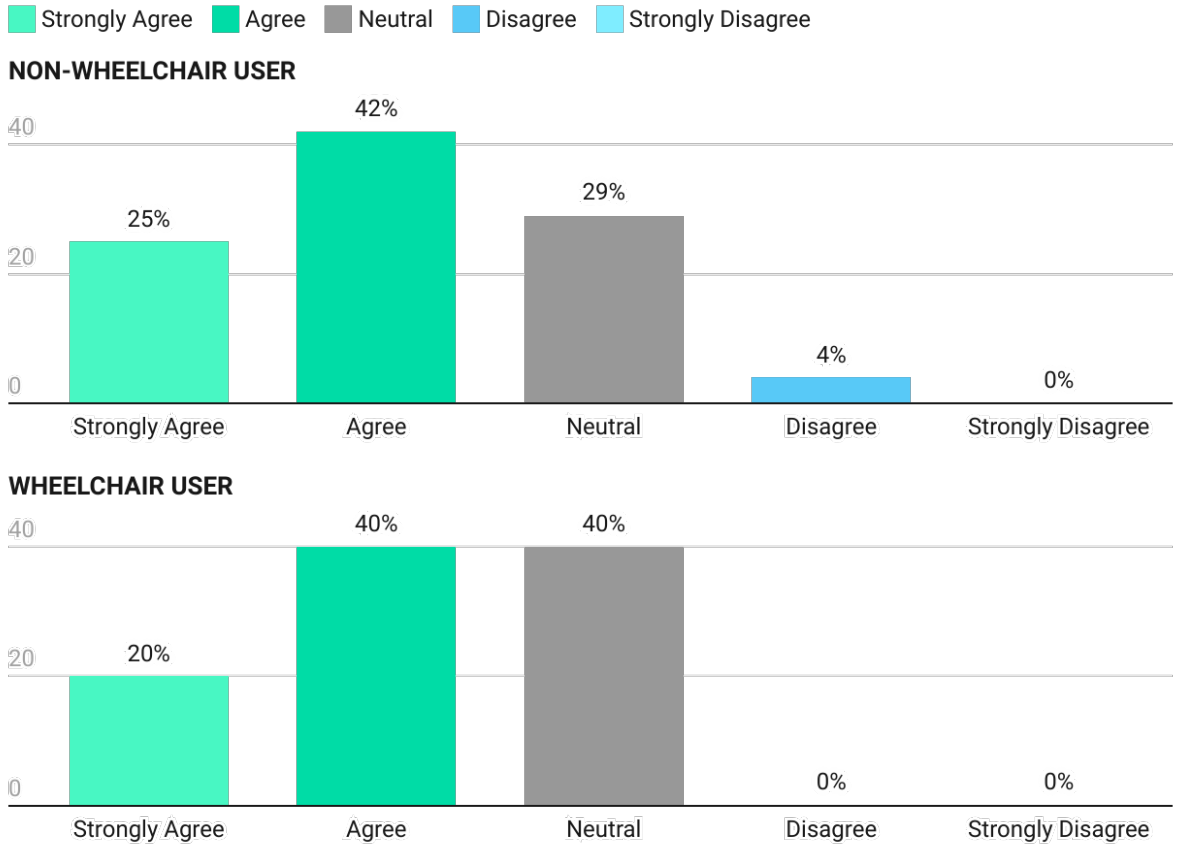
non-Wheelchair user N=24; wheelchair user N=10

Created with Datawrapper

For non-wheelchair users the online classes are viewed with a degree of ambivalence. Wheelchair users appear very much of the opinion that their posture has been improved by the online sessions.

SECTION 2, QUESTION 4

To what extent would you agree that engaging in online classes led by MD Support Centre therapists has improved your balance?



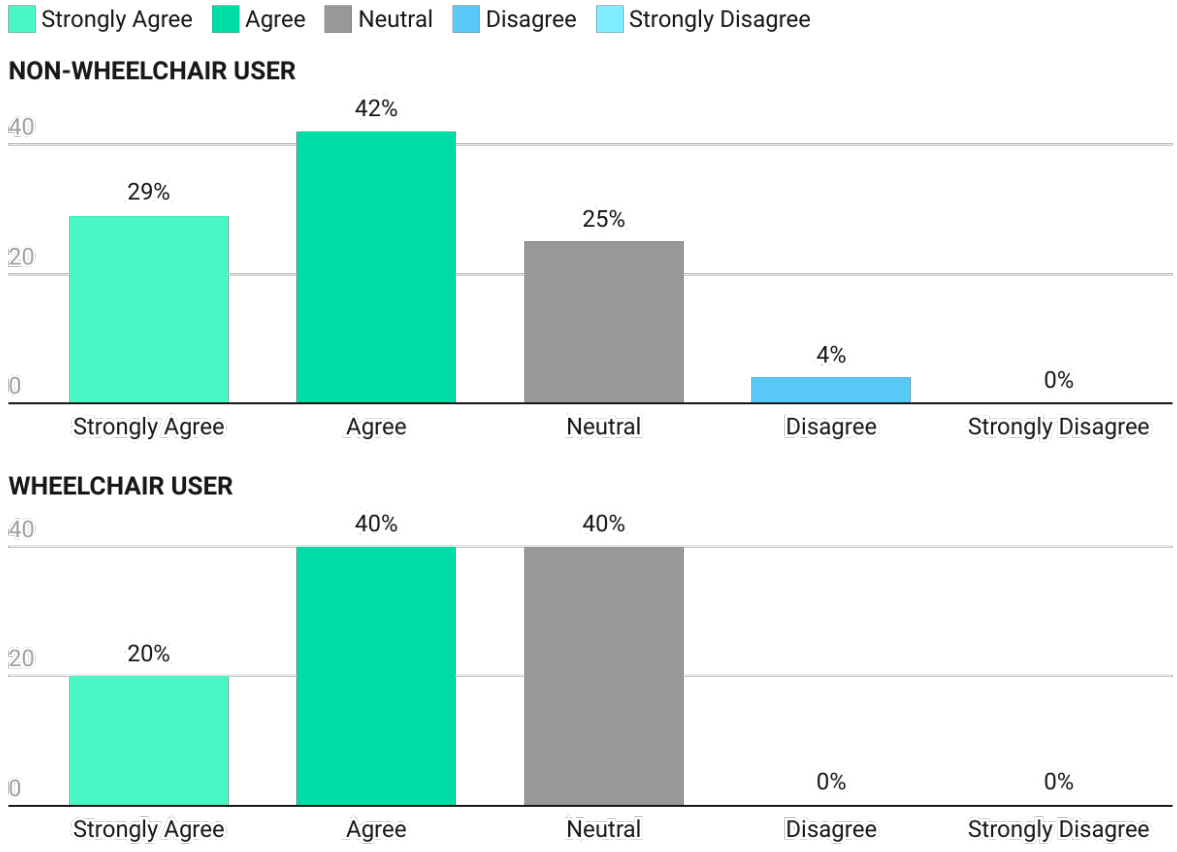
non-Wheelchair user N=24; wheelchair user N=10

Created with Datawrapper

There are mixed feelings here with regard to balance although the majority opinion does see an improvement.

SECTION 2, QUESTION 5

To what extent would you agree that engaging in online classes led by MD Support Centre therapists has improved your mobility?



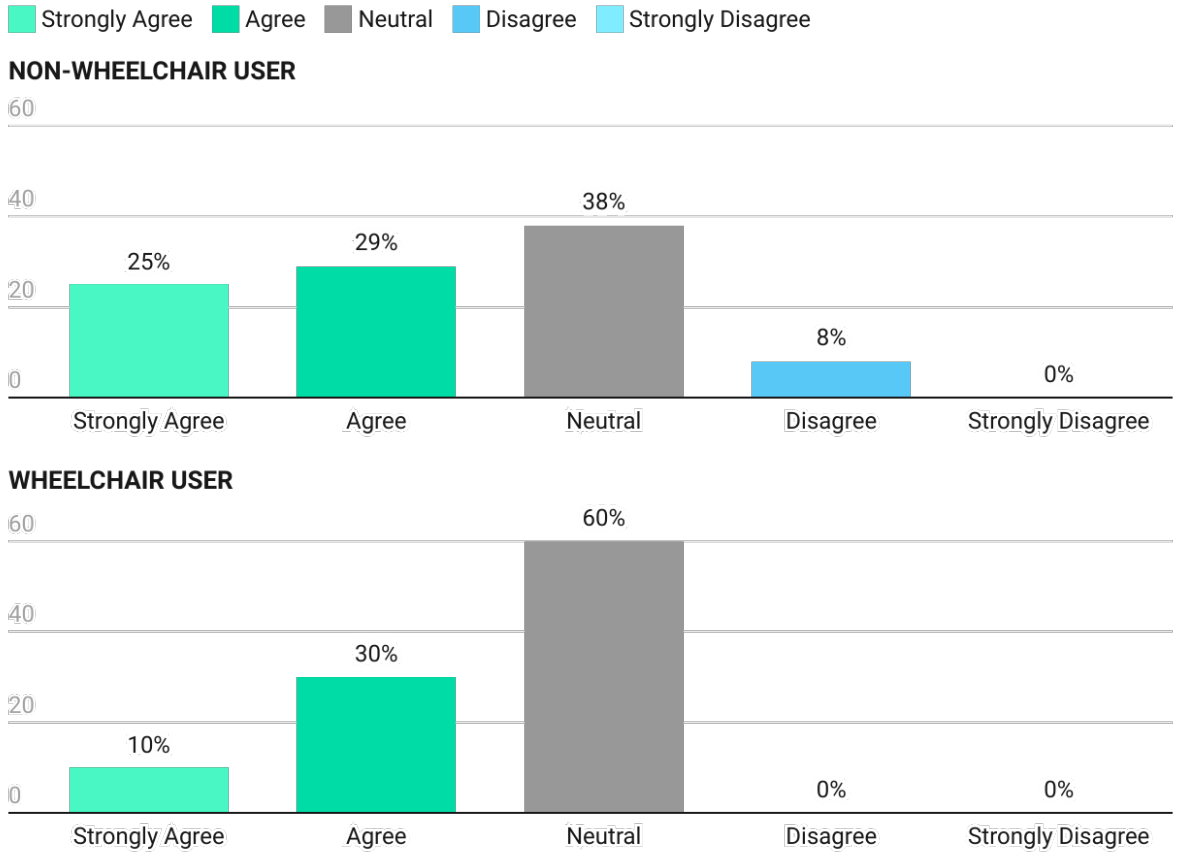
non-Wheelchair user N=24; wheelchair user N=10

