MDSC Service User Survey 2024

Survey Report

Prepared by

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Executive Summary

An annual survey of the MDC service users is made in order to gauge service user satisfaction with the facilities provided and the outcomes from the therapeutic interventions which they receive.

Questionnaire distribution commenced on the 1st of August 2024 and terminated on the 30th of September 2024. Distribution was electronic, via e-mail, and was transmitted to 586 addresses in the MDSC database. The survey achieved a response rate of 21% in terms of MDSC's registered service users.

A descriptive mode of analysis was adopted. Question formats were standardised where possible to single choice "radio button" variables (acting as ordinal variables). There were, in addition, three open text questions where respondents could provide more detailed answers. Results are presented in graphical form, as either bar graphs (for categorical variables) or segmented doughnut graphs (for ordinal variables).

Opinions regarding the efficacy and health promotional benefits of MDSC therapies were captured using ordinal variables, arranged on a five-point scale ranging from "strongly agree" to "strongly disagree". Survey responses were analysed alongside demographic data held by the MDSC.

Service users access therapies at the MDSC headquarters in Coventry (63% of users attend here) and at their satellite therapy clinics in Birmingham (16%), Leicester (6%), Daventry in Northants (4%-launched in 2024), Tipton in the Black Country (9%) and Droitwich (2%-Osteopathy only).

The majority of service users attending the MDSC are men (56% men, 44% women). The average ages are an arithmetic mean of 52.7 years for women (median 52.5 years) and an arithmetic mean of 50.5 years for men (median 49 years).

Attendance frequency ranged from once every fifty-two weeks to once every two and a quarter weeks. Nearly half of the service users attend at a frequency of at least one or more occasions per month. Forty-two percent are drawn from the west Midlands region, 13% from Leicestershire and Warwickshire, 9% from Worcestershire, 4% from Nottinghamshire and 3% from Northants, with other users travelling in from further afield.

In the main the respondents report that their presence in the Centre is mostly physical, attending face to face sessions, with only a relative minority (36%) choosing to access 'virtual', or online, therapies.

Among the principal findings in terms of the outcomes of MDSC support are:

94% of respondents agreed that physiotherapy and osteopathy had improved the flexibility of their joints. 90% of the respondents agreed that the use of adapted exercise equipment had improved joint flexibility, while 89% of respondents indicated that it was complementary therapies that had improved the flexibility of their joints.

Maintenance of muscle strength receives similarly high levels of agreement. 82% of respondents agreed that this was due to the use of adapted exercise equipment. 80% of respondents attributed maintenance of muscle strength to osteopathy, 72% to physiotherapy and 60% choosing complementary therapies.

73% attributed a reduction in falls to the use of adapted exercise equipment (available at the Coventry HQ). 71% cited physiotherapy as being responsible with 65% choosing osteopathy and 65% choosing complementary therapies.

83% indicated that the MDSC support they had received had helped keep them out of hospital and reduced their reliance on other healthcare services.

81% said the support of the MDSC had either prevented or slowed the deterioration of their condition.

87% of respondents agreed that participating in osteopathy had improved their pain control, 78% indicating complementary therapies to be responsible, 75% selecting physiotherapy and 49% reporting that the use of adapted exercise equipment was responsible.

91% agreed that the support of the MDSC, by helping the respondents to an improved understanding and management of their condition, allowed them to feel more confident and in control. 86% agreed that the MDSC support they had received assisted them to live well with their dystrophic condition.

86% said that our online support had helped them to maintain their emotional wellbeing, and 78% said our support helped their family and carers to feel supported.

Respondents view the clinical aspect of their relationship with the MDSC as very significant. 88% of the respondents believe that the MDSC therapists play the primary role in helping them manage their condition, which represents an increase on the 65% reported in the 2023 survey. By contrast, only 3% of the respondents report that their NHS consultant plays this role, down from the 16% reported in the 2023 survey.

Respondents believe they have been helped to remain in work through the support of the MDSC. More than half of those for whom this question was applicable felt the supportive impact of the MDSC had helped them remain in employment.

More than eighty percent of the respondents agreed that the support of the MDSC had allowed them to maintain independence and to do more with family and friends.

Respondents clearly felt that the range of interventions from the MDSC were very valuable.

It is apparent that in the view of those who responded that the work and support which the MDSC offers is seen as extremely valuable. Respondents put a high rating on the effect that the therapies they receive have in managing their conditions and allowing them to achieve an enhanced quality of life.

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MDSC Service User Survey 2024

(1) Introduction

An annual survey of the MDC service users is made in order to gauge service user satisfaction with the facilities, and therapeutic interventions, available through the various MDSC centres. Results from this survey are then shared with both service users and the charity's funding bodies.

(2) Methods

The survey was launched on the 1st of August 2024 and was terminated on the 30th of September 2024.

A publicity campaign accompanied the launch. Initial notification of the questionnaire was via e-mail and was transmitted to 586 addresses in the MDSC 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 returned surveys totalled 121 which represents a response rate of approximately 21%.

For the 2024 survey the questionnaire was re-designed, with questions being re-worded and re-formatted and reduced in number. These quite substantial changes to the questionnaire structure and content make direct comparison of the 2023 results with the 2024 results problematic.

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. Question formats were standardised where possible to single choice "radio button" variables (acting as ordinal variables). There were, in addition, three open text questions where respondents could provide more detailed answers.

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

- a first section 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.
- a second section asking for respondents' views regarding the various online therapies available; and,

[1] located at <www.questionpro.com>

〉 a third section seeking respondents' general views on the overall impact of the MDSC therapeutic regimes.

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

(3) Results

A descriptive mode of analysis was adopted. Results are presented in graphical form, as bar graphs (for categorical variables) or segmented doughnut graphs (for ordinal variables).[2] The number of responses available for analysis per question ranges between 78 and 121, except for those questions in section two specifically targeting online therapies where the number of responses is much lower.

A detailed breakdown of the quantitative survey results, in graphical and tabular form, is presented below in section one and section four of the Appendix.

The first question in section one asks about the frequency of visits to the MDSC and is discussed in detail below. The remaining nine questions in section one are oriented to the physiological and other impacts of the various therapeutic interventions. The therapies are organised under four headings: physiotherapy, osteopathy, complementary therapies and the use of adapted exercise equipment.

The dimensions of health and social function covered by the variables include, inter alia, mobility, muscle strength, pain control and activities of daily living. These variables are ordinal, arranged on a five-point scale ranging from "strongly agree" to "strongly disagree" with a sixth option of "not applicable. One option only from these can be selected by the respondents.

Each of these questions allows the respondent to rate the impact of the therapeutic intervention separately, thus allowing for a greater discrimination in the assessment. It should be noted that while every respondent will be receiving - or will at some point in time have received - physiotherapy only a smaller number will have access to, or be able to make use of, the other therapeutic interventions. For instance, adapted exercise equipment is only available in Coventry.

The number of respondents providing answers regarding osteopathy, for example, ranges from 47 to 33, while the numbers for physiotherapy fluctuate from 69 to 110. It is apparent from the tenor of the answers given that respondents remain very satisfied with the quality and range of services provided by the MDSC.

This continues the trend reported in the 2023 survey. Respondents continue to rate the different therapeutic interventions as very effective in maintaining their muscle strength, joint flexibility, core stability and ability to undertake activities of daily living.

[2] All graphical material was prepared using the Datawrapper package, <www.datawrapper.de>.

Still in section one, questions eleven and twelve are more general, as they are not broken down by individual therapy, and are focussed on the use of NHS services and personal self-confidence. Answers to both of these questions suggest that respondents firmly believe they have fewer falls (thus reducing demand on NHS services) and that they are more confident and more in control of their lives.

Question thirteen specifically targets the extent to which respondents believe they have been helped to remain in work through the support of the MDSC. The responses for this question include a large number of answers in the "not applicable" category. Of those who did express an opinion more than half felt the supportive impact of the MDSC had helped them remain in employment.

Overall independence was the topic of question fourteen, and more than eighty percent of the respondents agreed that the support of the MDSC had allowed the respondents to maintain independence and to do more with family and friends.

Question fifteen asked for an overall assessment as to whether the respondent's condition had improved or not while receiving MDSC therapy. More than one third of the respondents felt that their condition was very much, or much, improved with a quarter answering that it was moderately improved. While only six percent of those responding answered that it was not at all improved.

Finally, question sixteen asked respondents to describe the general impact the MDSC's services had on their condition. The responses were overwhelmingly positive with more than eighty percent of the respondents saying that the MDSC therapies had either prevented the condition from deteriorating or slowed the rate of deterioration. Only one respondent out of the eighty-seven persons providing answers felt that the therapies had increased the rate of deterioration.

The online therapies available from the MDSC were the topic of section two. Of the 85 answers given, when asked whether respondents participated in the online sessions 31 respondents answered "yes".

The section comprised seven questions. The number of responses per question fluctuated between 29 and 30. The questions sought respondents' opinions regarding the extent to which core stability, muscle strength, posture, balance, mobility, pain control, and emotional wellbeing had been improved by participating in the online sessions.

Analysing the results it can be seen that while the topics of core stability, posture and emotional wellbeing were viewed as being improved (more than 75% of the respondents agreeing with this) this did not hold for the other four questions.

Regarding muscle strength, balance and mobility the percentages agreeing a positive effect were greater than half but with approximately a third of the respondents expressing a neutral opinion.

When pain control was considered the positive agreement percentage declined to 38%, with 59% of the respondents being neutral about this and three percent disagreeing that there had been any beneficial effect at all.

(4) Discussion

To view the results in graphical and tabular form please see section one and section four of the Appendix.

Regarding the patterns of service usage please see Appendix section two where information on service user demographics and use of the various facilities is to be found. The analysis presented in section two is derived from data abstracted from the MDSC clinical records system, PracticePal. This information was not collected by means of the survey.

It can be seen from the results that respondents indicate a very high level of agreement concerning the beneficial impact the therapies have.

- When looking at individual therapeutic interventions, osteopathy receives its highest rating for its effect upon posture, mobility, balance, activities of daily living and pain control.
- Adapted exercise equipment receives the highest rating for maintaining core stability, reducing falls and promoting muscle strength.
- Physiotherapy, while generally being well rated, receives its highest rating only for joint flexibility.
- The complementary therapies option, only available in one centre, has correspondingly fewer respondents able to comment on it.

It is the case that all those who attend the MDSC engage with physiotherapy to a greater or lesser extent with some attendees also utilising physiotherapy in conjunction with one or more other therapies. Thus, there is for those respondents who are receiving multiple therapies an opportunity to compare the efficacy of physiotherapy against one or more of the other therapies. It must be borne in mind though that any apparent difference in efficacy rating is based on quite low numbers.

It is certainly possible that there is a synergistic relationship between physiotherapy and the other therapies which enhances their beneficial effect for specific problems, like joint flexibility, balance, etc. The user survey though is essentially an observational exercise. It does not attempt to put, or to answer, questions regarding causality.

Thus, it is not possible with the data from this survey to explain, or explore in more detail, why a particular therapy received a higher rating on one aspect of anatomical function than it did on another. Examining the causal pathways at work here would require supplementary research to explore this question in more detail.

At present with the data to hand it is not possible to identify a causal pathway that would explain how or why multiple therapeutic inputs improve outcomes.

The remaining questions in section one are more generally focused and look at the overall impact MDSC support has had on psychosocial function.

From the answers given to these questions it can be seen that respondents continue to rate the value of the MDSC interventions as very beneficial.

Despite the objective demonstration of such benefit being difficult, or impossible, to achieve (due to lack of suitable comparators) there seems no doubt that, from the respondents' perspective, the improved function is unambiguous. It is also the case that dystrophic conditions rarely (if ever) show improvement over time.

Yet, when asked about the impact of the therapies, a large majority of the respondents feel that either their deterioration has been arrested or that the rate of deterioration has been greatly slowed by the interventions of the MDSC. Again, while there is no easily available comparator to allow any effect on the rate of deterioration to be demonstrated clinically respondents are of the opinion that this is occurring.

Respondents view the clinical aspect of their relationship with the MDSC as very significant. 88% of the respondents believe that the MDSC therapists play the primary role in helping them manage their condition, which represents an increase on the 65% reported in the 2023 survey. By contrast, only 3% of the respondents report that their NHS consultant plays this role, down from the 16% reported in the 2023 survey.

Other key findings included that:

94% of respondents[3] agreed that physiotherapy and osteopathy had improved the flexibility of their joints, 90% of the respondents agreed that the use of adapted exercise equipment had improved joint flexibility while 89% of respondents indicated that it was complementary therapies[4] that had improved the flexibility of their joints.

Maintenance of muscle strength receives similarly high levels of agreement. 82% of respondents agreed that this was due to the use of adapted exercise equipment, 80% attributing this to osteopathy, 72% to physiotherapy and 60% choosing complementary therapies.

73% attributed a reduction in falls to the use of adapted exercise equipment, 71% cited physiotherapy as being responsible with 65% choosing osteopathy and 65% choosing complementary therapies.

83% indicated that the MDSC support they had received had helped keep them out of hospital and reduced their reliance on other healthcare services.

81% said the support of the MDSC had either prevented or slowed the deterioration of their condition.

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[3] The format for these questions - a statement to which respondents indicate their degree of agreement - generates four separate answers (relating to the four therapy options – physiotherapy, osteopathy, complementary therapies and the use of adapted exercise equipment) to each statement. If the respondent has not received a particular therapy they can select the "not applicable" option. In computing the figures presented here only the respondents offering an opinion about a therapy are counted; the "not applicables" are excluded. Thus the number of respondents who are counted as agreeing will vary from question to question. For the full figures please consult the tables at the end of the report.

[4] Complementary therapies are only available in one centre, hence the number of respondents who are able to offer an opinion is relatively low.

87% of respondents agreed that participating in osteopathy had improved their pain control, 78% indicating complementary therapies to be responsible, 75% selecting physiotherapy and 49% reporting that the use of adapted exercise equipment was responsible.

91% agreed that the support of the MDSC, by helping the respondents to an improved understanding and management of their condition, allowed them to feel more confident and in control, and 86% agreed that the MDSC support they had received assisted them to live well with their dystrophic condition.

86% said that our online support had helped them to maintain their emotional wellbeing, and 78% said our support helped their family and carers to feel supported.

In the main the respondents report that their presence in the Centre is mostly physical, attending face to face sessions, with only a relative minority (36%) choosing to access 'virtual', or online, therapies.

Supplementary tables, giving a full numerical breakdown of the survey results are also included in the Appendix.

(5) Conclusion

The survey appears to have been well received by the MDSC service users and achieved a good response rate. It is apparent that, in the view of those who responded whether via quantitative or qualitative questions, the work and support that the MDSC undertakes is seen as being of excellent value.