Created with Datawrapper

The non-wheelchair users appear more likely to see a mobility improvement than the wheelchair users.

SECTION 2, QUESTION 6

To what extent would you agree that engaging in online classes led by MD Support Centre therapists has improved your pain control?



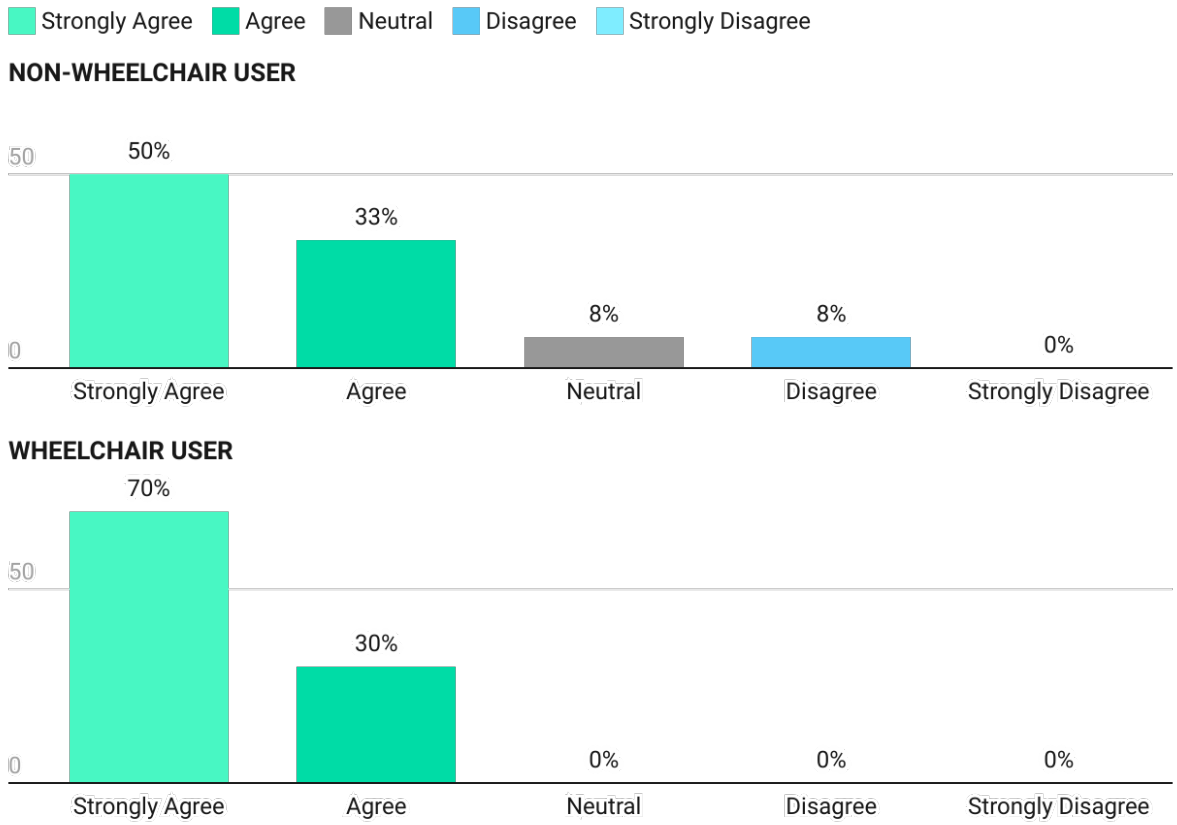
non-Wheelchair user N=24; wheelchair user N=10

Created with Datawrapper

For both groups the impact on pain control is muted, particularly so for the wheelchair user group.

SECTION 2, QUESTION 7

To what extent would you agree that engaging in online classes led by MD Support Centre therapists has improved your emotional well-being?



non-Wheelchair user N=24; wheelchair user N=10

Created with Datawrapper

A very positive assessment here from both wheelchair and non-wheelchair users with respect to the impact the online classes have had on emotional wellbeing.

Appendix 1d Overall user assessment

The final part of this Appendix concerns the respondents' overall views on the impact of the Charity's therapy provision. This information is derived from Section 3 of the questionnaire.

SECTION 3

MD Support Centre activities and therapies respondents believe they have benefited from.

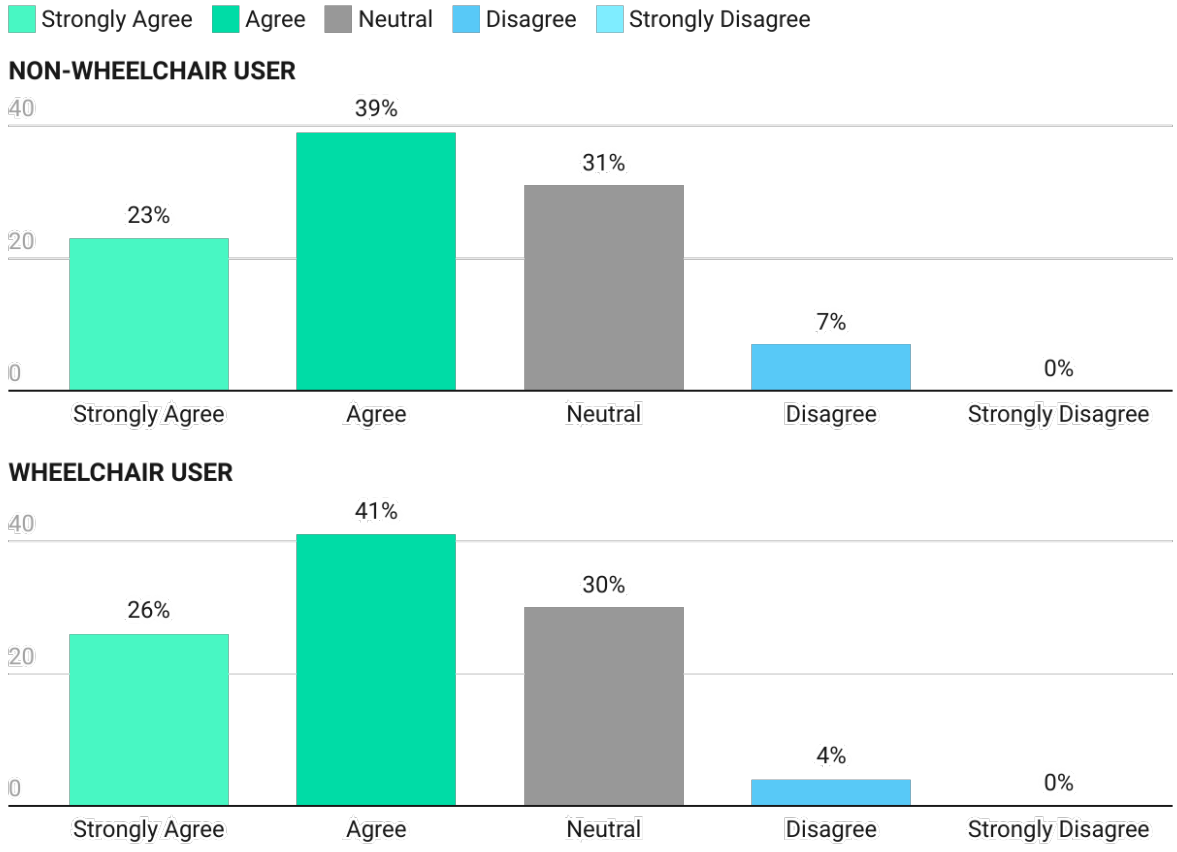
Non-Wheelchair user N=99: wheelchair user N=40

Created with Datawrapper

Non-wheelchair users see the Charity magazine and the Charity website as significant facilities they have benefited from. The wheelchair users have a greater range of the Charity activities and service from which they feel they can benefit. The magazine and website score well, together with the Wellness hub and the Charity open day

SECTION 3, QUESTION 1

Viewed overall, would you agree or disagree that the MD Support Centre activities and therapies you have benefited from has helped you to connect with others?



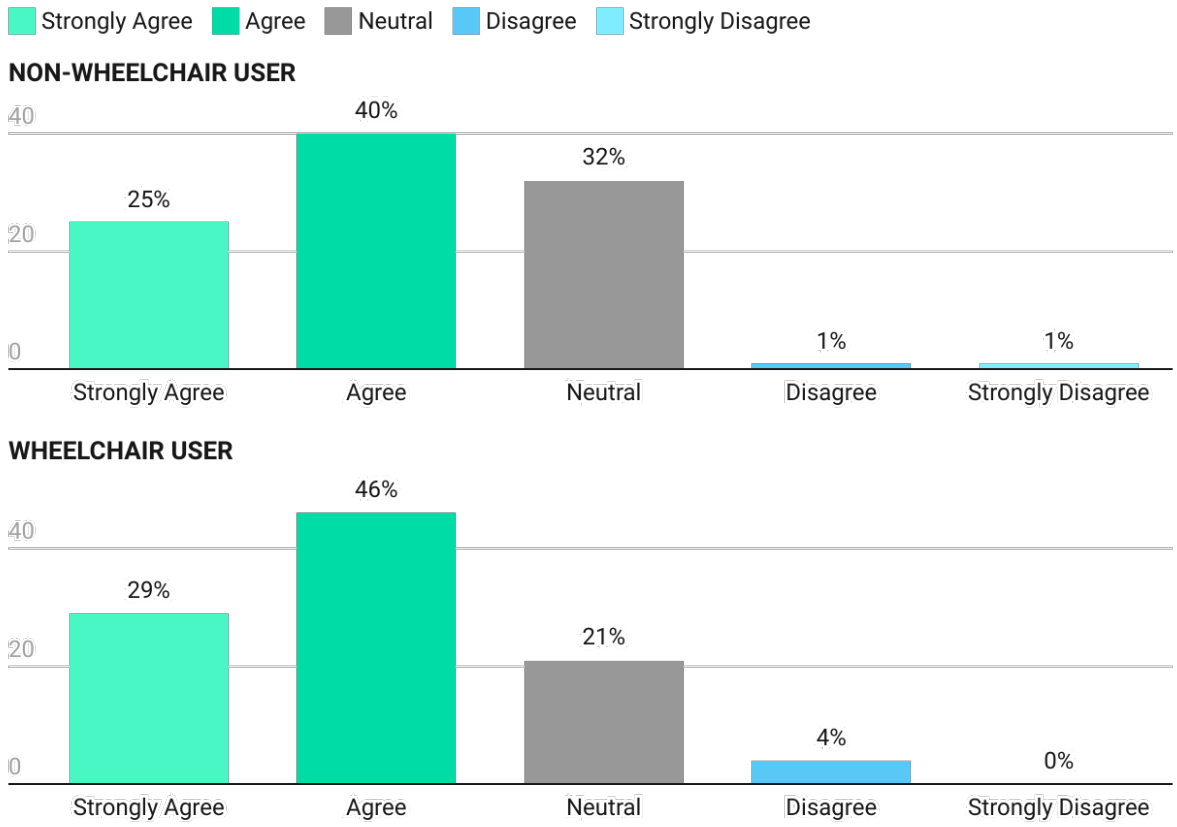
non-Wheelchair user N=82; wheelchair user N=30

Created with Datawrapper

For both groups the impact of the Charity in helping them connect with others is seen similarly.

SECTION 3, QUESTION 2

Viewed overall, would you agree or disagree that the MD Support Centre activities and therapies you have benefited from has given you a community to feel part of?



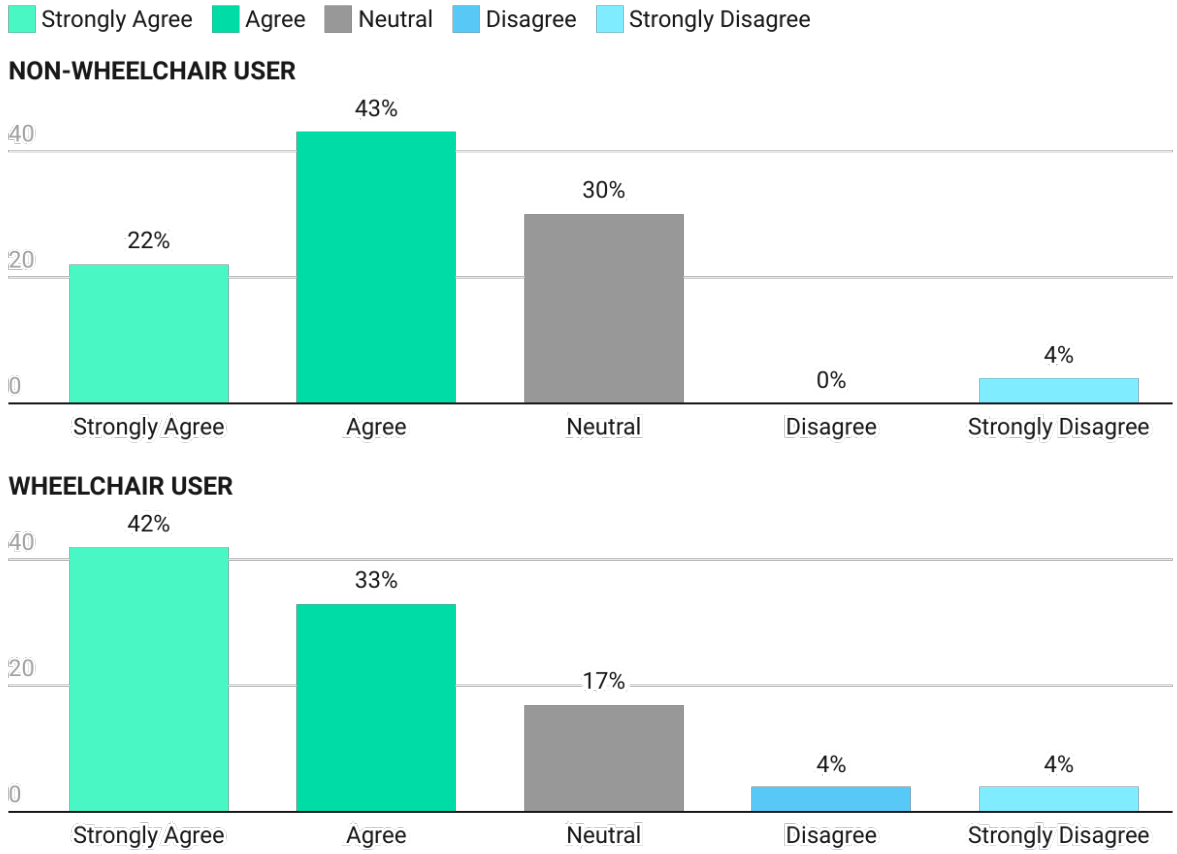
non-Wheelchair user N=82; wheelchair user N=30

Created with Datawrapper

Although both groups express agreement regarding the existence of a community this sentiment is more marked among the wheelchair users than the non-wheelchair users.

SECTION 3, QUESTION 3

Viewed overall, would you agree or disagree that the MD Support Centre activities and therapies you have benefited from has helped your family and/or carers to feel supported?