Respondents put a high rating on the effect that the therapies they receive have in helping to manage their conditions and to allow them to achieve richer and more rewarding lives. For every question in the questionnaire which seeks an opinion as to the impact the MDSC and its services have the respondents express strongly positive opinions.

This is also the case with the qualitative, open text, questions where respondents can express opinions in their own words. Through the various means made available users of the MDSC services who answered this survey continue to offer support for, and much appreciation of, the work that the MDSC undertakes.

Appendix

Results in detail

Section 1 - The user assessed impact on physiology and function.

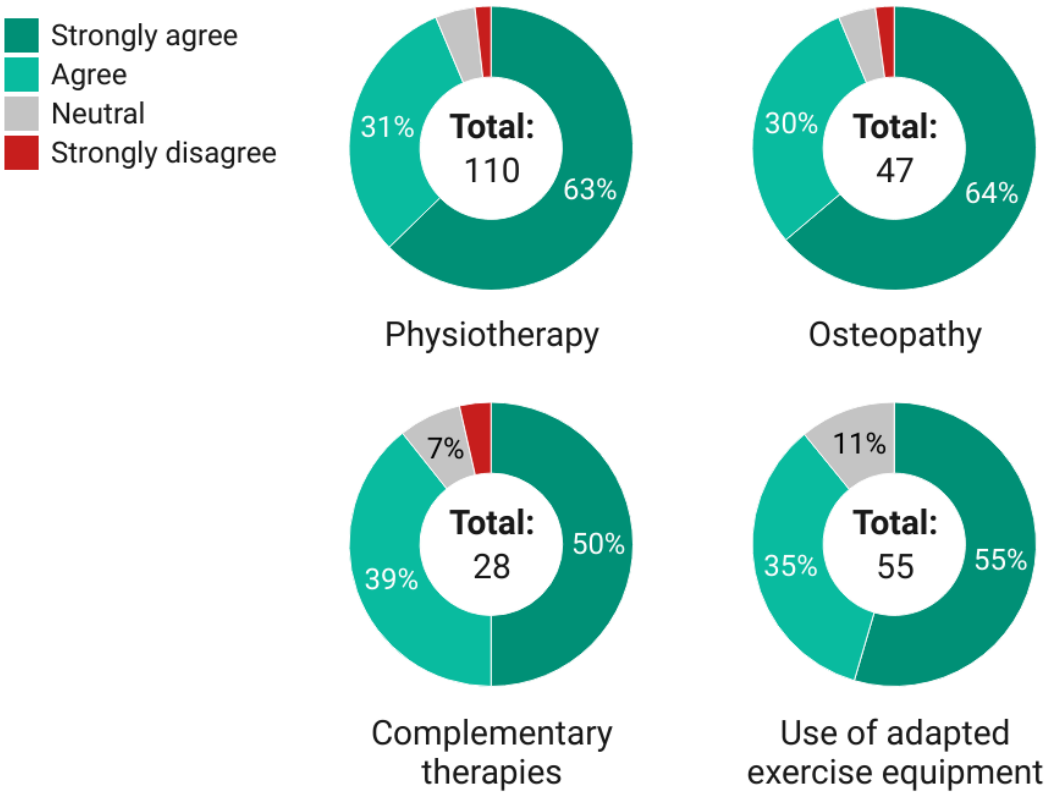
This section presents results pertaining to the respondents' views regarding the impact of the various therapeutic interventions which they receive. Data is harvested here via ordinal variables utilising a five-point scale from "strongly agree" to "strongly disagree". A "not applicable/don't know" category was also an option. For the purposes of reporting these results only percentages indicating a preference (i.e. either agreement or disagreement) are shown in the graphs. The number in the centre of the doughnut is the total number of responses received for that question not counting those respondents who answered "not applicable". In section four will be found tables giving the full numerical breakdown of responses for each question.

The focus in this section is primarily on anatomical function with additional questions addressing pain and activities of daily living. To begin with the questions are centred on functional efficacy, with the responses broken down by the four therapeutic interventions that the MDSC offers.

Please note that the results here begin at question 2, as question 1 in this section explores the frequency of visits to the MDSC which is analysed elsewhere.

Section 1, question 2

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



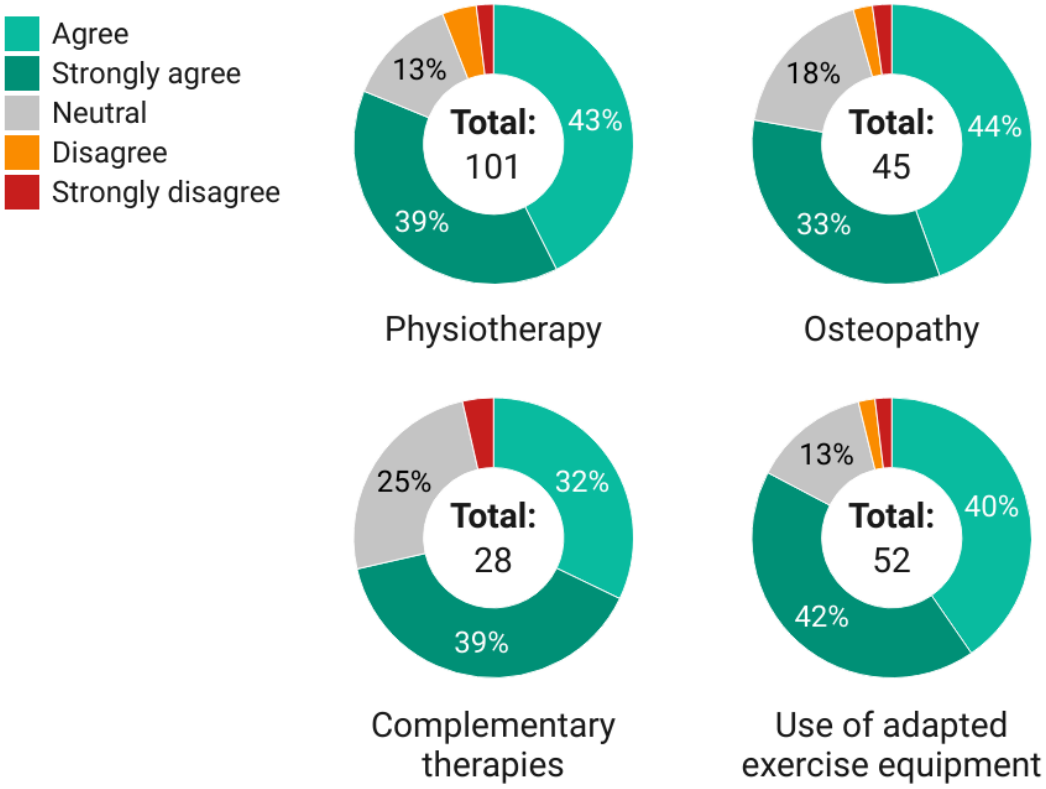
Respondents answering "not applicable" not included in these figures.

Created with Datawrapper

It should be noted that all respondents receive physiotherapy with the other three therapeutic interventions being in addition to physiotherapy. For joint flexibility, across all four interventions, user satisfaction is very high, with physiotherapy and osteopathy, jointly, receiving marginally better ratings than complementary therapies or adapted exercise equipment.

Section 1, question 3

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



Respondents answering "not applicable" not included in these figures.

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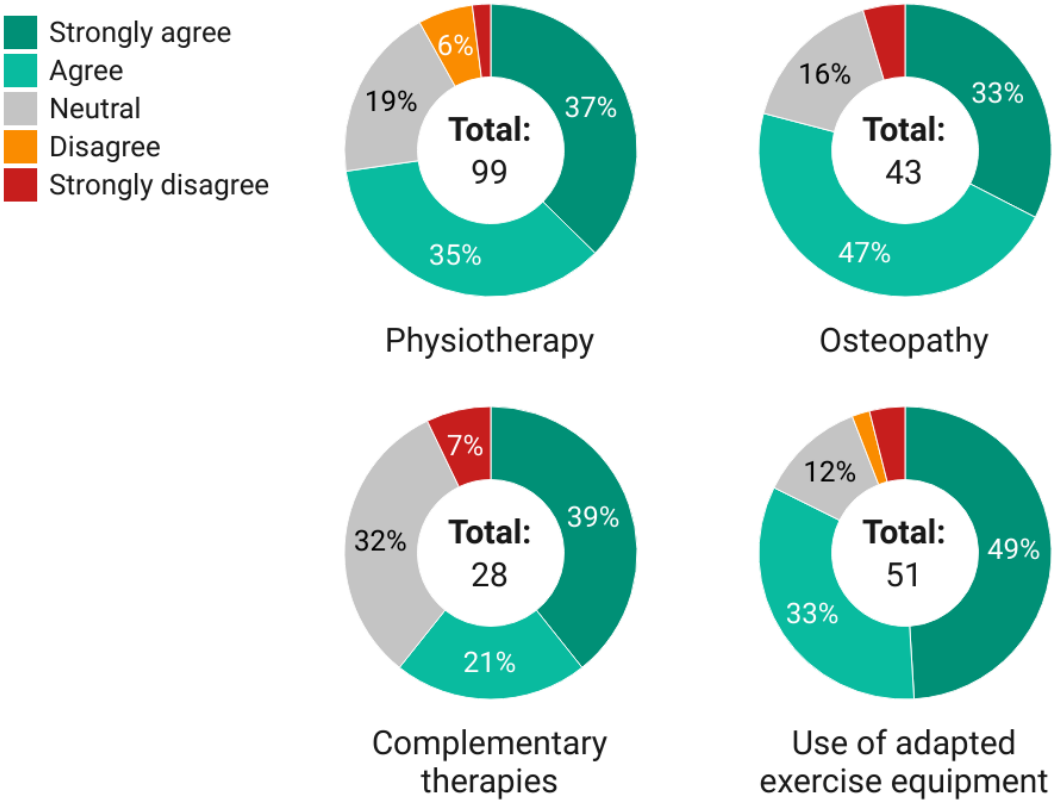
Question three concerns core stability. While the satisfaction levels remain high across the board it can be seen that physiotherapy and adapted exercise equipment receive somewhat higher ratings than the other two interventions.

Section 1, question 4

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



Respondents answering "not applicable" not included in these figures.

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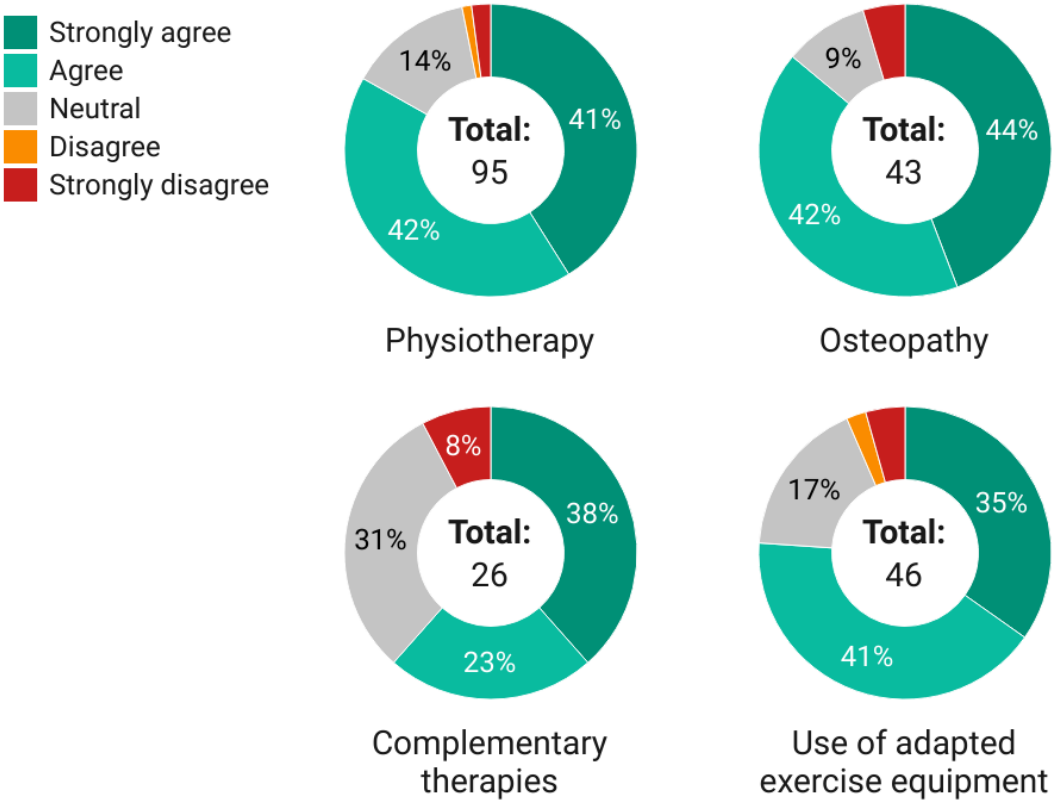
Muscle strength is the focus of question four. The use of adapted exercise equipment is clearly well regarded by those who use it, closely followed by the osteopathy group.

Section 1, question 5

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



Respondents answering "not applicable" not included in these figures.

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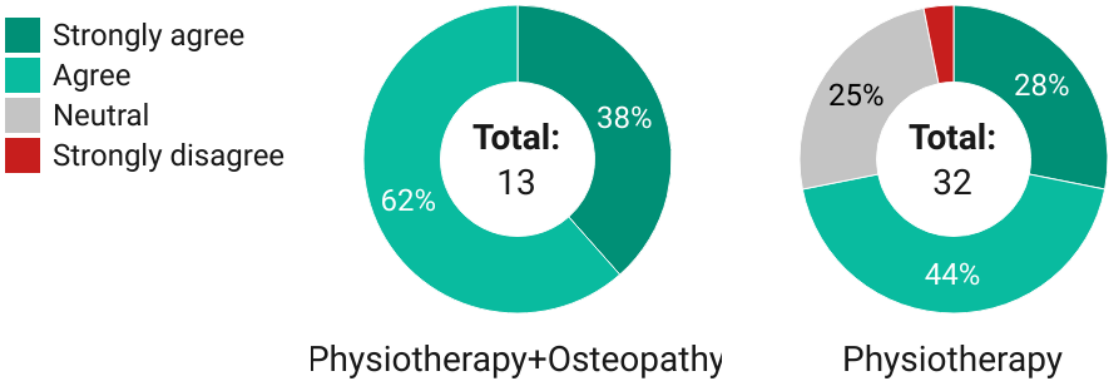
As further commentary on Section 1 question 5 it can be seen that osteopathy is the most positively rated therapy for posture. Since all osteopathy users receive physiotherapy one can ask whether this rating is a result of comparing osteopathy to the other interventions, in terms of its direct therapeutic benefit. Other factors may be at work. It may be that there is something in the nature of the individuals who seek out, or who are recommended to receive, osteopathy that renders them more susceptible to the beneficial effect. Or it may be there is, as mentioned earlier, some degree of synergistic relationship at work here. The figure below breaks the figures down further. Looking at the responses given by those who receive physiotherapy alone (as one group), and by those who receive both physiotherapy and osteopathy[5] (as a second group), it can be seen that the combination of physiotherapy and osteopathy greatly improves the respondents' ratings. The number of respondents involved though is low so caution should be exercised in interpreting these results.

[5] This second group excludes any respondents who also receive complementary therapies or the use of adapted exercise equipment.

Section 1, question 5 (supplemental)

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



Only respondents receiving physiotherapy, or physiotherapy plus osteopathy included here. "Not applicable" cases excluded.

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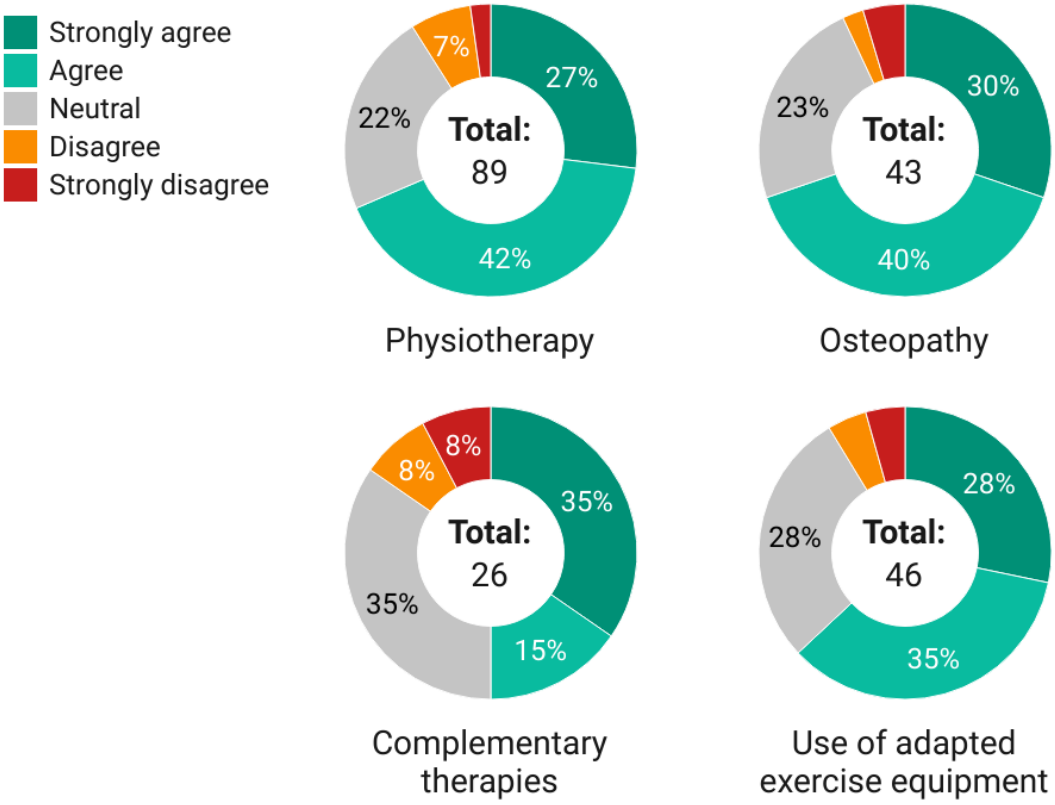
Section 1, question 6

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



Respondents answering "not applicable" not included in these figures.

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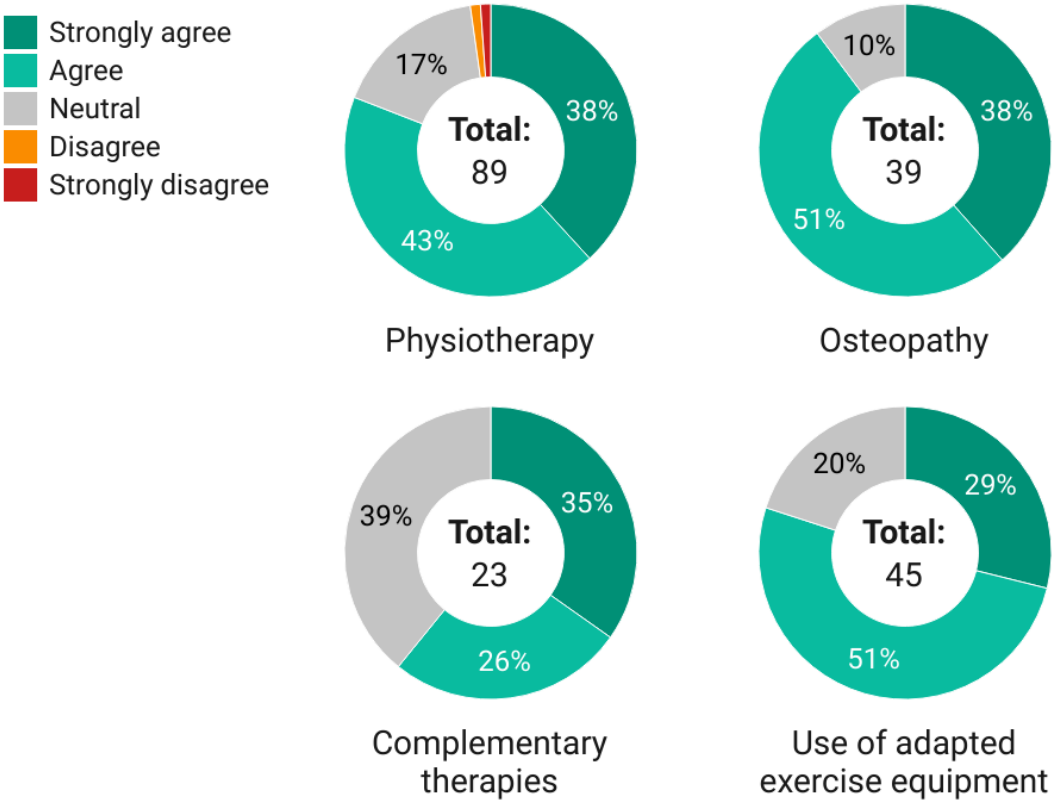
Osteopathy continues as the best-favoured therapy, albeit by a slim margin.

Section 1, question 7

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



Respondents answering "not applicable" not included in these figures.

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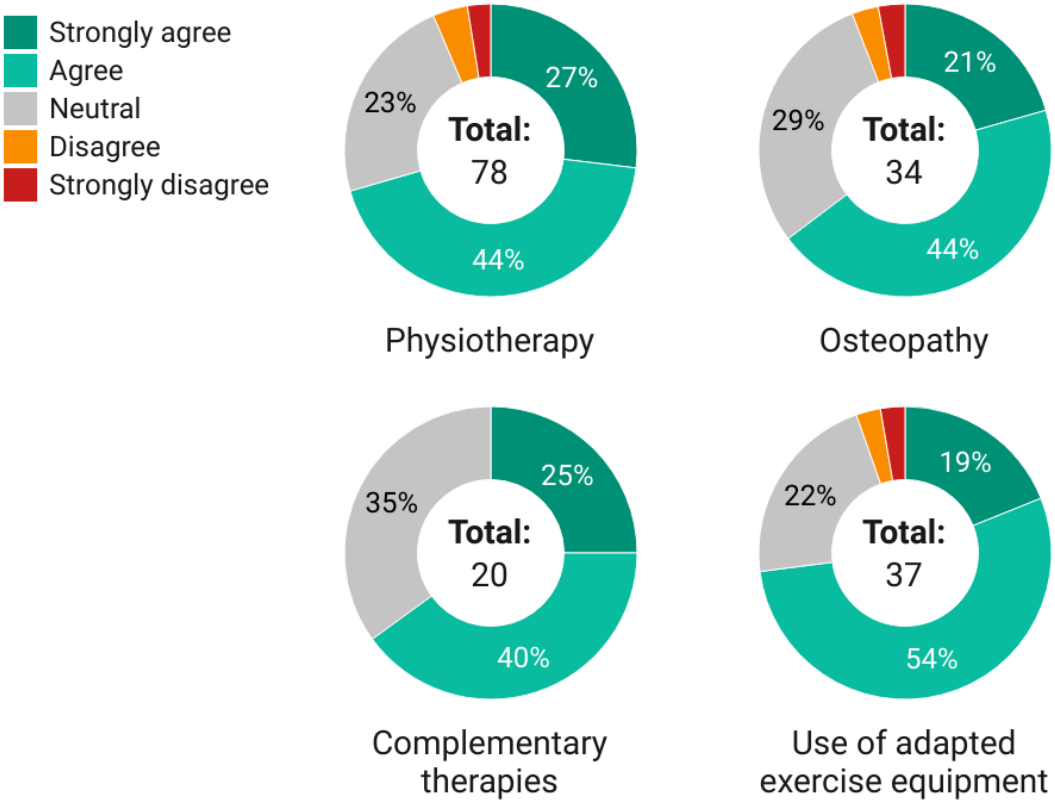
Osteopathy clearly the best-favoured intervention for improving mobility.

Section 1, question 8

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



Respondents answering "not applicable" not included in these figures.

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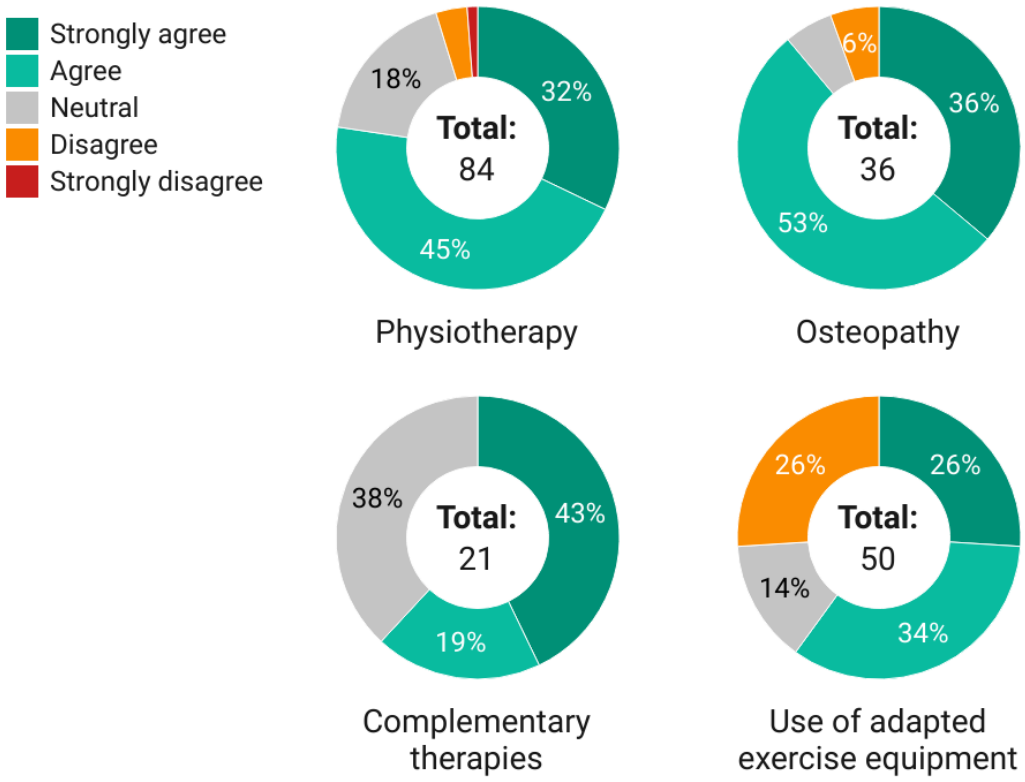
Here we see the adapted exercise equipment intervention as being the better-favoured intervention.

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)?"



Respondents answering "not applicable" not included in these figures.

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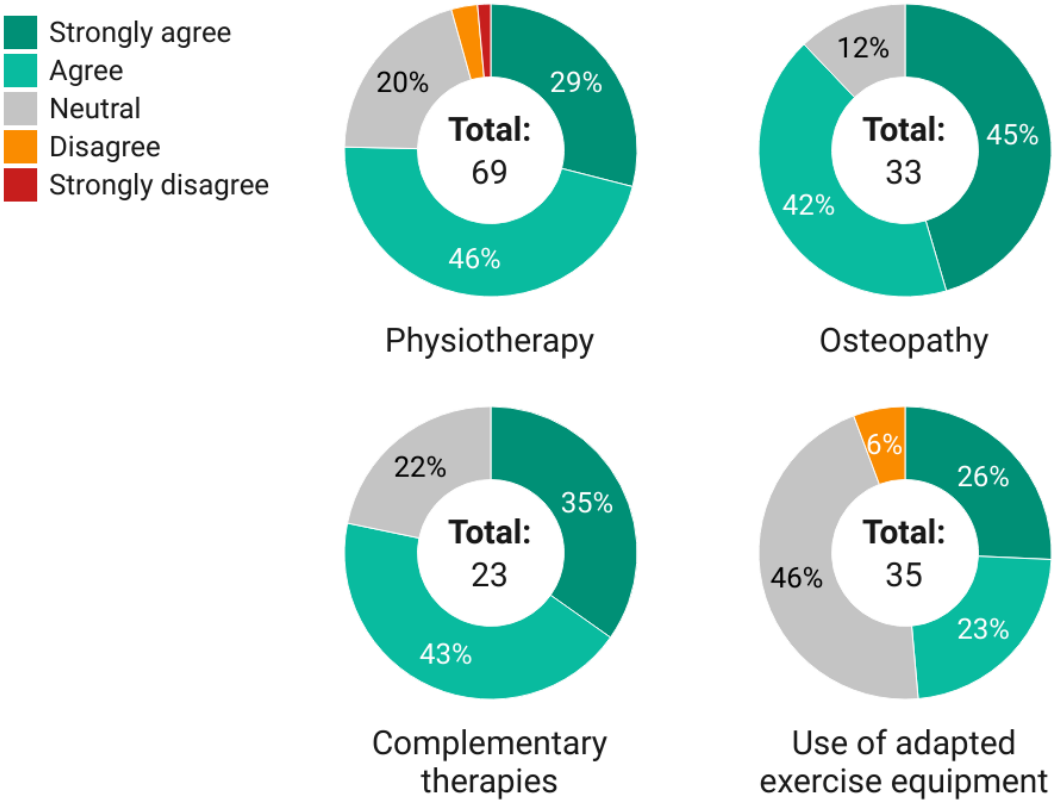
For these activities of daily living osteopathy is once more the clear winner.