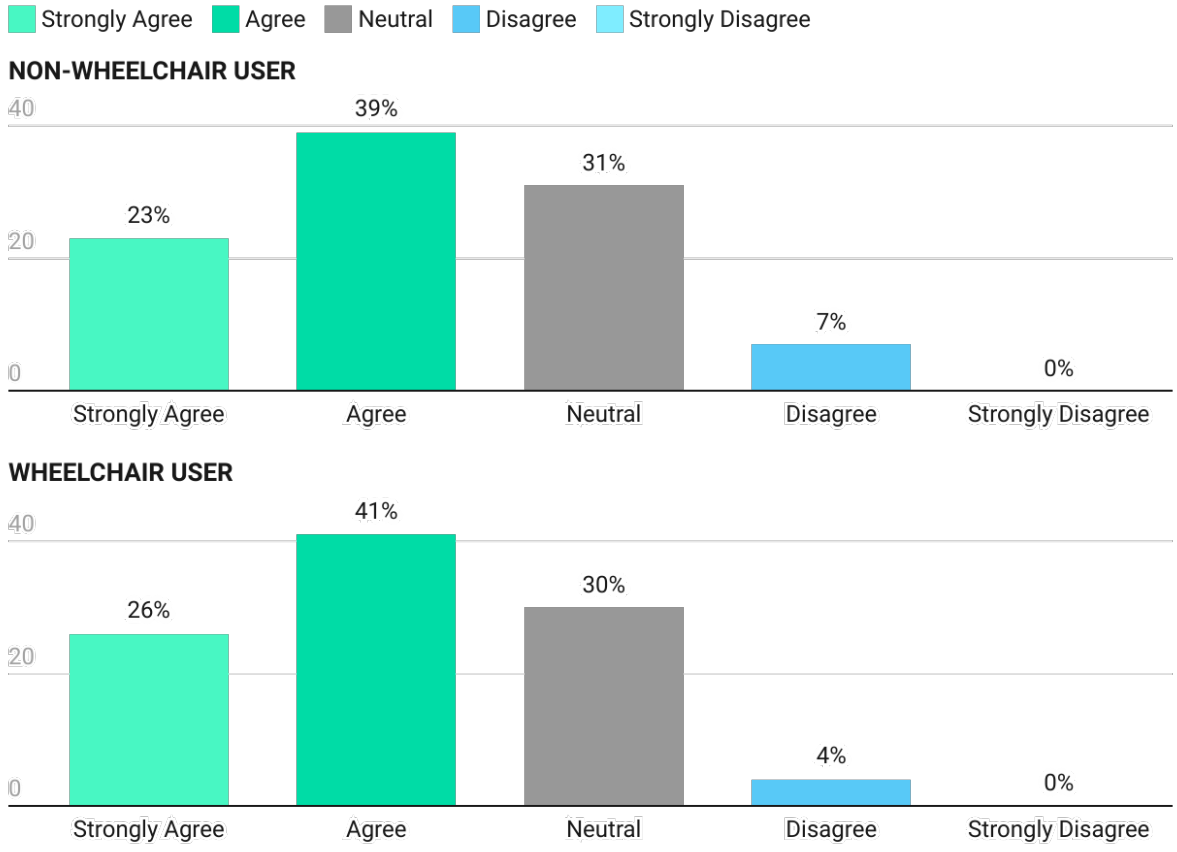
non-Wheelchair user N=82; wheelchair user N=30

Created with Datawrapper

Both groups feel well supported by the Charity.

SECTION 3, QUESTION 4

Viewed overall, would you agree or disagree that the MD Support Centre activities and therapies you have benefited from has helped you to accept and live well with your condition?



non-Wheelchair user N=82; wheelchair user N=30

Created with Datawrapper

There are good levels of agreement here from both groups that the Charity services they received have helped them to accept and live well with their condition.

Appendix 1e Supplementary tables

In this part will be found tables giving a full numerical breakdown of the responses per question. The order followed is as used above for the graphs.

BIOGRAPHY QUESTION 2

Could you please indicate your gender?

	Female	Male	Would rather not say	Valid	Total
NON-WHEELCHAIR USER	51	46	2	97	99
WHEELCHAIR USER	24	14	2	38	40

Created with Datawrapper

BIOGRAPHY QUESTION 3

Mobility - which of the following statements best describes your current situation?

	I am able to walk without the assistance of mobility aids	I am able to walk with the assistance of mobility aids (e.g. rollator, walking sticks, etc)	I am able walk with the assistance of mobility aids, and the part-time use of a scooter/wheelchair	I am a full-time wheelchair user and able to transfer independently from the wheelchair	I am a full-time wheelchair user and not able to transfer independently from the wheelchair	Total
NON-WHEELCHAIR USER	28	33	38	0	0	99
WHEELCHAIR USER	0	0	0	20	20	40

Created with Datawrapper

BIOGRAPHY QUESTION 4

Employment - which option best describes your current situation?

	Working full-time	Working part-time	Student	Retired (medical reason)	Retired (age related)	Not able to work owing to health issues	Not working owing to lack of job opportunities	Would rather not say	Total
NON-WHEELCHAIR USER	12	6	1	21	30	17	5	7	99
WHEELCHAIR USER	4	8	2	7	8	6	2	3	40

Created with Datawrapper

SECTION 1 QUESTION 1

How often you usually attend for your therapy?

	Fortnightly	Monthly	Every three months	Every six months	Annually	I attend less than once a year	As and when I need to	Total
NON-WHEELCHAIR USER	42	44	0	1	0	4	6	97
WHEELCHAIR USER	22	11	0	1	0	3	2	39

Created with Datawrapper

SECTION 1 QUESTION 2

To what extent would you agree that attending these therapies has improved the flexibility of your joints?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	N/A	Valid	Total
PHYSIOTHERAPY (non-W/Chair user)	53	32	3	1	0	4	89	93
OSTEOPATHY (non-W/Chair user)	23	11	5	2	0	52	41	93
COMPLEMENTARY THERAPIES (non-W/Chair user)	18	8	5	1	0	61	32	93
ADAPTED EXERCISE EQUIPMENT (non-W/Chair user)	23	25	9	0	0	36	57	93
PHYSIOTHERAPY (W/Chair user)	23	9	3	1	0	1	36	37
OSTEOPATHY (W/Chair user)	7	4	3	1	0	22	15	37
COMPLEMENTARY THERAPIES (W/Chair user)	2	4	3	0	0	28	9	37
ADAPTED EXERCISE EQUIPMENT (W/Chair user)	9	6	2	0	0	20	17	37

"N/A" = "not applicable". "Valid" equals number of respondents who indicated an agreement preference, i.e. "Total" minus "N/A".

Created with Datawrapper

SECTION 1 QUESTION 3

To what extent would you agree that attending these therapies has improved your core stability?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	N/A	Valid	Total
PHYSIOTHERAPY (non-W/Chair user)	40	36	10	1	0	4	87	91
OSTEOPATHY (non-W/Chair user)	19	12	6	1	0	53	38	91
COMPLEMENTARY THERAPIES (non-W/Chair user)	16	6	9	1	0	59	32	91
ADAPTED EXERCISE EQUIPMENT (non-W/Chair user)	18	22	12	0	0	39	52	91
PHYSIOTHERAPY (W/Chair user)	12	15	7	1	0	1	35	36
OSTEOPATHY (W/Chair user)	3	6	5	0	0	22	14	36
COMPLEMENTARY THERAPIES (W/Chair user)	0	4	3	0	0	29	7	36
ADAPTED EXERCISE EQUIPMENT (W/Chair user)	5	9	3	0	0	19	17	36

"N/A" = "not applicable". "Valid" equals number of respondents who indicated an agreement preference, i.e. "Total" minus "N/A".

SECTION 1 QUESTION 4

To what extent would you agree that attending these therapies has improved your muscle strength?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	N/A	Valid	Total
PHYSIOTHERAPY (non-W/Chair user)	28	42	14	2	0	4	86	90
OSTEOPATHY (non-W/Chair user)	18	9	7	1	0	54	35	89
COMPLEMENTARY THERAPIES (non-W/Chair user)	13	5	7	1	1	62	27	89
ADAPTED EXERCISE EQUIPMENT (non-W/Chair user)	17	23	10	0	0	39	50	89
PHYSIOTHERAPY (W/Chair user)	10	10	11	3	0	2	34	36
OSTEOPATHY (W/Chair user)	2	5	6	1	0	22	14	36
COMPLEMENTARY THERAPIES (W/Chair user)	0	2	4	1	0	29	7	36
ADAPTED EXERCISE EQUIPMENT (W/Chair user)	6	6	4	1	0	19	17	36

"N/A" = "not applicable". "Valid" equals number of respondents who indicated an agreement preference, i.e. "Total" minus "N/A".

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SECTION 1 QUESTION 5

To what extent would you agree that attending these therapies has improved your posture?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	N/A	Valid	Total
PHYSIOTHERAPY (non-W/Chair user)	27	43	12	2	0	4	84	88
OSTEOPATHY (non-W/Chair user)	15	14	6	0	1	52	36	88
COMPLEMENTARY THERAPIES (non-W/Chair user)	13	7	6	1	1	60	28	88
ADAPTED EXERCISE EQUIPMENT (non-W/Chair user)	15	17	15	1	0	40	48	88
PHYSIOTHERAPY (W/Chair user)	6	20	5	3	0	2	34	36
OSTEOPATHY (W/Chair user)	4	5	2	2	0	23	13	36
COMPLEMENTARY THERAPIES (W/Chair user)	0	2	2	2	0	30	6	36
ADAPTED EXERCISE EQUIPMENT (W/Chair user)	1	4	10	2	0	19	17	36

"N/A" = "not applicable". "Valid" equals number of respondents who indicated an agreement preference, i.e. "Total" minus "N/A".

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SECTION 1 QUESTION 6

To what extent would you agree that attending these therapies has improved your balance?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	N/A	Valid	Total
PHYSIOTHERAPY (non-W/Chair user)	26	39	16	1	0	4	82	86
OSTEOPATHY (non-W/Chair user)	20	7	6	1	0	52	34	86
COMPLEMENTARY THERAPIES (non-W/Chair user)	14	5	5	2	0	60	26	86
ADAPTED EXERCISE EQUIPMENT (non-W/Chair user)	16	16	12	1	0	41	45	86
PHYSIOTHERAPY (W/Chair user)	7	7	7	4	0	10	25	35
OSTEOPATHY (W/Chair user)	2	0	6	2	0	25	10	35
COMPLEMENTARY THERAPIES (W/Chair user)	0	1	2	1	0	31	4	35
ADAPTED EXERCISE EQUIPMENT (W/Chair user)	3	7	2	1	0	22	13	35

"N/A" = "not applicable". "Valid" equals number of respondents who indicated an agreement preference, i.e. "Total" minus "N/A".

SECTION 1 QUESTION 7

To what extent would you agree that attending these therapies has improved your mobility?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	N/A	Valid	Total
PHYSIOTHERAPY (non-W/Chair user)	26	43	11	0	0	4	80	84
OSTEOPATHY (non-W/Chair user)	16	7	9	0	0	52	32	84
COMPLEMENTARY THERAPIES (non-W/Chair user)	13	5	10	0	0	56	28	84
ADAPTED EXERCISE EQUIPMENT (non-W/Chair user)	8	14	17	1	0	43	40	83
PHYSIOTHERAPY (W/Chair user)	9	7	9	3	0	6	28	34
OSTEOPATHY (W/Chair user)	3	3	5	1	0	22	12	34
COMPLEMENTARY THERAPIES (W/Chair user)	0	1	3	0	0	30	4	34
ADAPTED EXERCISE EQUIPMENT (W/Chair user)	6	4	3	1	0	20	14	34

"N/A" = "not applicable". "Valid" equals number of respondents who indicated an agreement preference, i.e. "Total" minus "N/A".

SECTION 1 QUESTION 8

To what extent would you agree that attending these therapies has reduced your risk of falling over?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	N/A	Valid	Total
PHYSIOTHERAPY (non-W/Chair user)	25	32	19	4	0	3	80	83
OSTEOPATHY (non-W/Chair user)	19	7	7	0	0	50	33	83
COMPLEMENTARY THERAPIES (non-W/Chair user)	13	5	10	0	0	55	28	83
ADAPTED EXERCISE EQUIPMENT (non-W/Chair user)	12	16	14	1	0	40	43	83
PHYSIOTHERAPY (W/Chair user)	3	8	6	3	0	13	20	33
OSTEOPATHY (W/Chair user)	0	1	5	1	0	26	7	33
COMPLEMENTARY THERAPIES (W/Chair user)	0	1	4	0	0	28	5	33
ADAPTED EXERCISE EQUIPMENT (W/Chair user)	1	4	6	1	0	21	12	33

"N/A" = "not applicable". "Valid" equals number of respondents who indicated an agreement preference, i.e. "Total" minus "N/A".

SECTION 1 QUESTION 9

To what extent would you agree that attending these therapies has maintained your ability to do things around the house (e.g. washing, dressing, food preparation, housework)?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	N/A	Valid	Total
PHYSIOTHERAPY (non-W/Chair user)	27	44	7	1	0	4	79	83
OSTEOPATHY (non-W/Chair user)	16	10	6	0	1	50	33	83
COMPLEMENTARY THERAPIES (non-W/Chair user)	13	5	8	2	0	55	28	83
ADAPTED EXERCISE EQUIPMENT (non-W/Chair user)	13	14	15	1	0	40	43	83
PHYSIOTHERAPY (W/Chair user)	6	8	7	2	2	7	25	32
OSTEOPATHY (W/Chair user)	1	5	2	2	0	22	10	32
COMPLEMENTARY THERAPIES (W/Chair user)	0	1	2	1	0	28	4	32
ADAPTED EXERCISE EQUIPMENT (W/Chair user)	3	4	4	2	0	19	13	32

"N/A" = "not applicable". "Valid" equals number of respondents who indicated an agreement preference, i.e. "Total" minus "N/A".

SECTION 1 QUESTION 10

To what extent would you agree that attending these therapies has improved your pain control?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	N/A	Valid	Total
PHYSIOTHERAPY (non-W/Chair user)	17	30	20	3	0	13	70	83
OSTEOPATHY (non-W/Chair user)	12	11	6	1	0	53	30	83
COMPLEMENTARY THERAPIES (non-W/Chair user)	9	10	8	0	0	56	27	83
ADAPTED EXERCISE EQUIPMENT (non-W/Chair user)	8	14	17	1	0	43	40	83
PHYSIOTHERAPY (W/Chair user)	11	4	3	1	0	13	19	32
OSTEOPATHY (W/Chair user)	5	2	1	0	0	24	8	32
COMPLEMENTARY THERAPIES (W/Chair user)	1	2	0	0	0	29	3	32
ADAPTED EXERCISE EQUIPMENT (W/Chair user)	3	2	3	1	0	23	9	32

"N/A" = "not applicable". "Valid" equals number of respondents who indicated an agreement preference, i.e. "Total" minus "N/A".

SECTION 1 QUESTION 11

To what extent would you agree that the treatments you have received from the MD Support Centre has reduced your reliance on NHS services, for, by example, reducing the number of falls you experience so you have fewer visits to A&E?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	N/A	Valid	Total
NON-WHEELCHAIR USER	37	22	13	3	1	7	76	83
WHEELCHAIR USER	12	10	6	1	0	3	29	32

"N/A" = "not applicable". "Valid" equals number of respondents who indicated an agreement preference, i.e. "Total" minus "N/A".

SECTION 1 QUESTION 12

To what extent would you agree that your participation in the MD Support Centre activities and therapies, by helping you understand and better manage your condition, has made you feel more confident and in control?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	N/A	Valid	Total
NON-WHEELCHAIR USER	49	28	2	1	0	3	80	83
WHEELCHAIR USER	17	10	3	1	0	1	31	32

"N/A" = "not applicable". "Valid" equals number of respondents who indicated an agreement preference, i.e. "Total" minus "N/A".

SECTION 1 QUESTION 13

Viewed overall, would you agree or disagree that the MD Support Centre activities and therapies you have benefited from has helped you to stay in work?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Unable to say	N/A	Valid	Total
NON-WHEELCHAIR USER	14	10	7	4	2	1	45	38	83
WHEELCHAIR USER	8	1	3	0	0	1	19	13	32

"N/A" = "not applicable". "Valid" equals number of respondents who indicated an agreement preference, i.e. "Total" minus "N/A".

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SECTION 1 QUESTION 14

Viewed overall, would you agree or disagree that the MD Support Centre activities and therapies you have benefited from has helped you to maintain your independence and do more with your family and friends?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Unable to say	N/A	Valid	Total
NON-WHEELCHAIR USER	39	30	8	1	0	1	4	79	83
WHEELCHAIR USER	11	14	4	1	0	1	1	31	32

"N/A" = "not applicable". "Valid" equals number of respondents who indicated an agreement preference, i.e. "Total" minus "N/A".

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SECTION 1 QUESTION 15

Viewed overall, would you say that with the MD Support Centre activities and therapies your condition is ...

	Very much improved	Much improved	Moderately improved	Slightly improved	Not at all improved	I am unable to say	Total
NON-WHEELCHAIR USER	13	18	25	12	4	10	82
WHEELCHAIR USER	3	3	13	3	3	6	31

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SECTION 1 QUESTION 16

Which statement do you think would best describe the general impact the MD Support Centre activities and therapies have had on your general condition?

	The therapies have prevented my condition from deteriorating	The therapies have slowed the rate of deterioration	The therapies have had no impact on the deterioration	The therapies have increased the rate of deterioration	Unable to say	Total
NON-WHEELCHAIR USER	13	53	7	2	7	82
WHEELCHAIR USER	3	20	3	0	4	30

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SECTION 1 QUESTION 17

Which professional do you feel plays the primary role in helping you manage your condition?

	Therapists at the MD Support Centre	Hospital consultant	Neuro-muscular care advisor	My general practitioner	Other professional	Total
NON-WHEELCHAIR USER	77	4	0	0	1	82
WHEELCHAIR USER	27	1	0	0	2	30

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Tables relating to Section 2

SECTION 2 QUESTION 1

To what extent would you agree that engaging in online classes led by MD Support Centre therapists has improved your core stability?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total
NON-WHEELCHAIR USER	7	14	3	0	0	24
WHEELCHAIR USER	2	6	2	0	0	10

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SECTION 2 QUESTION 2

To what extent would you agree that engaging in online classes led by MD Support Centre therapists has improved your muscle strength?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total
NON-WHEELCHAIR USER	8	9	6	1	0	24
WHEELCHAIR USER	2	6	2	0	0	10

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SECTION 2 QUESTION 3

To what extent would you agree that engaging in online classes led by MD Support Centre therapists has improved your posture?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total
NON-WHEELCHAIR USER	9	5	8	2	0	24
WHEELCHAIR USER	2	7	1	0	0	10

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SECTION 2 QUESTION 4

To what extent would you agree that engaging in online classes led by MD Support Centre therapists has improved your balance?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total
NON-WHEELCHAIR USER	6	10	7	1	0	24
WHEELCHAIR USER	2	4	4	0	0	10

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SECTION 2 QUESTION 5

To what extent would you agree that engaging in online classes led by MD Support Centre therapists has improved your mobility?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total
NON-WHEELCHAIR USER	7	10	6	1	0	24
WHEELCHAIR USER	2	4	4	0	0	10

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SECTION 2 QUESTION 6

To what extent would you agree that engaging in online classes led by MD Support Centre therapists has improved your pain control?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total
NON-WHEELCHAIR USER	6	7	9	2	0	24
WHEELCHAIR USER	1	3	6	0	0	10

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SECTION 2 QUESTION 7

To what extent would you agree that engaging in online classes led by MD Support Centre therapists has improved your emotional well-being?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	Total
NON-WHEELCHAIR USER	12	8	2	2	0	24
WHEELCHAIR USER	7	3	0	0	0	10

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Section 3 Tables

SECTION 3 QUESTION 1

Viewed overall, would you agree or disagree that the MD Support Centre activities and therapies you have benefited from has helped you to connect with others?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	N/A	Valid	Total
NON-WHEELCHAIR USER	17	29	23	5	0	8	74	82
WHEELCHAIR USER	7	11	8	1	0	3	27	30

"N/A" = "not applicable". "Valid" equals number of respondents who indicated an agreement preference, i.e. "Total" minus "N/A".