Section 1, question 10

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



Respondents answering "not applicable" not included in these figures.

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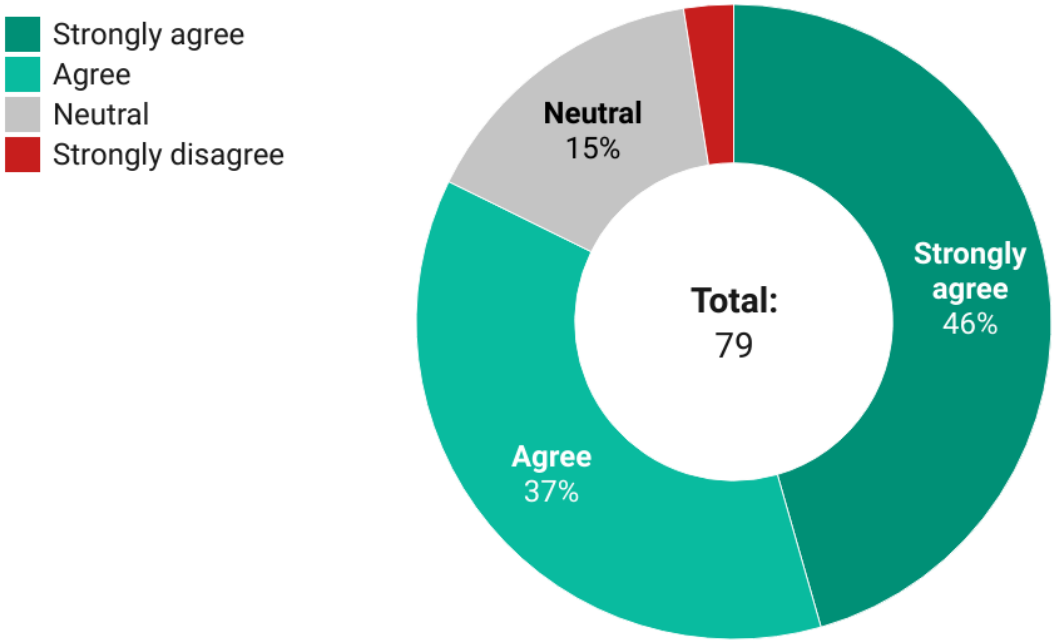
Pain control is a significant problem for many. Osteopathy, once more, and complementary therapies are the most favourably viewed interventions.

The focus now shifts to a more overall viewpoint. Questions 11, 12, 13 and 14 of section one are all concerned with a user assessment of the support that the MDSC offers and how this support feeds through, or has an impact upon, assorted physiological, clinical or psychosocial factors. In questions 15 and 16 there are overall assessments of MDSC support on the rate of deterioration and the overall condition.

Section 1, question 11

"To what extent would you agree that the MDSC support you have received 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?"



Respondents answering "not applicable" not included in these figures.

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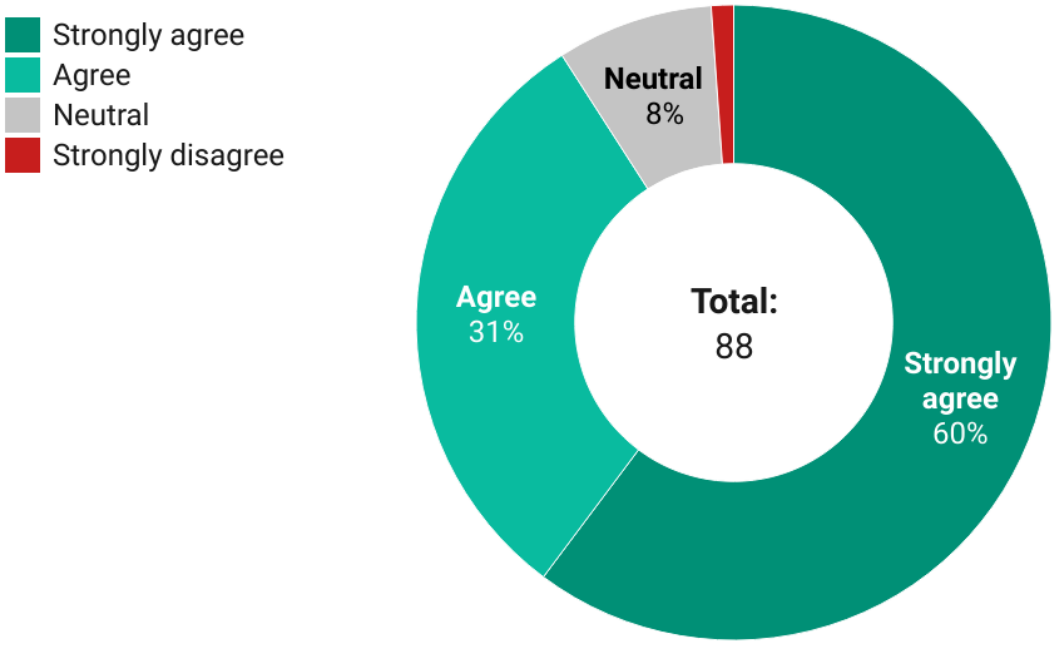
There is a substantial majority here supporting the view that MDSC support has led to decreased usage of NHS facilities and reduced the number of falls.

Section 1, question 12

"To what extent would you agree that MDSC support, by helping you understand and manage your condition better, has made you feel more confident and in control?"



Respondents answering "not applicable" not included in these figures.

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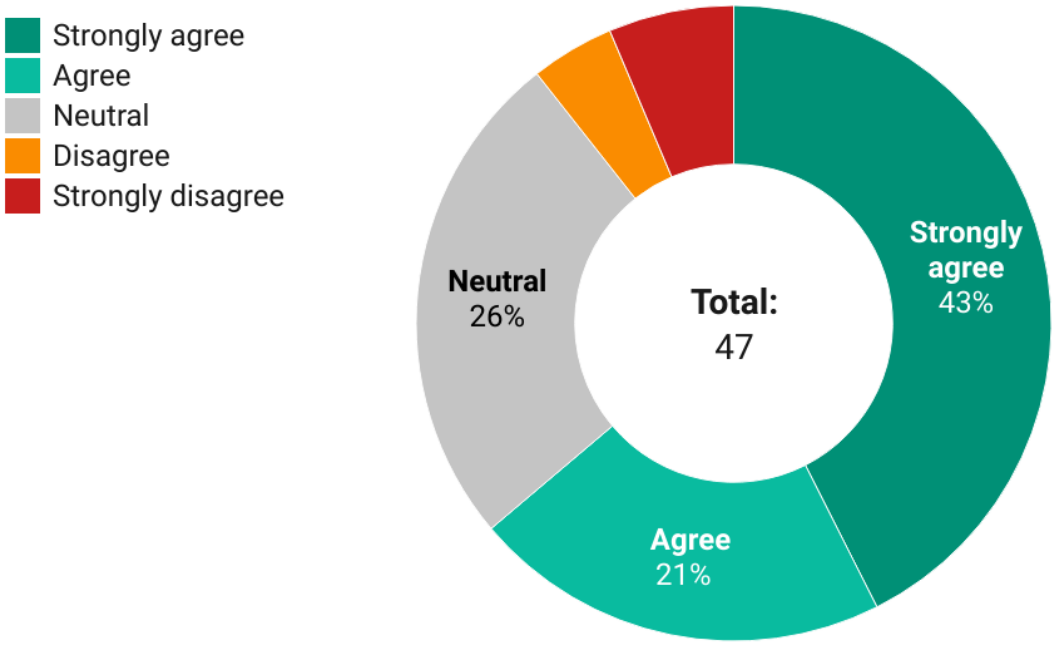
Respondents agree by a wide margin that the ability of the MDSC to act as a source of knowledge regarding the various dystrophic conditions leads to improved self-confidence and an enhanced sense of being in control.

Section 1, question 13

"Viewed overall, would you agree or disagree that the MDSC support you have benefited from has helped you to stay in work?"



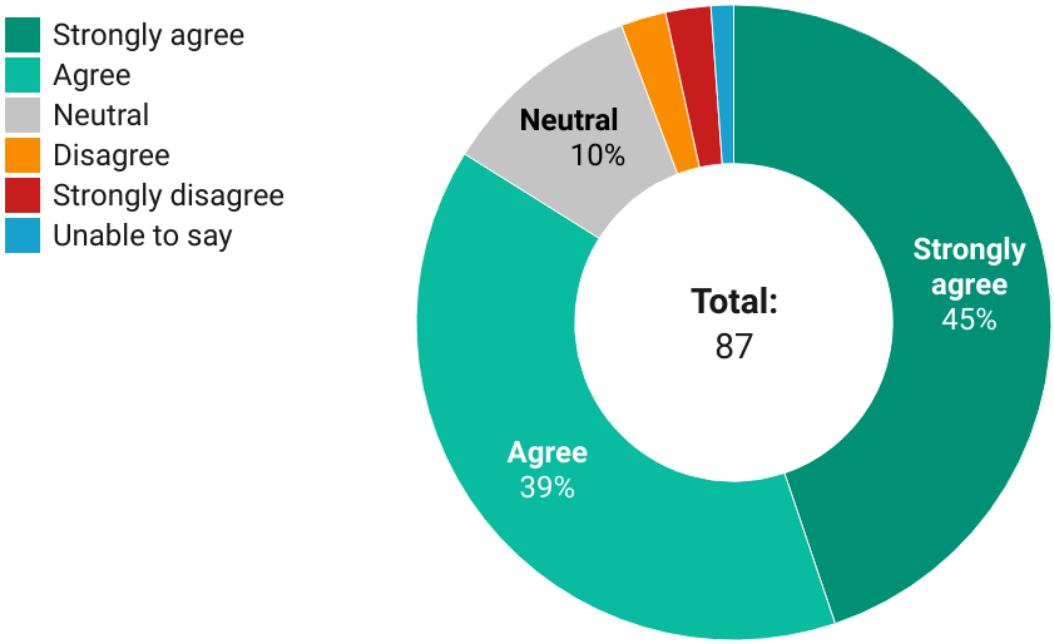
Respondents answering "not applicable" not included in these figures.

Created with Datawrapper

A majority of the respondents agree that MDSC support has helped them stay in employment.

Section 1, question 14

"Viewed overall, would you agree or disagree that the MDSC support you have benefited from has helped you to maintain your independence and do more with your family and friends?"



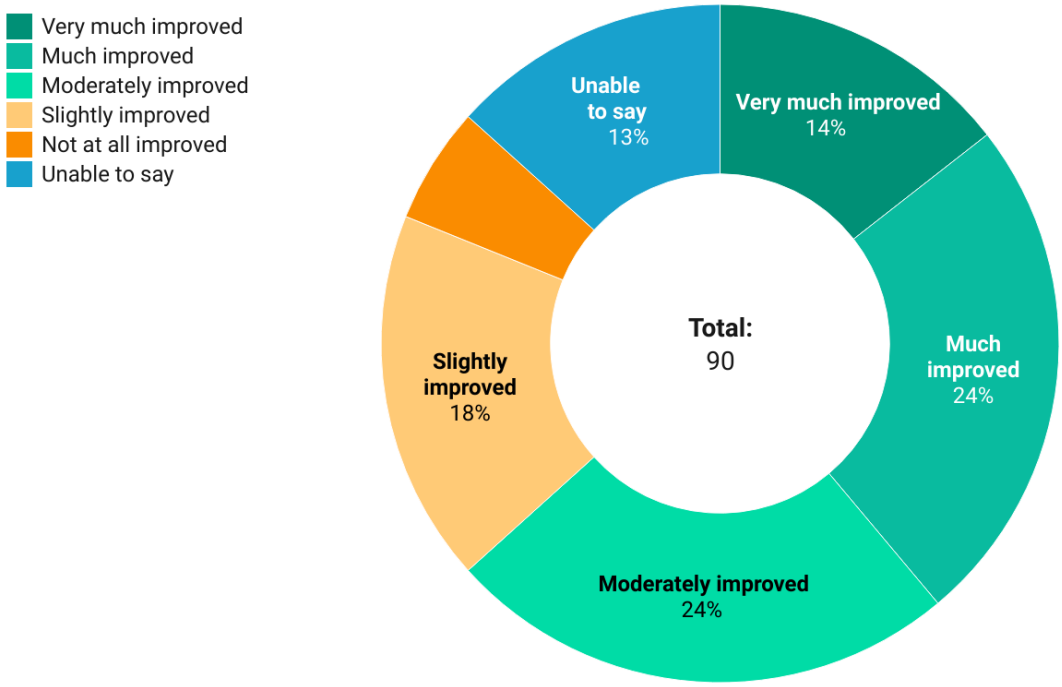
Respondents answering "not applicable" not included in these figures.

Created with Datawrapper

Again, a substantial majority agreeing with the statement that MDSC support maintains independence and allow respondents to undertake more activities with their families.

Section 1, question 15

Viewed overall, would you say that with the MDSC services your condition is ...



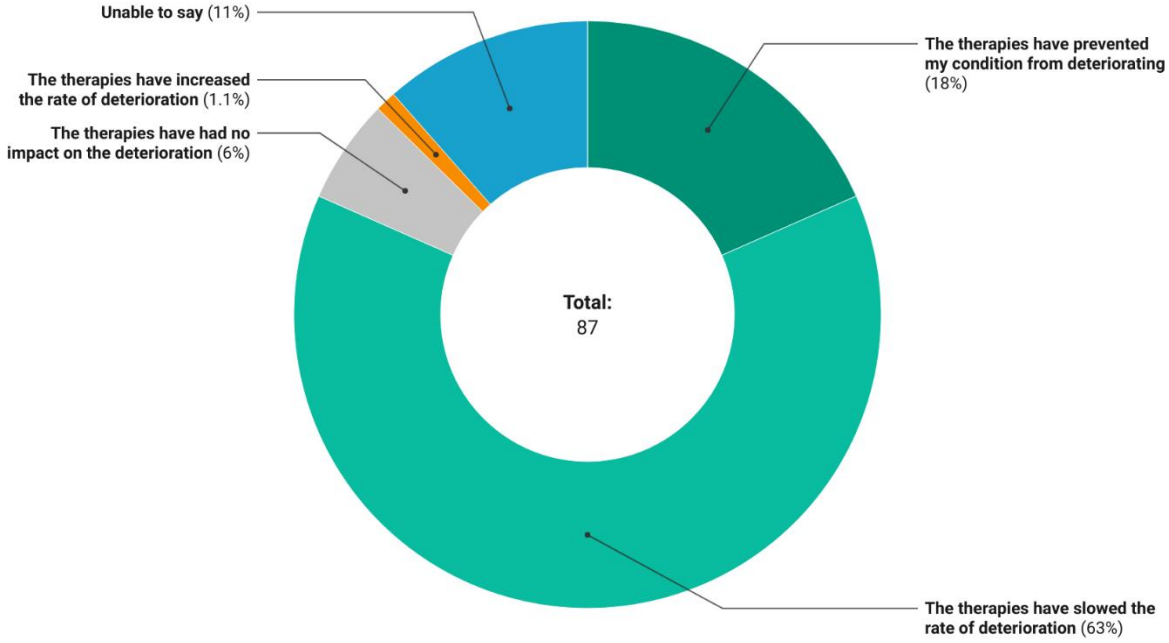
Respondents answering "not applicable" not included in these figures.