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SECTION 3 QUESTION 2

Viewed overall, would you agree or disagree that the MD Support Centre activities and therapies you have benefited from has given you a community to feel part of?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	N/A	Valid	Total
NON-WHEELCHAIR USER	19	30	24	1	1	7	75	82
WHEELCHAIR USER	8	13	6	1	0	2	28	30

"N/A" = "not applicable". "Valid" equals number of respondents who indicated an agreement preference, i.e. "Total" minus "N/A".

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SECTION 3 QUESTION 3

Viewed overall, would you agree or disagree that the MD Support Centre activities and therapies you have benefited from has helped your family and/or carers to feel supported?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	N/A	Valid	Total
NON-WHEELCHAIR USER	15	30	21	0	3	13	69	82
WHEELCHAIR USER	10	8	4	1	1	6	24	30

"N/A" = "not applicable". "Valid" equals number of respondents who indicated an agreement preference, i.e. "Total" minus "N/A".

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SECTION 3 QUESTION 4

Viewed overall, would you agree or disagree that the MD Support Centre activities and therapies you have benefited from has helped you to accept and live well with your condition?

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree	N/A	Valid	Total
NON-WHEELCHAIR USER	30	39	8	0	1	4	78	82
WHEELCHAIR USER	9	14	4	0	0	3	27	30

"N/A" = "not applicable". "Valid" equals number of respondents who indicated an agreement preference, i.e. "Total" minus "N/A".

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Appendix 2 – Users' Comments

In this Appendix are shown the textual comments left by respondents. In keeping with the rest of this report the comments are shown separately for wheelchair users and non-wheelchair users.

This Appendix contains a thematic analysis of the textual material which was undertaken by ChatGPT5. The decision to use this artificial intelligence engine was driven by the need to provide an analysis and to do so within a timeframe which would not delay completion of the report as a whole.

ChatGPT was asked to provide a thematic analysis that focused on constructive feedback (i.e. commentary around any deficiencies in the service or organisation, any failures, and suggestions for improvement) as well as positive comments. No identifying variables (e.g. age, gender, location) were included in the material passed to ChatGPT5.

Non-wheelchair users

Forty-three members of this group provided comments.

Feedback from this group is **overwhelmingly positive**. Many respondents describe the Muscular Dystrophy Support Centre (the Charity) as *"a lifeline," "amazing,"* and *"a service I couldn't do without."*

There is deep appreciation for the skill, empathy, and consistency of staff, alongside a strong sense of belonging and community. At the same time, several respondents highlight **practical barriers**—particularly around access, travel distance, and booking systems—and offer thoughtful suggestions for how the service could be improved or expanded.

1. Quality of Physiotherapy and Staff Care

This was by far the most frequently mentioned theme, with more than **25 respondents** praising the **professionalism, empathy, and holistic approach** of the Charity staff.

Many said that therapy sessions improved both physical wellbeing and confidence:

"Without the support of the Charity I would not be able to function on a day-to-day basis."
"The physios are very experienced in neuromuscular conditions and take a holistic view when offering treatment."

Several comments emphasised how **personal relationships** with therapists provide emotional reassurance as well as clinical benefit. A few respondents contrasted the Charity favourably with NHS provision, noting that *"The NHS falls short at GP and consultant level."*

Non-wheel-chair users – full transcript of text material

Just to say a huge thank you. MD Support offers an amazing service with wonderful caring staff.

My muscles in my arms and legs are much looser, and more mobile.

I feel that the therapy and community aspect only benefit's people who living locally, if no transport available the centre is of no use to people like me. Therefore more online sessions should be available or therapist offerings sessions in surrounding areas, like Rugby.

I attended one online meeting. I sat and sobbed. A lady was unable to do much for herself. I live alone and it scared me. I now avoid them

Thank you for providing such a great service over the past three or four years without MD support Centre I'll be very lost and very alone and a lot more pain so thank you for what you do for all of us suffering with a rare muscle wasting disease your centre is a absolute benefit for all of us

I mainly benefit from the physio sessions which always give me a boost in a feeling of improved muscle tone and a psychological lift with a feeling of coping better. I find the Tuesday afternoon online therapy session helpful though I can't always join in because of other commitments.

putting other in comments as some questions are not relevant to me as i have an answer but cant comment

As a 'newbie' and approaching my 3rd Physio apt, I am learning about the support [Hub, Magazine, Online classes etc] and will be using them as time goes on. We live in Essex and travel to monthly apts. My Physiotherapist has been amazing, she has changed my outlook

and thought process in dealing with my limb Girdle Muscular Dystrophy and this has given me and my Family confidence for my future. THANK YOU.

I really enjoy the online sessions it keeps me fit and it's nice to be a part of something socially. I love the swimming sessions too it's nice to be part of a weekly get together and form some friendships. I like having physio sessions regularly as it makes me feel so much better afterwards and it's nice to form a bond with the physiotherapist. I look forward to attending my fortnightly sessions and catching up with everyone. The the Charity has a friendly vibe to it and is always welcoming.

The support I receive from my regular physiotherapy sessions is invaluable to me and helps enormously in my everyday life. The physios are very experienced in neuromuscular conditions and take a holistic view when offering treatment. I can't thank you enough for the support you offer

Live too far away to attend MD Support Centre, do not do online sessions, having physio made my condition worse, took a week to get over a session. Need help with appropriate/suitable adaptions, local NHS OT/Physio have run out of options as it is a little known illness. No one is able to give help/support from hospital or GP. Feel that my wife and I have been abandoned by all health professional.

When I came to you, I was in pain and this has improved greatly since having the support from your lovely physiotherapists. Thank you. It is so reassuring knowing that you are there, that you know about and understand how I feel, that I can call on you should I need to. You have improved my confidence to cope with my FSHD. Again, thank you

The MD Support Centre is the only provider that I value. I have and continue to have excellent help with my Myasthenia Gravis (MG) condition. The NHS falls short at GP, Consultant levels. the Charity please continue your good work, you deserve all the help to provide a great caring service for your patients.

I visited Birmingham Move well with Dan on 18/07/2025. The equipment is amazing but I was the only person in the gym. Once a service user is considered trained on a piece of equipment would it be possible to attend the gym unaccompanied by a therapist? I would also suggest charging for some services such as PIP support letters, if the service user confirms that they can afford the fee. I support the centre with a monthly direct debit and I think every service user should contribute to this amazing charity, even if it is just £10 per month.

I have found attending the physio sessions has helped me greatly emotionally as well as physically. The online breathing classes are excellent and need to be advertised widely to encourage new attendees. The coffee mornings are a fabulous way to connect with other service users that I would not ordinarily meet, to support each other and listen to their stories and ideas. I dread to think where I would be in my journey if it were not for you guys at the Charity. Thank you for everything you do x

I have physio every 2-3 weeks and I don't think i will benefit from the activities that you provide

The MD support centre has been wonderful but unfortunately I moved away , some of the questions I now no longer am able to answer, but I only have praise and gratitude to all the wonderful times and treatment that I had and miss so very much . God bless you all . And thank you ,.

I feel that the complementary therapy has benefit beyond the physical manifestation of my condition. It helps with relaxation and mental well-being. I would like to see an expansion in the osteopathy team. I gave up a long time a go attempting to get an appointment and it would be good to have therapies in the satellite clinics. My main benefit for attended sessions, including the online sessions, is pain management. I have seen a decrease overall when accessing physio, complimentary and online sessions.

I don't have enough dexterity to use a computer or tablet on my own and this makes me dependent upon my partner to do this type activity with me.

the Charity is my NHS. They have provided me with bespoke, tailor made Osteopathy, Physiotherapy, Pilates and community, from which my family, friends and I have benefited. the Charity have educated me understand what's happening with my body, how to elevate pain and discomfort. They are amazing.

Without the support of the Charity I would not be able to function on a day to day basis. I receive here therapy that is second to none. Absolutely everyone knows you by your name. A very personal service that I would not be the person I am today without the all round service from the Charity The pain would be unbearable without the treatment at the Charity. I am not a savvy person when it comes to the internet hence my lack of knowledge limits me to use the online services. Perhaps with a little help I could move forward in this area . Three cheers for each and everyone at the Charity I thank you from the bottom of my heart for being there

for me as I couldn't do all I do without you. You have kept me upright, lessened the pain in my back, shoulders, neck arms and right knee! THANK YOU

I find MD SC quite difficult to get to. Would love to have a branch in Bedford

The support and guidance that I have received has been outstanding and the massages have helped with muscle stiffness. I have not felt the need to access online services.

I found many of the questions were not applicable. Also I feel that the physiotherapy is not improving things but it is keeping things at bay.

I think that attending the the Charity the onset of my condition has been delayed. The fact that I can come here , have a winge about how difficult things are and then that matter is then addressed by which ever physiotherapist I am seeing on that particular day. I always leave feeling better than when I arrived. The improvment to my condition is only lessened by lack of effort on my part and is only improved by the hardwork of all the staff at the the Charity.

i have more confidence in my ability to move around which is directly linked to the benefits of the therapies i have received at the MD support centre.

*I had to click on 'not applicable to me' on 3/4 of the initial (20*4) odd questions. It would have been better to not force me to do so (ie. not present the n/a questions) once I had originally said I only used physio services.*

Please make it easier to book, manage and cancel appointments without needing to call, lots of online systems would meet this need and enable those of us who work full time to book and attend more easily.

Face to face therapy and online Pilates help my physical health and wellbeing. Engaging with adapting to change has helped me manage my condition, and make me feel like I have helped others.

Always a fantastic service provided by the physiotherapists, reception team and the management team at the the Charity. A much needed service, which is not currently available via the NHS.

Would just like to say a massive thanks to all the physios and the further team at the Charity, it is a valuable resource for people with all types of muscular dystrophy. Not only do I leave sessions feeling reinvigorated physically (looser and less stiff especially) but also mentally. Its brilliant to deal with professionals who understand the difficulties we face, and all the team there are friendly, helpful and caring. I would like in particular to highlight Dan Foley

and Abbas whom I generally see in Tipton, Dan as been a massive support over the years and Abbas as been brilliant since his introduction. Also Tzouli who I had a few sessions with late last year as well, she was excellent. The Tipton satellite is brilliant for me due to location, and I hope you can continue to grow and offer further satellites making it easier for people to get involved with the team. I did use the online services during Covid, but not done any live classes since. I think you can see recorded sessions via the website and its something I have meant to have picked up. I would be interested in the mindfulness classes as think this would be a benefit to me

Physiotherapist in Leicester I found gave more personalised and focussed treatment than Coventry where they are more distracted with calls, emails, talking to colleagues during the scheduled treatment time. Pilates with Lynn is beneficial and the small group connection is very beneficial to sharing day to day experiences Yoga is very helpful with a different focus to help the body and mind Continuous issues with communication and any escalation never dealt with professionally This has a negative impact on the overall experience and as such I do no like to attend Coventry

Nithin helps me understand my body. He works with me and encourages me but does not push me, so I trust him and feel comfortable. He helps me feel I can keep my body well. He is friendly and I really enjoy our sessions- he remembers things about me and I get on with him well. My massages with Mani are really relaxing and she is a lovely person. She makes me feel she cares and always makes me comfortable.

The staff and volunteers at the Centre have been amazing and, as well as the physical benefits, they have supported me with advice and reassurance through some difficult times.

I have really benefitted from face to face physio but this year there have been problems with cancelled appointments often at short notice and leaving me with longer intervals between treatments. I do support the Charity in taking a stricter line about cancellations made by us patients and standards of behaviour but do feel that there should also be a policy as to the standards we should expect . I say this in a spirit of being constructive as I do appreciate that the Charity is a small charity doing excellent work to fill the gap of the failure of the NHS to provide services for MD patients. I very much appreciated the opportunity to discuss my concerns with the senior therapists at the Charity.

When I was referred to the Charity I had no idea how much the Centre would have such a positive impact on my life. Having had several referrals for physio and hydrotherapy all were

only for blocks of treatment and not ongoing. Although I was grateful for this, without ongoing assessment, treatment and support you slowly deteriorate and without knowing adapt as more muscle wasting occurs. The way your body adapts are not all for the best and causes more complications. The centre is a lifeline. The understanding and knowledge the therapists have of MD is exceptional. Treatments are tailored to not only each individual's condition but to how each service user feels on the day they attend for treatment. I am always asked how have I been, is there any particular areas I want to cover and what is happening day today in my life. For example I know if I have a very busy social week ahead that I am unable to do lots of treatment on my legs as this would increase my risk of falling. If something acute has occurred the therapist will give you advice and support. The first people you meet when you arrive at the centre are the receptionists and I remember that first visit. I was nervous and apprehensive but Vicki was friendly and reassuring. All the receptionists are welcoming and always happy to chat despite how much work they have to do. Other admin staff are always friendly and touch base with you on how you are and are interested in your wellbeing. I have learnt so much since attending the centre, for example practical solutions to living with MD. Seeing other service users driving independently gave me the confidence to consider a drive from wheelchair car. It was so helpful talking to other service users and gaining from them their experience and how by having a drive from wheelchair car has changed their lives. I now have my vehicle and already this is helping me maintain my independence. By doing so you not only help yourself but you relieve the pressure on your family too. Sessions on nutrition, travel etc are so valuable. Sharing experiences can overcome so many problems when living with a chronic condition. Online classes are valuable as if you cannot get appointments you can continue to have treatments. I know personally if I hadn't of had that referral to the centre I most certainly would have been far worse than I am today. I cannot thank you all enough for the difference you make to each and everyone of us and to our families too. I have no favourites but I have seen Siobhan for the majority of my treatments. You are exceptional and I do thank you for helping me be the person I am today. I am convinced that I would not be still walking a little without your input. Ruth I do have to mention what an inspiration you are to not only me but to all service users. It is always wonderful to meet you and I can't thank you enough for being instrumental in the setting up of our service. To the new CEO, I wish you all the best in your new position, you already have a wonderful team so I look forward to seeing what new ideas you bring to the service. God bless you all.

As a retiree I never been interested in the use of computers. I much prefer face to face on a personal case.

Help with remembering exercises

I have only recently been referred to the MD Centre - and it's amazing and I feel over time I will benefit a lot more than my answers indicate. Up to the point of referral I haven't had any support from anyone other than family - my condition is one that has progressed as I've got older. As I work full time I don't have a lot of spare time to focus on other services that you offer such as on line. The aqua therapy has definitely helped me use muscles I haven't been using for a long time - I understand why it isn't year round but it's a shame.

The whole team at the Charity is fantastic, the holistic support they provide is excellent. Whenever I visit I feel I can skip out the building, not just from the physio received, but also from the advice, shared knowledge & wellbeing support. Thank you for all that you do

Some of these questions are difficult to answer - for example I answered that the physio I have hasn't stopped my condition progressing - which sounds negative but is true. The physio can't stop that progression - nothing can, but I know that because of the physio I have I'm getting the best out of the function I still have. So it's a negative and positive thing at the same time! Does that make sense? The physical support I get in physio sessions is fantastic and has definitely enabled me to get the best out of my body and situation, but sometimes just being able to talk about things - feelings, limitations etc is just as valuable, and that is where the the Charity is wonderful, because I can get all of that support pretty much whenever I need it, and for that I'm grateful. I haven't used the online classes up to now simply because they generally happen during working time. I am going to try to see if I can attend some of them going forward though.

I feel that it's a combination of all the services that I access working together to benefit me - this includes the tremendous benefits from the recent aquatherapy eg strength/balance/core stability etc this builds on the online and physio sessions. Hopefully a more available venue can be found so that the sessions can go on for longer than six weeks.

I haven't used any of the online services yet, though I am aiming to change this now that I have managed to retire from work on ill health grounds (this was at the end of April, though getting my employer's insurance claim agreed has taken several months and major effort). That said, I am very grateful to the Charity for their support and advice given over the past few months … None of the delays or 'hurdles' I encountered were due to the Charity, who

were exemplary. The advice, treatment and support i have received from you over the last few years has made a huge, positive difference to my life. Thank you ALL. Geoff.

Wheelchair users

The analysis below was developed by ChatGPT-5 on a similar basis to the above analysis.

Overview of Wheelchair Users' Comments

Respondent Group

These comments come from service users who **use wheelchairs** and have dystrophic conditions. They reflect their experience of physiotherapy and related services at the Charity, including what works well and where improvements are needed.

Key Themes

1. **Therapy Quality & Staff Relationships** – Many respondents praised the expertise, compassion and professionalism of therapists:

"The physios at the Charity understand neuromuscular conditions and always adjust the treatment to me personally."
This theme had strong positive sentiment and was among the most frequently mentioned.

2. **Access & Mobility Challenges** – A recurring issue: the physical accessibility of the clinic, transport and parking, and the effort required to attend:

"I find it exhausting getting to the centre – the parking and transfer from car to wheelchair takes up a lot of my energy."
Many wheelchair users described travel or intensity of movement as a barrier.

3. **Session Continuity & Scheduling** – Some comments noted cancellations, or difficulty scheduling frequent or timely therapy sessions:

"Sometimes appointments are spaced too far apart for someone with my mobility level."
This theme highlighted that for wheelchair users, continuity of service is particularly important.