Created with Datawrapper

That there is a beneficial impact upon the respondents' condition from the MDSC services is agreed upon by a majority of respondents.

Section 1, question 16

"Which statement do you think would best describe the general impact the MDSC's services have had on your general condition?"



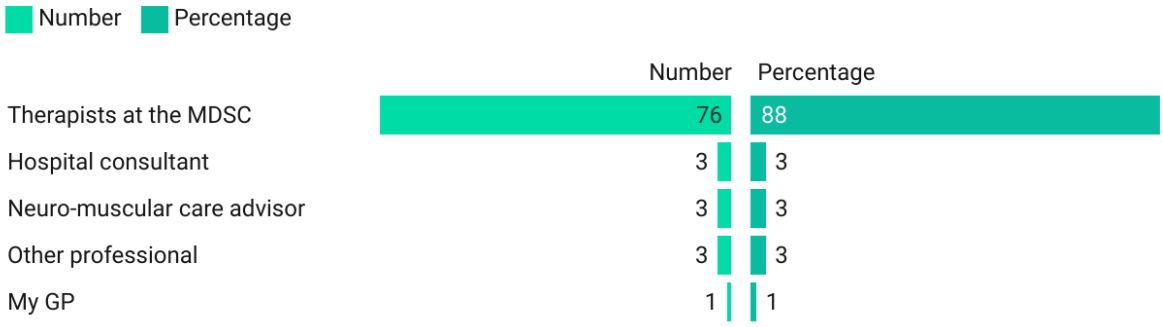
Respondents answering "not applicable" not included in these figures.

Created with Datawrapper

In keeping with the sense of the preceding graphs question 16 shows that respondents consider that the rate at which they are deteriorating is beneficially affected. The point to bear in mind here is that dystrophies, and related conditions, tend to be characterised by a process of relentless deterioration. Although this cannot be empirically demonstrated, respondents consider their deterioration has been halted or slowed thanks to the MDSC.

Section 1, question 17

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



Total number of responses = 86. Percentages may not total to 100% due to rounding errors.

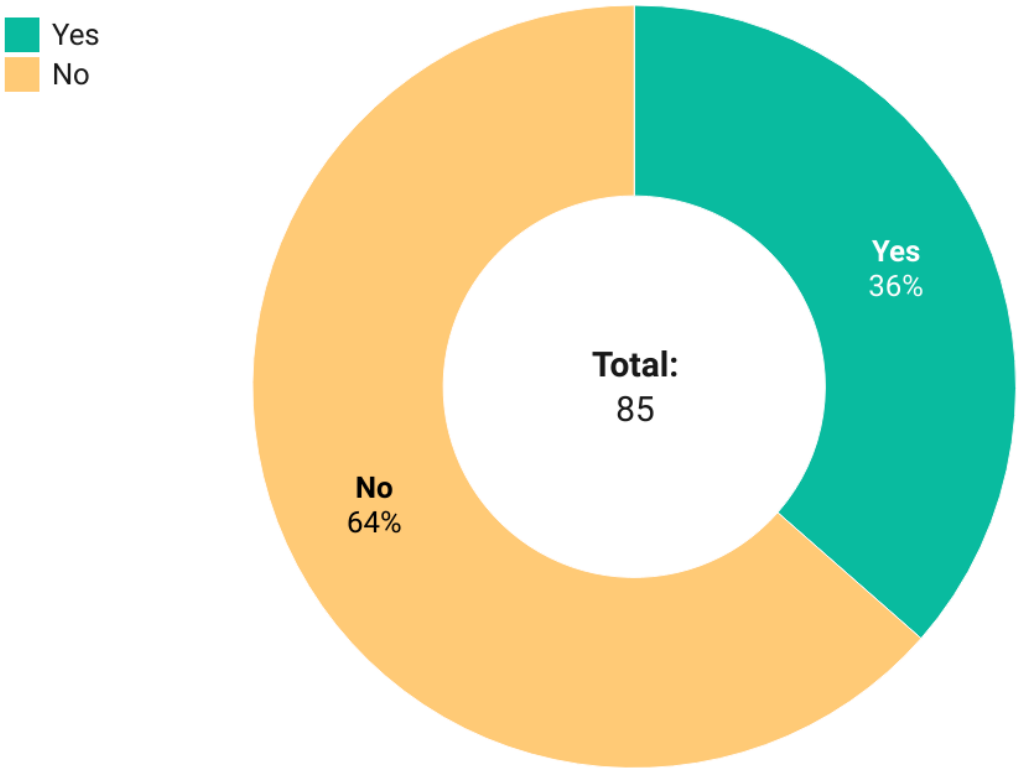
Created with Datawrapper

For the respondents it is clear that the MDSC and its staff are the most important for clinical management of their condition.

The graphs that follow all refer to section two of the questionnaire, which looked only at the online therapies offered by the MDSC.

Section 2 filter question

Have you engaged in any of the online classes led by MDSC therapists (e.g. seated or standing classes, yoga, pilates, breathwork, and / or pre-recorded classes available on the MDSC website)?'

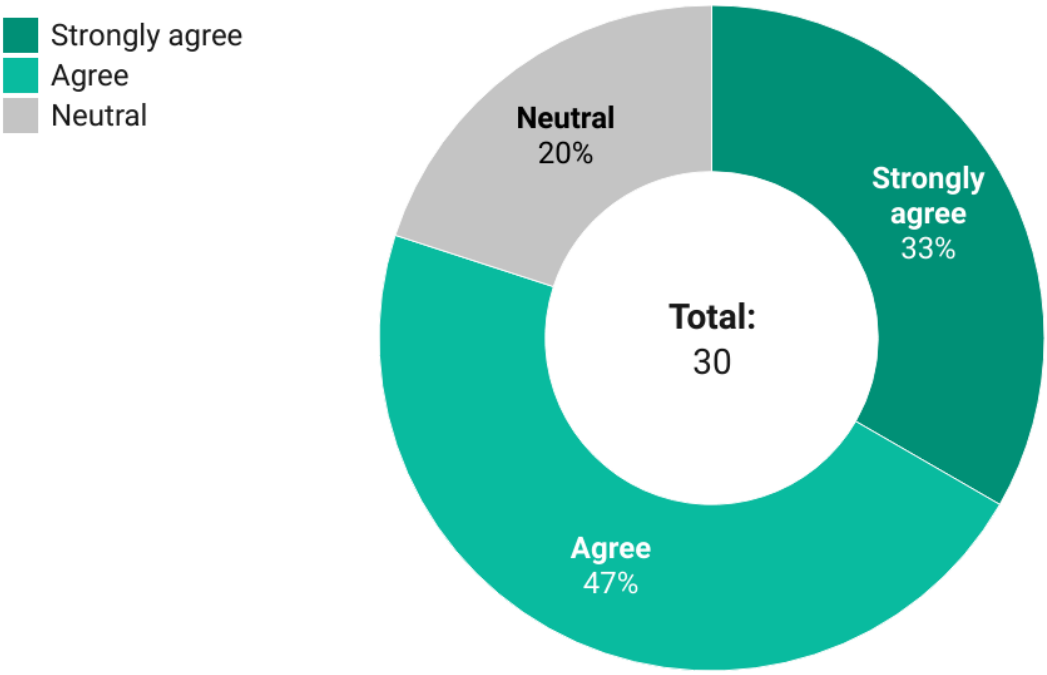


Respondents answering "not applicable" not included in these figures.

Created with Datawrapper

Section 2, question 1

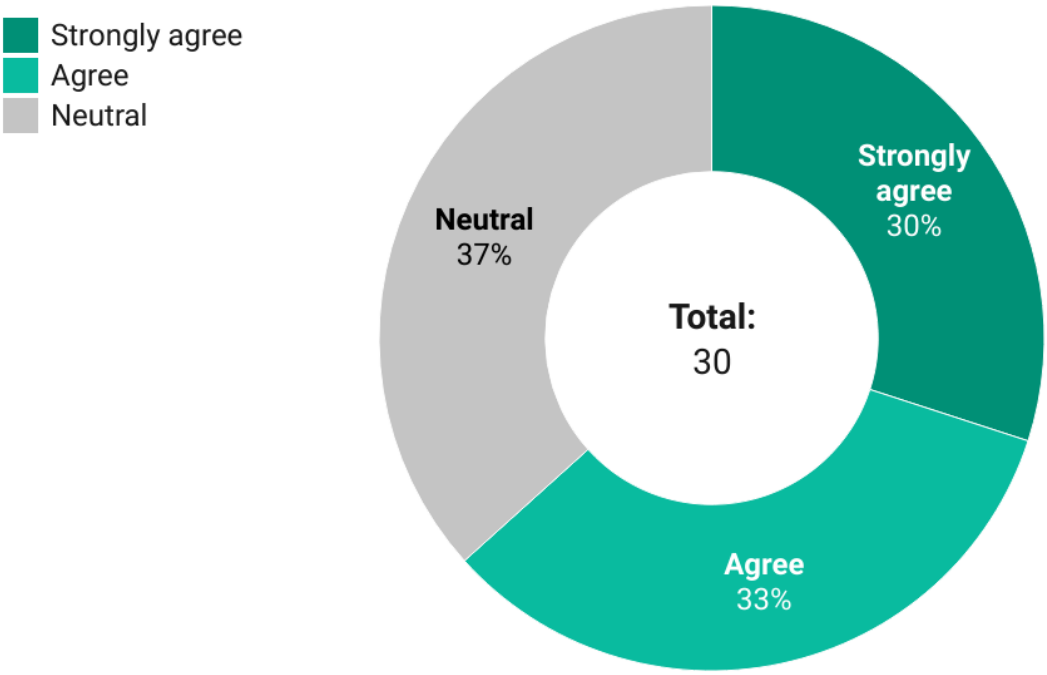
To what extent would you agree that engaging in online classes led by MDSC therapists has improved your core stability?



Created with Datawrapper

Section 2, question 2

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



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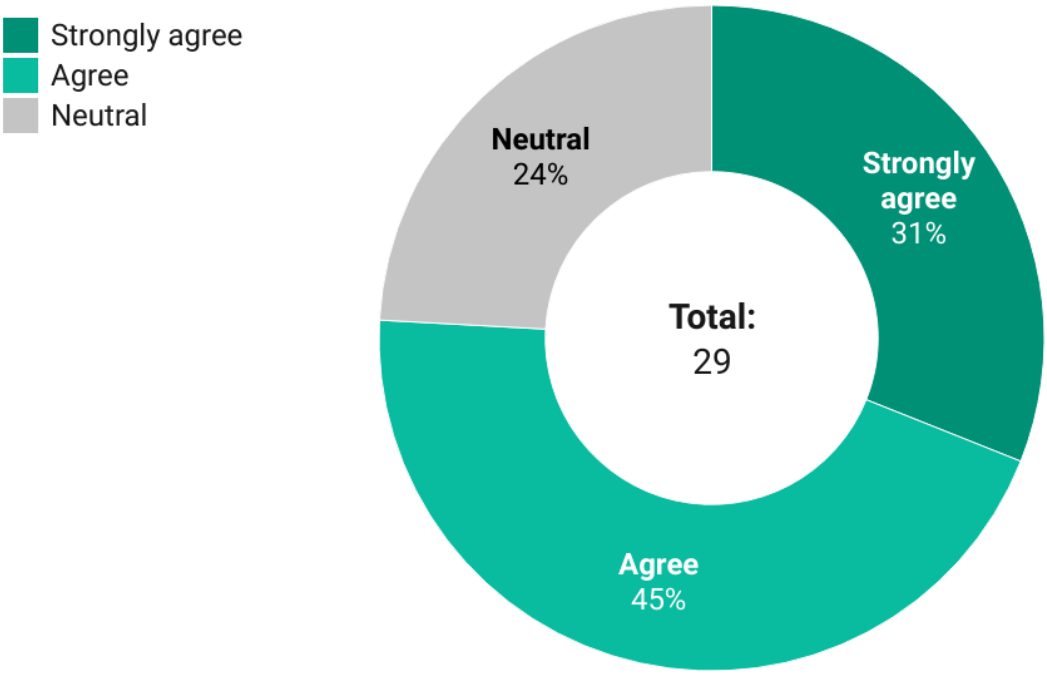
Section 2, question 3

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



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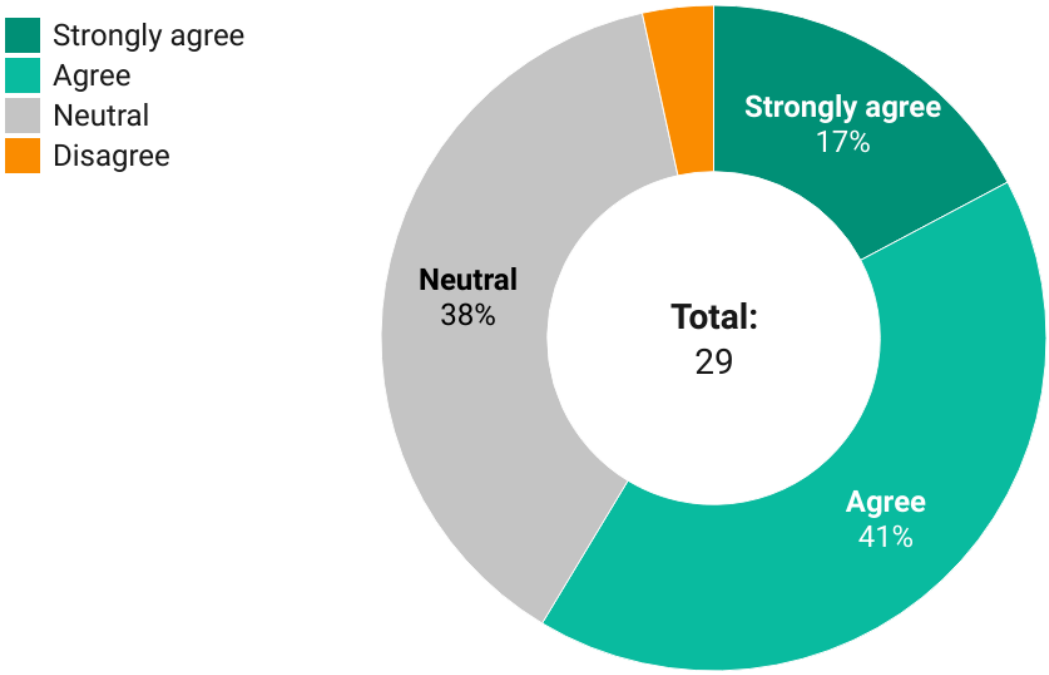
Section 2, question 4