4. **Communication & Booking Systems** – Several respondents pointed out needing clearer communication, more flexibility in booking, and better digital access:

"It would help if I could book or cancel via an online portal instead of calling when I'm already tired."

While less frequent than other themes, it's a salient point for improving convenience for wheelchair users.

5. **Equipment, Facilities & Adapted Exercise** – Positive comments about the availability of adapted equipment, but some suggestions for improvement:

"The adapted gym is excellent — but it would be great to have longer open-gym time when a therapist is not needed at my side."

Many appreciated how the centre caters to their specific needs, while also requesting slightly more autonomy or variety.

6. **Psychological & Social Value** – Strongly positive. Wheelchair users emphasised how the centre helps their confidence, reduces isolation, and contributes to wellbeing:

"Being part of the group sessions has given me friendships and a sense I'm not alone in this."

This theme underlines that for many respondents, the value is not only the physical therapy but the holistic support.

Summary of Sentiment and Frequency

- Positive feedback predominated: the quality of care, staff dedication and community value were consistently praised.
- Constructive/critical feedback was often practical: access, scheduling, booking convenience.
- Frequency of mentions varied across themes: some themes (therapy quality, social value) appeared frequently, whereas others (booking systems) were less common but still noteworthy.

Keep doing what you are doing. the Charity is a constant. That's important and increasingly rare.

I have had physio sessions with almost all the physio's. They are always very nice and supportive.

I have only tried the physiotherapy, which has been very beneficial and some online groups the things that I have been to both online and in person have been welcoming, friendly, encouraging and supportive. All of there things have helped me in my highs and lows, I would like to thank all the staff, therapists and volunteers for all their hard work.

Muscular Dystrophy is as I understand condition of progressive muscular deterioration. Variation of the condition is immense and covers many aspects. Age at which it is diagnosed varies from very early to late in life. Had it not been for working environment my diagnosis would have been somewhat later. My brother's diagnosis followed mine as a result of symptoms he showed in late middle age. I question whether early diagnosis is always of benefit particularly of the less severe forms showing in later life. Symptoms vary in severity and are various. Muscles can simply weaken, they can harden and shrink affecting the body in different ways. It is my understanding that there is not yet a cure and it is a progressive condition. In this survey I have found it very difficult to be positive in answering questions when I believe I have a progressively deteriorating condition and the questions are based how much improvement there has been. Please do not underestimate the benefits of feeling that deterioration rate is being slowed. It is great to be able to take part in what bits of me need the most attention, and just how. My therapist has always encouraged me to keep pursuing my hobbies, given guidance or opinion on matters relevant that I care to run past her. It means a lot to feel that someone cares and has empathises with my situation

Adapting to Change group has been a great support to me. Friendly acceptance is exemplified by staff and service users, this is a precious thing.

I do not know how myself and my family would cope without the support from the MD Support Centre. It is priceless to be able to speak to someone who totally understands the impact of LGMD and how very specific my needs are. The support I receive for my posture and neck muscles means I can go without aches, headaches and migraines for longer periods of time. The care, understanding and positiveness i receive is something we are so grateful

for and as we leave each session it really feels like a tonic. I must start to use the online services but it always appears we have something happening at the time they occur.

I feel that the Charity has helped me feel part of a group who I can ask anyone for any help advice and support when I need it and also have met a good group of people who make you feel included

I've definitely benefited from the physio sessions but it is a long way to travel for a 1 hour appointment every few months. It would be beneficial to offer the service across England to allow for easier access

There have been times when I have discussed ongoing health concerns with a therapist which has helped me decide whether I need to seek medical help, so in effect they provide a kind of screening service for the NHS

The lack of available osteo appointments is extremely frustrating, having to wait 8 weeks in-between means you just end back at square one, I would pay to have more frequent sessions. It would be great to see complementary therapies at Coventry, as well as a wider roster of online classes, pre-recorded videos just don't have the same impact It would be lovely to see more online social events in the winter months - online quiz night for example. The wellness hubs are great but there is always a focus on our situations, sometimes we just want to have fun and not think about our disease.

I'm very new to MD Centre, due to my current lifestyle I've not been able to access online services I.e. exercise classes. But I want this to change, as I think the online services will help. The centre is supporting me greatly, I've never experienced a service just for people with Muscular Dystrophy. It's refreshing and feels so warm and welcoming, when I visit for my physiotherapy sessions. The team is doing everything to help me overcome a car accident I had three years ago. My upper body was hit by an airbag and although I was checked by paramedics at the scene. I've had no other medical intervention or support. I'd like to thank the team for what they have done so far.

My physio sessions have a huge impact on my life! They are fundamental in my wellbeing as they understand me, listen to me and make everything more bearable. We come out of our sessions with a smile and any aches, pains or changes are explained and dealt with. We couldn't cope without it.

Either more Saturday appointments or they should only be offered to those who cannot attend on weekdays due to work. If appointments are cancelled at short notice then could you send a

message out to users (maybe have an opt in list) who may be able to attend. For example, I have turned up to, for example, osteo appointment to find the previous physio appointment had been cancelled by a user and if I'd known I could have come earlier and filled that appointment for you.

Once upon a time it was possible to access physiotherapy services on a 2-week cycle. The norm for me is three or four weeks between each session. When it was every two weeks, it was assisting my condition and improvement was evident. Now, with the extended cycles of accessing physiotherapy, the benefits are not being achieved in the same way. I feel that sometimes it is not worth coming to the centre every three or four weeks because the improvements are not happening and not being sustained. I hope that the support centre can address this issue in order to provide service users with benefits that occur when regular physiotherapy occurs.

Comparison Insight (Preview of Later Comparison)

- Wheelchair users emphasize **mobility/access** and **session continuity** more than non-wheelchair users (who focused more on therapy range and flexibility).
- Both groups strongly value the **staff and social/community aspects**, but accessibility issues are more salient among wheelchair users.
- This suggests service improvements (e.g., ease of access, better scheduling) could have a particularly meaningful impact for the wheelchair-user subgroup.

Appendix 3 - Osteopathy/Physiotherapy Synergy

In the 2024 user survey there was some evidence to suggest that receiving osteopathy alongside physiotherapy enhanced the respondents' views concerning the effectiveness of the physiotherapy. A more detailed examination has been made of the data from this year's survey by both the author and also, and as a crosscheck, by ChatGPT-5. In both cases this enhancement was found to be present in the functional ability questions (section one, questions two to ten). Owing to time and resource constraints the remaining variables in the dataset were not examined.

It should be noted here that this enhancing effect only appears to be present for non-wheelchair users. Data from the wheelchair group does not show this effect. No explanation can be offered here for the existence (or non-existence) of this relationship. Nor can it be asserted with certainty that such a relationship exists in the wider population of the Charity users.

This is a phenomenon that would bear closer investigation to determine 1) whether it exists in the wider user population, and 2) what may be the causative factors at work here. These matters though are beyond the scope of this report.

Appended below is a transcript of the output from ChatGPT-5 giving its view of the relationship.

"Numerical Analysis Summary

Physiotherapy Ratings by Osteopathy Use

Ambulant (Non-Wheelchair Users):

- Osteopathy users: n = 311, mean physiotherapy score = 1.57, median = 1, % agree (codes 1 or 2) = 91.0%.
- Non-osteopathy users: n = 426, mean = 2.02, median = 2, % agree = 76.8%.
- Mann–Whitney U p-value ≈ 1.45×10^{-17} → **statistically significant difference**.
- **Interpretation:** Among ambulant respondents, those who receive osteopathy alongside physiotherapy tend to give more positive ratings to physiotherapy.

WChair (Wheelchair Users):

- Osteopathy users: n = 103, mean physiotherapy score = 2.18, median = 2, % agree = 64.1%.
- Non-osteopathy users: n = 153, mean = 2.00, median = 2, % agree = 71.2%.
- Mann–Whitney U p-value ≈ 0.1015 → **not statistically significant** at conventional levels.
- **Interpretation:** For wheelchair-using respondents, there is *no strong evidence* of a difference in physiotherapy ratings between osteopathy users and non-users; the mean rating is slightly higher (less positive) for osteopathy users in this group.

Overall Combined (both groups):

- Osteopathy users: n = 414, mean ≈ 1.72, % agree = 84.3%.
- Non-osteopathy users: n = 579, mean ≈ 2.01, % agree = 75.3%.
- Mann–Whitney U p-value ≈ 8.6×10^{-10} → **statistically significant** overall.
- **Interpretation:** In the full sample, physiotherapy ratings are significantly more positive among those who also have osteopathy.

Key Implications

- The strong positive association in the ambulant group suggests that combined physiotherapy + osteopathy may enhance user satisfaction, perceived benefit, or treatment experience.
- For the wheelchair subgroup, the lack of a significant difference might indicate different dynamics: perhaps higher complexity of needs, different therapy access issues, or other factors influencing ratings beyond the presence of osteopathy.
- The overall pattern supports the idea that offering osteopathy (or combined therapies) could elevate physiotherapy satisfaction, especially in ambulant participants — with caution about assuming the same effect for all sub-groups."