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



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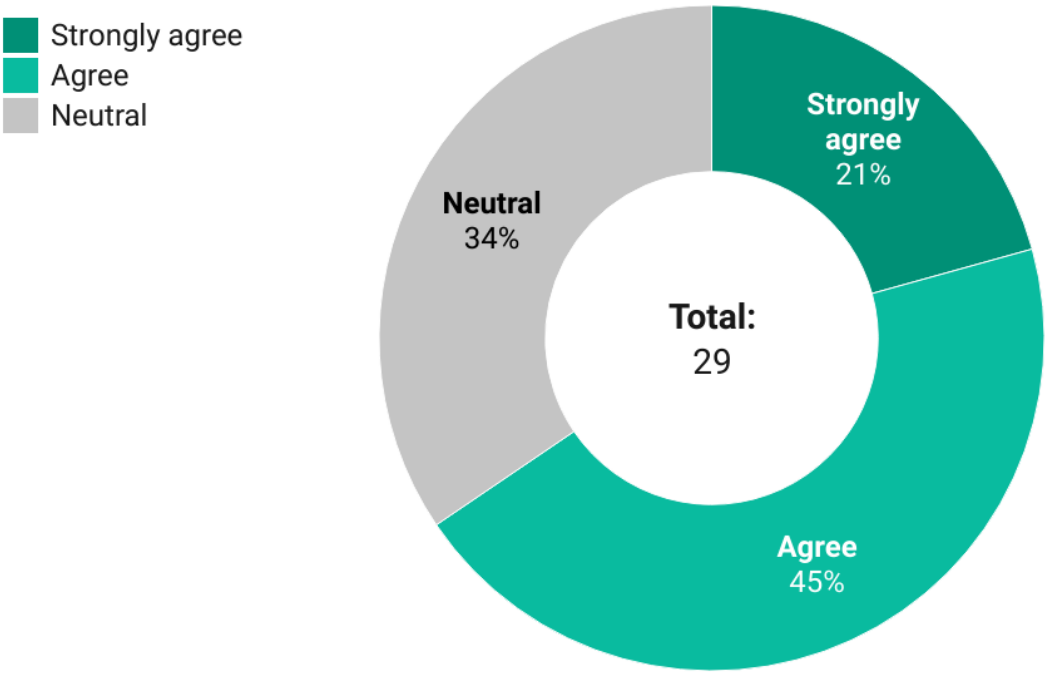
Section 2, question 5

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



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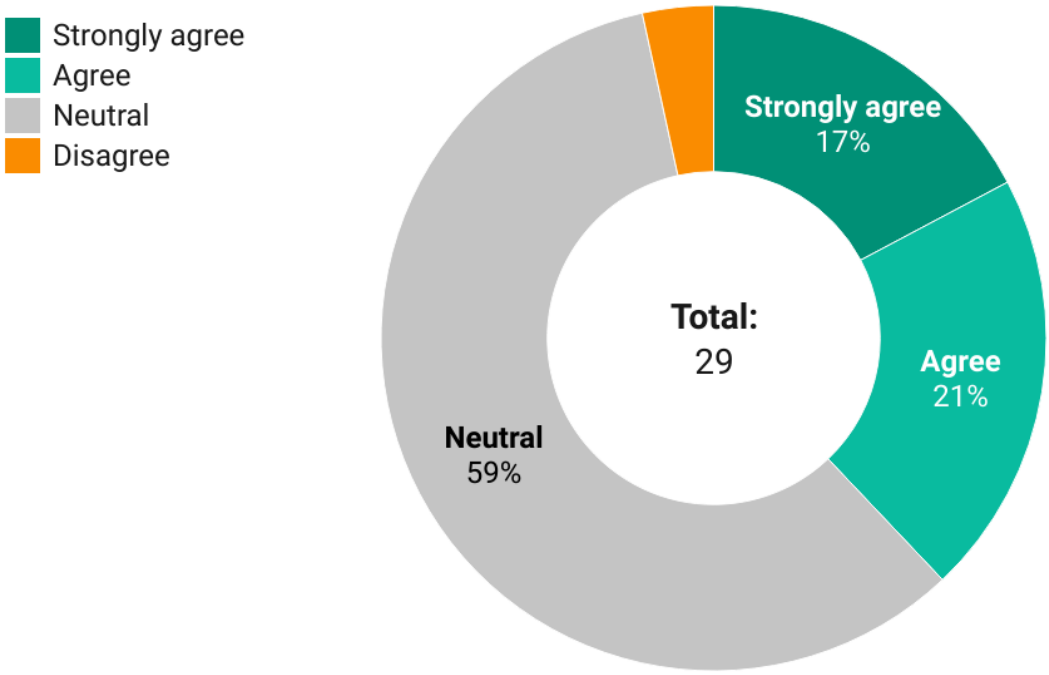
Section 2, question 6

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



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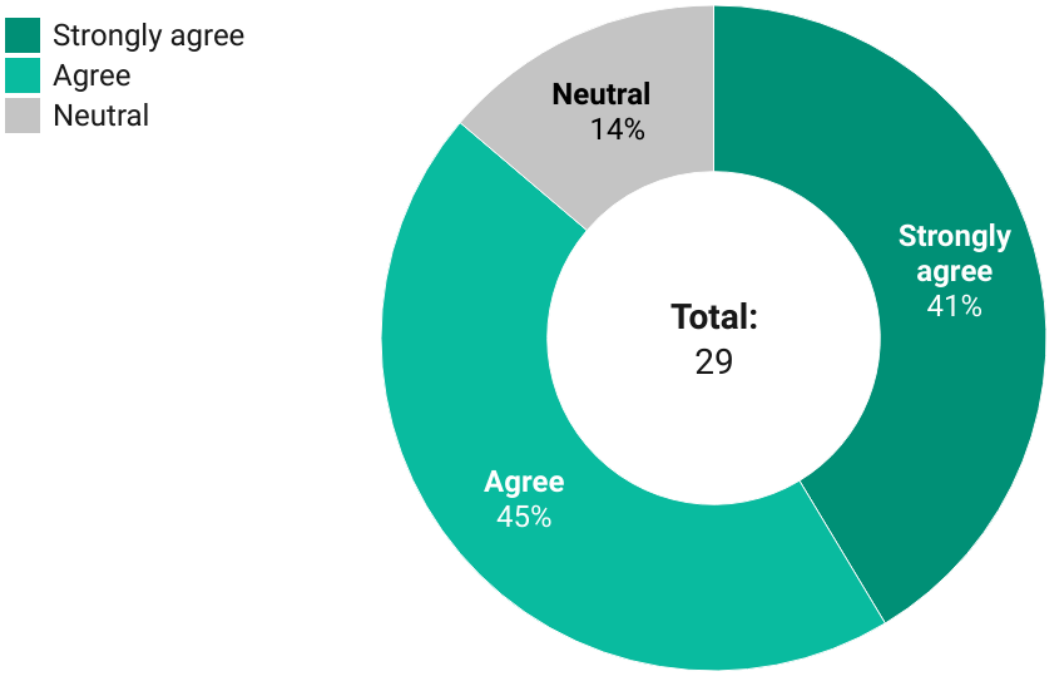
Section 2, question 7

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

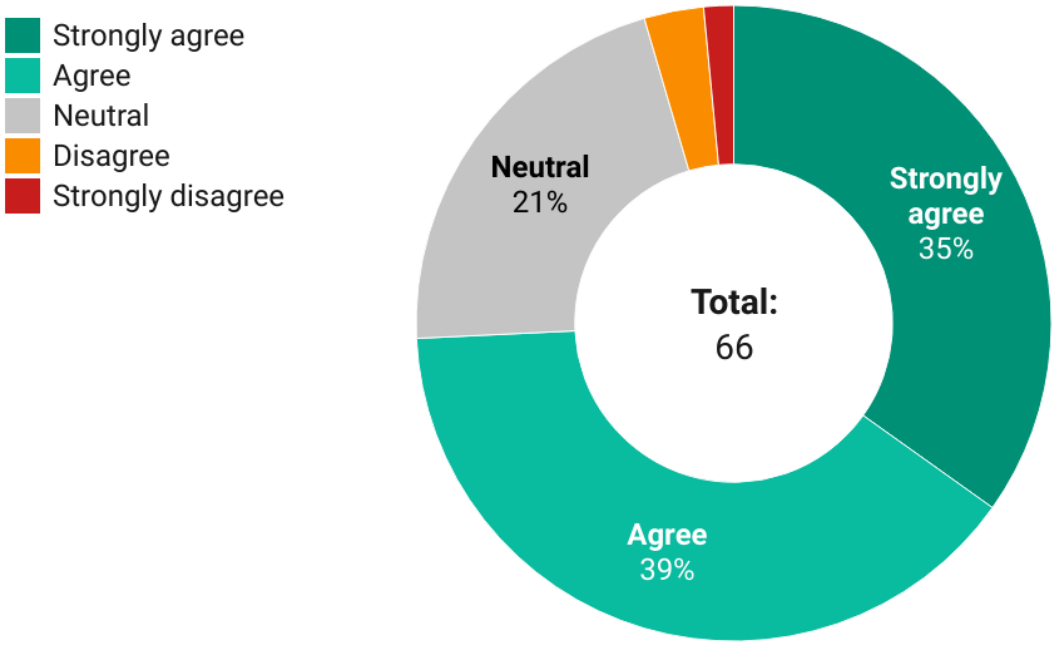


Created with Datawrapper

In section 3 the questions focus on an overall view of MDSC support and are not specifically focussed on therapeutic intervention.

Section 3, question 1

Viewed overall, would you agree or disagree that the MDSC support you have benefited from has helped you to connect with others?



Respondents answering "not applicable" are not included here.

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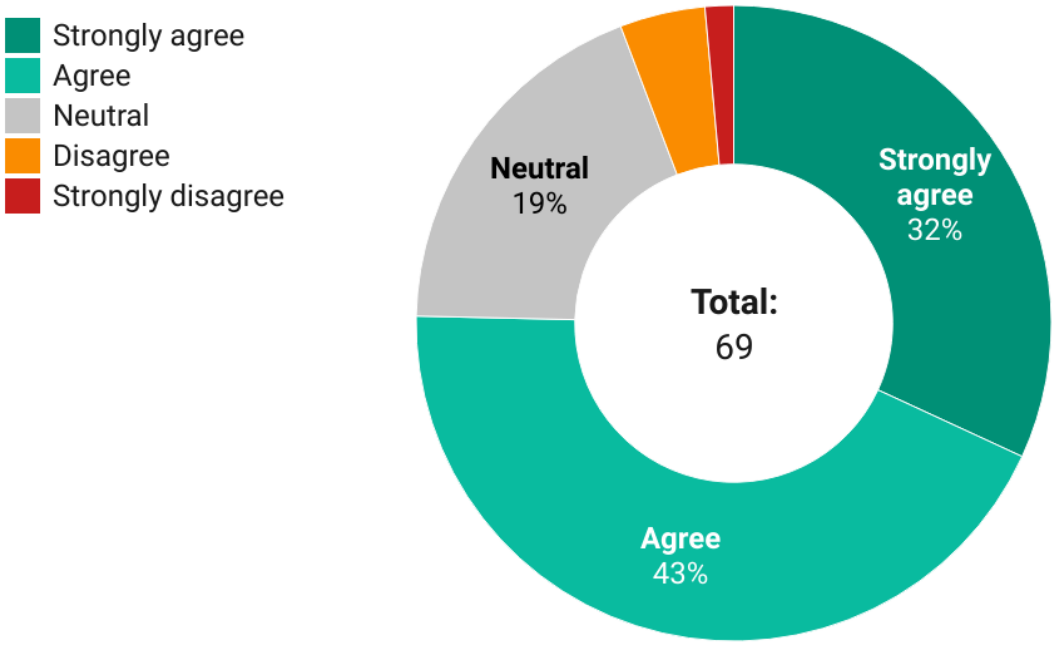
Section 3, question 2

Viewed overall, would you agree or disagree that the MDSC support you have benefited from has given you a community to feel part of?

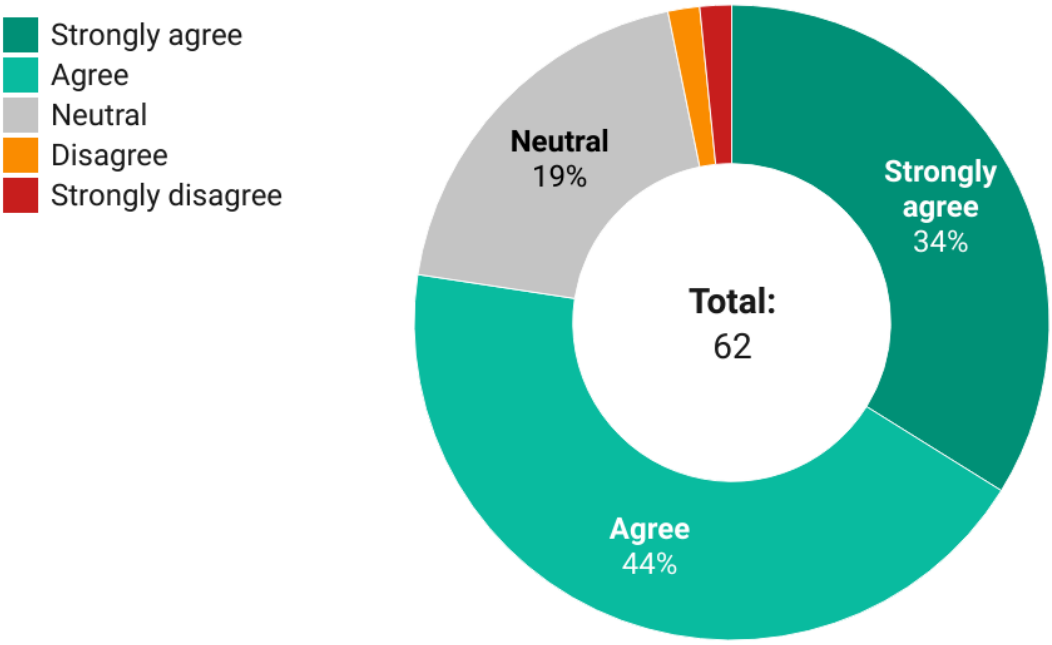


Respondents answering "not applicable" are not included here.

Created with Datawrapper

Section 3, question 3

Viewed overall, would you agree or disagree that the MDSC support you have benefited from has helped your family and/or carers to feel supported?

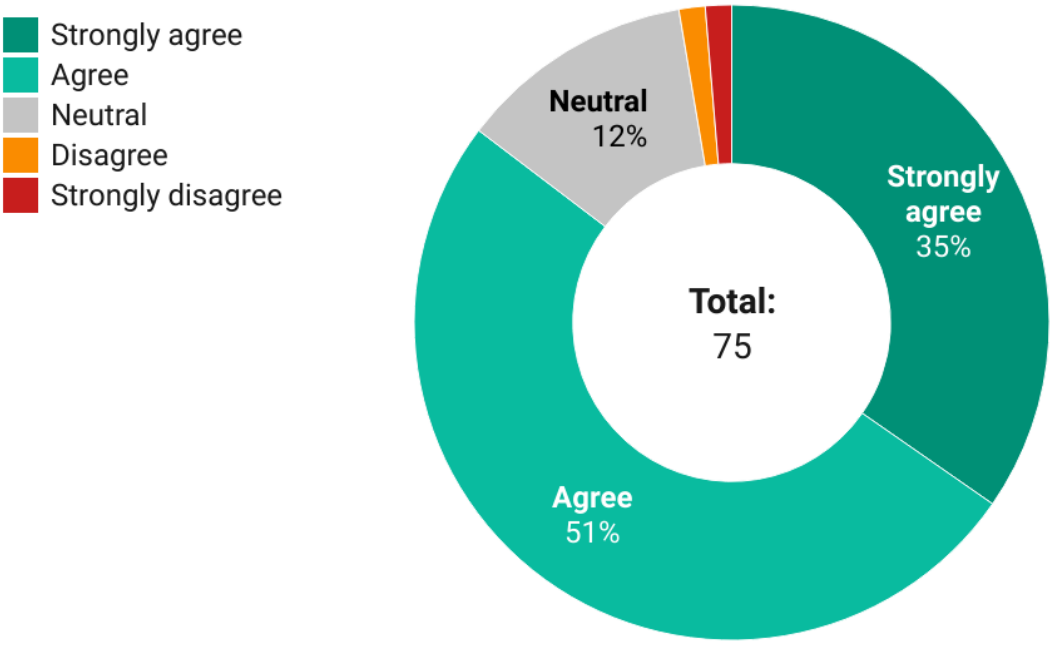


Respondents answering "not applicable" are not included here.

Created with Datawrapper

Section 3, question 4

Viewed overall, would you agree or disagree that the MDSC support you have benefited from has helped you to accept and live well with your condition?



Respondents answering "not applicable" are not included here.

Created with Datawrapper

Qualitative results

As a supplement to the quantitative data collected respondents were able, if they wished, to append free text comments relating to the way being a service user has affected their lives. Please see section three of the Appendix for this data. The comments remain, as last year, in a strongly positive vein and show that respondents greatly value the effect the MDSC is having on their condition.

Section 2 Service user characteristics

This section presents results regarding various aspects of the respondents' demographic and clinical background. Data presented in this section has been drawn from the MDSC's own clinical records system. It is included here to provide some demographic and other detail concerning the individuals who make up the MDSC's client base. It is not possible to present the same details for the survey respondents.

Gender breakdown – Figure 1

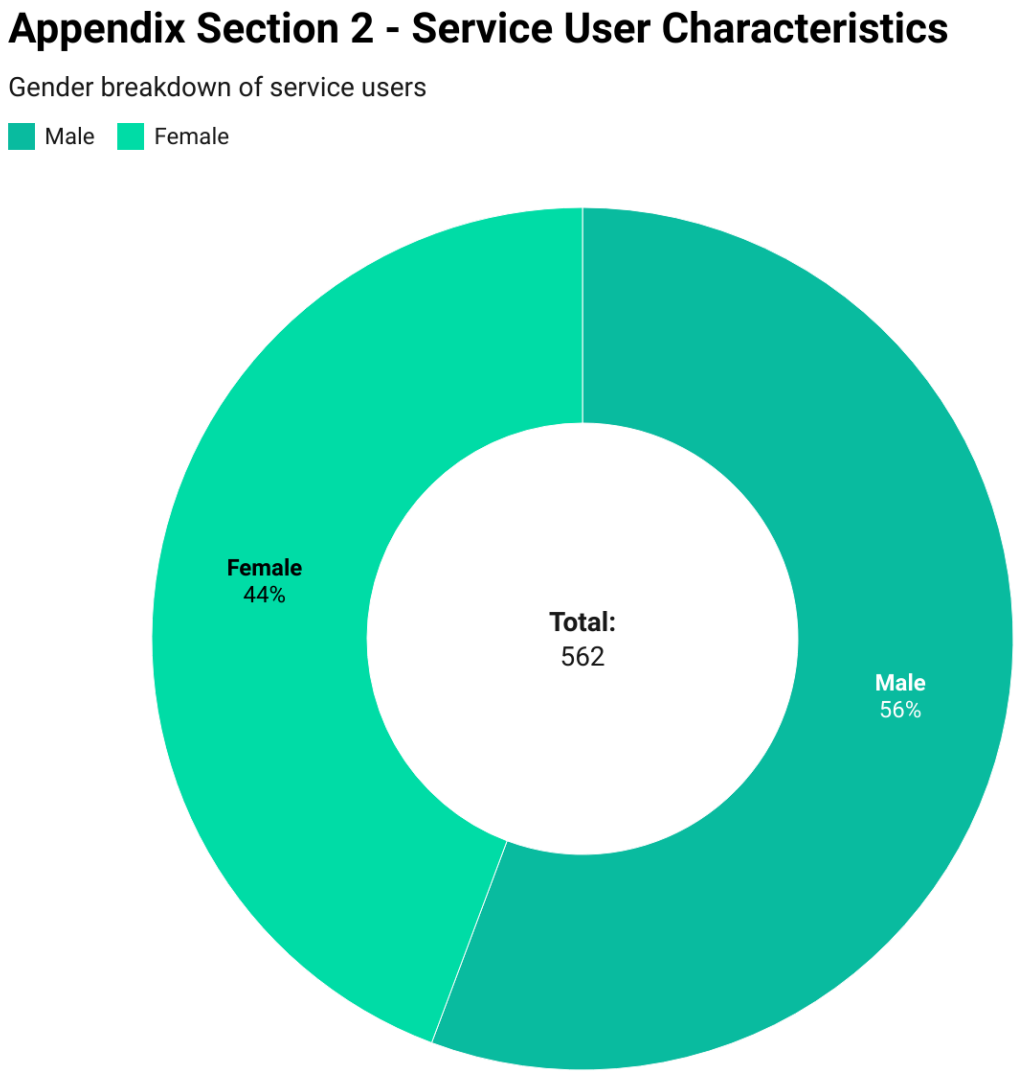


FIGURE 1

Source: Data derived from Clinical Records System. • Created with Datawrapper

At 56% of the total the majority of service users attending the MDSC are men.

Age – Figure 2

Appendix Section 2 - Service User Characteristics

Breakdown of service users by age band. Figures above each bar represent the number of individuals in that category.

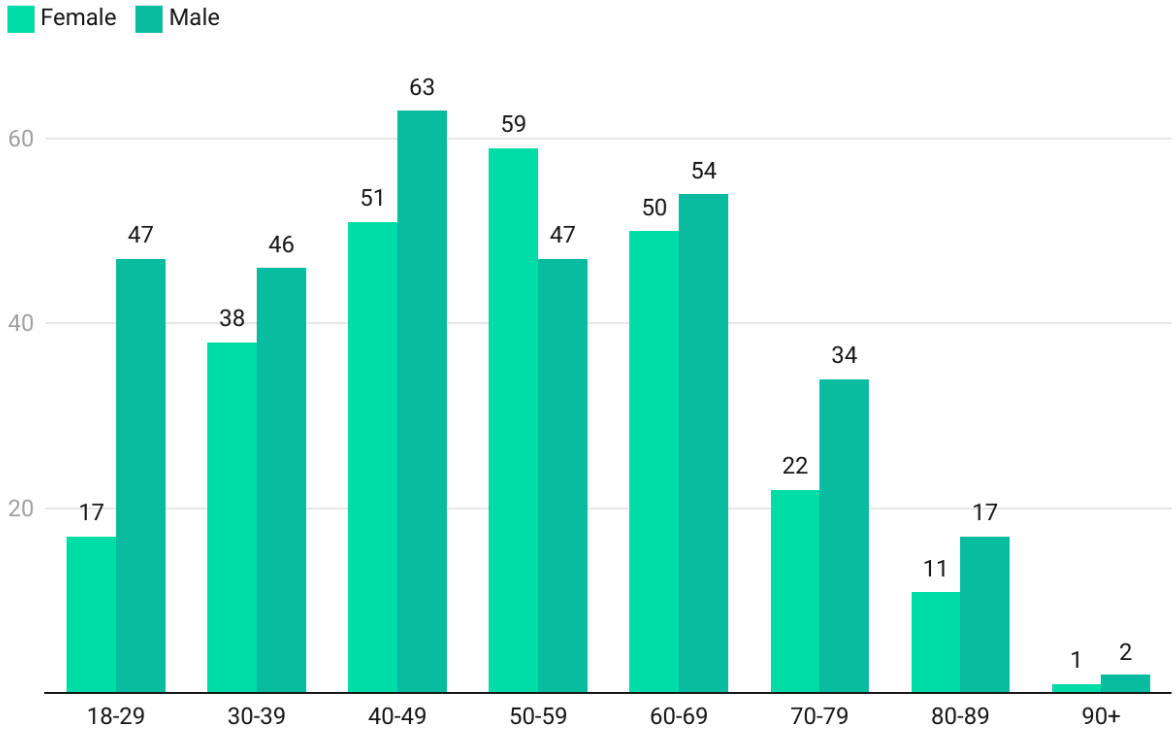


FIGURE 2 Total cases: female = 249; male = 310.

Source: Data derived from Clinical Records System. • Created with Datawrapper

The average ages for users are an arithmetic mean of 52.7 years for women (median 52.5 years) and an arithmetic mean of 50.5 years for men (median 49 years).

Diagnosis – Figure 3

Appendix Section 2 - Service User Characteristics

Attendee diagnoses, in alphabetical order.

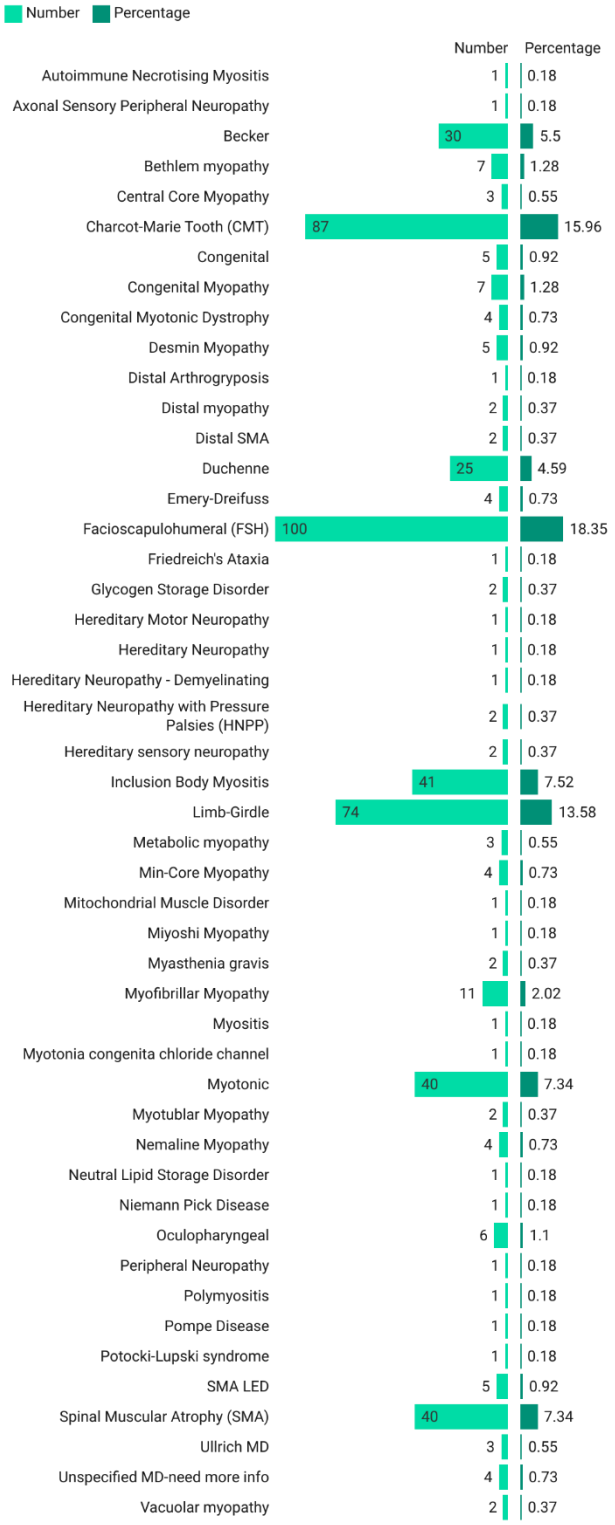
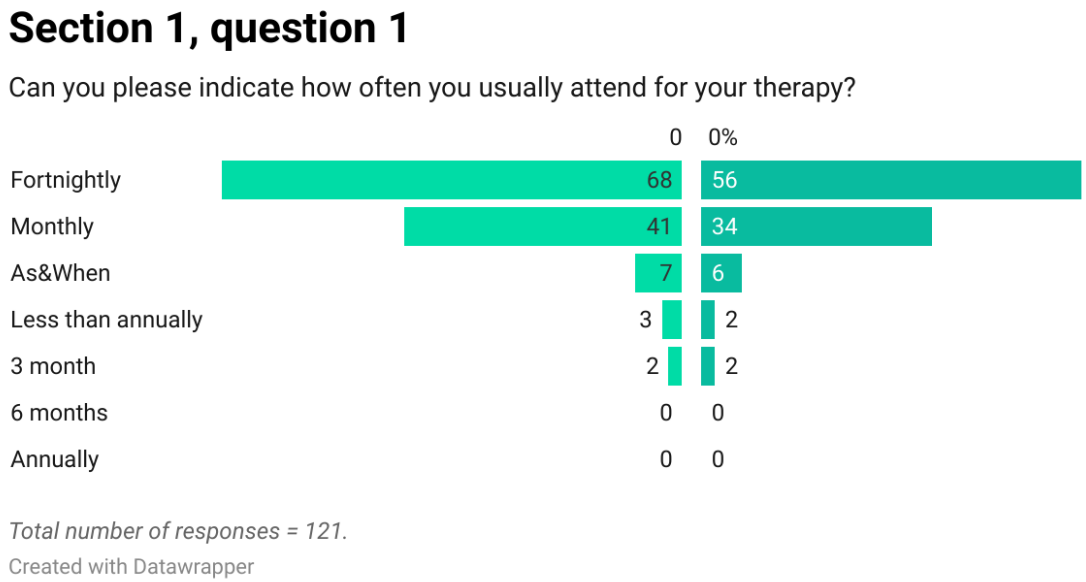


FIGURE 3 Total of cases = 545.

Source: Data derived from Clinical Records System • Created with Datawrapper

Fascioscapulohumeral, CharcotMarie-Tooth and Limb Girdle are the three most commonly recorded dystrophies.

Attendance interval in weeks – Section1, question1 and Figure 4



The data in the graph Section 1 Question 1 is taken from answers given in the survey questionnaire. An alternative summation of attendance frequencies can be derived from the MDSC clinical records system (CRS, see below Figure 4). Using this data a total of 316 individuals for whom a frequency of attendance could calculated were identified. As physiotherapy is the universal therapy received, at some time point, by all MDSC attendees a proxy attendance frequency figure was calculated based on these attendances. The time frame was the year starting the 1st of August 2023 and ending on the 31st of July 2024. According to the CRS data attendance frequency ranged from once every fifty-two weeks to once every two and a quarter weeks. As can be seen, nearly half of the attendees attend at a frequency of at least one or more occasions per month.

Appendix Section 2 - Service User Characteristics

Frequency of attendance, 1st August 2023 to 31st July 2024

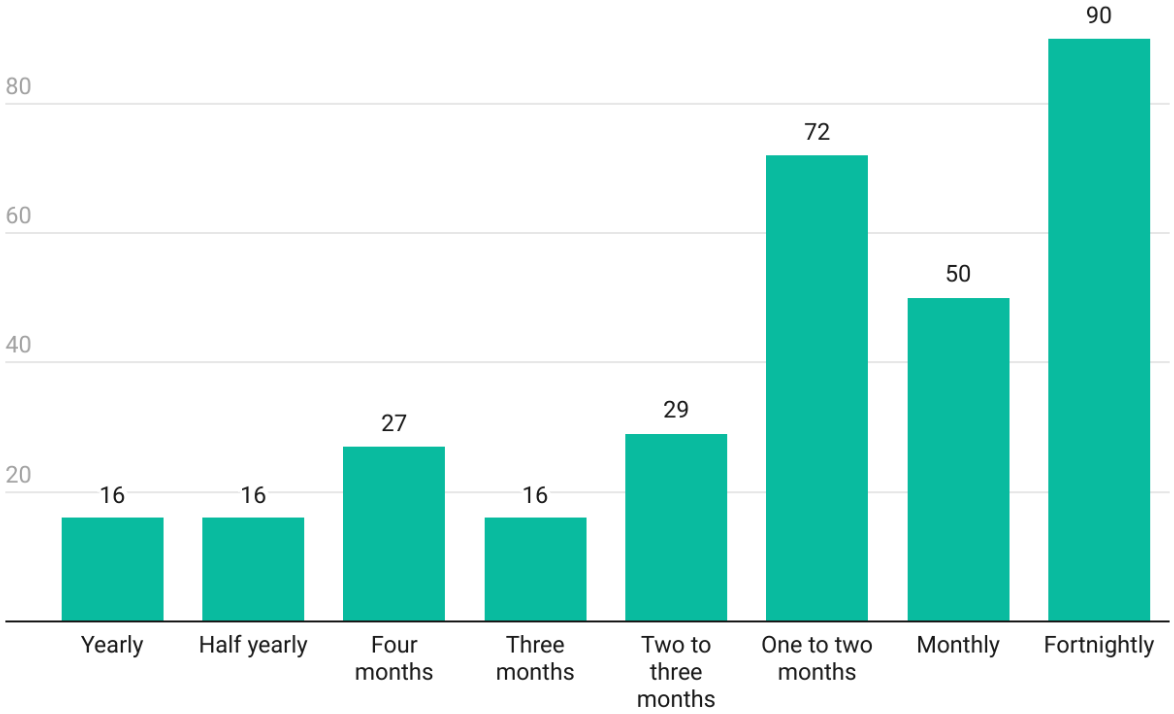


FIGURE 4 Total number of cases = 316.

Source: Data derived from Clinical Records System • Created with Datawrapper

Attendees' county of origin – Figure 5

Appendix Section 2 - Respondent Characteristics

Service users by county of residence

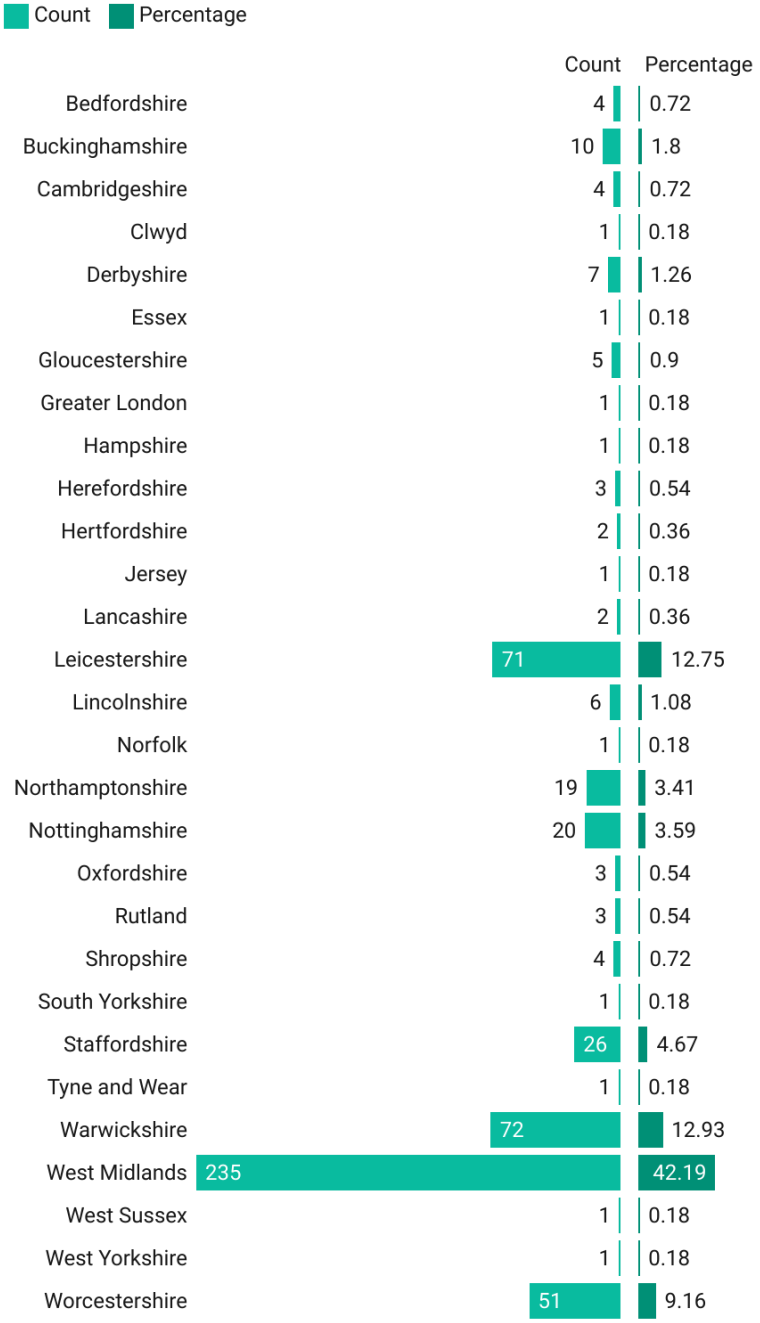


FIGURE 5 Total of cases = 557

Source: Data derived from the Clinical Records System • Created with Datawrapper

Information on service users county of residence is seen here. While the majority of users (42%) emanate from the west Midlands region there are users travelling in from further afield.

Centre attended – Figure 6

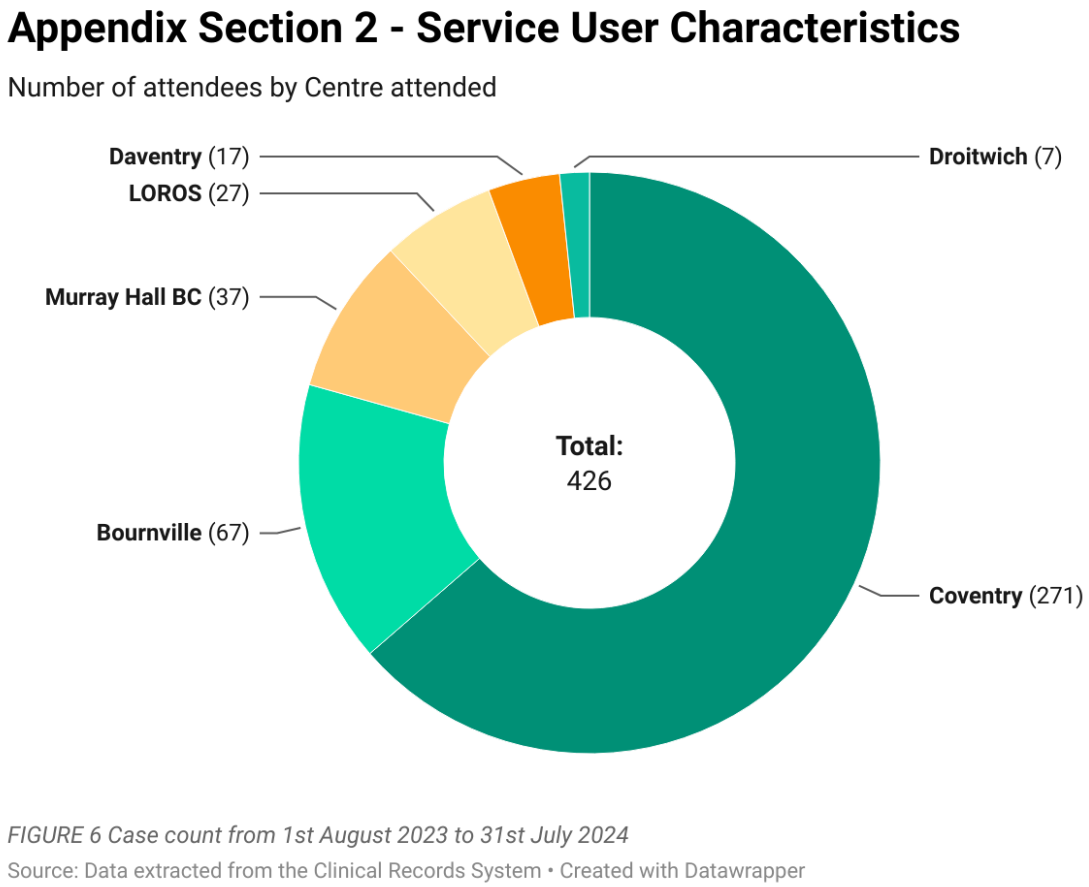


FIGURE 6 Case count from 1st August 2023 to 31st July 2024

Source: Data extracted from the Clinical Records System • Created with Datawrapper

Coventry remains the busiest centre with more attendees than the other centres combined.

Section 3 - Qualitative and textual data

In this year's survey three open text questions are included. The verbatim answers are given below.

Section1, Question 18 Are there any other benefits of therapy support that you have experienced that we have not mentioned here? For example, improvements to upper limb or hand mobility?

Therapy I receive helps to maintain upper body movement.

No

Improvements to energy levels when regularly using the equipment and reduced pain

Improved confidence. General improvement in well being. Stronger for longer.

The therapy has helped me to understand and try to adjust the way I stand and walk due to the muscle in-balances caused by my condition

Feel that overall things are doing slightly better

My overall well-being

I've increased my range of movements and learnt how to exercise effectively. The difference has been remarkable.

No

None

None

Confidence with transfers. Transition to being in a wheelchair. Sense of self worth. Relaxation via France session on Fridays albeit infrequent attender

Support and communications with other professionals. Helping with pain not is not a regular occurrence

Keeping in contact with others with Neuromuscular Conditions.

Hand mobility caused by Carpal Tunnel.

none

Due to my condition my expectations have never been high. However I do feel that there has been success in slowing the rate of deterioration. Also having someone to discuss any issues with gives great encouragement.

As a relatively new user of your great facility, I feel the therapy is right at the beginning for me having joined after having a few falls, progress has been slow as I am now recovering from injuries and years of struggling by, thus caused certain muscle memories that I am undoing and working around. Awareness of how I sit, stand and even breathing now is helping all due to you guys.

No not really.

It has improved my confidence and general mental health

Yes hand mobility

Improved overall wellbeing

Manage shoulder pain better

It gives me a sense of control and agency in the face of a progressive condition

My core strength has improved which has helped other parts improve along with it so strengthen the core and other parts will follow that's how it seemed.

Understand how to control the pain associated with my condition especially muscle groups after suffering an injury. The use of a massage gun, the use of stretching exercises etc to bring back pain free mobility.

keeps me as active and stable as is possible when fighting against a muscle wasting disease and aging.

Mental resilience and kindness of team who care and listen

I find attending my physiotherapist sessions helps me to re-engage with the world especially when I'm able to chat with other who have md

General well-being having support from an experienced physio who understands my condition. Thank you

N/A

Just great advice on how to manage my condition and especially fatigue. What to do and what not to do and this has given me confidence to make good decisions. It has also helped me express some of the struggles I was experiencing to my employer which has brought about changes to my role to help me manage.

I feel that seeing Dan has improved my ability to live with my condition. The point of contact and understanding is priceless. I really feel my mental health is supported as much as my condition.

Hand mobility

Jaw manipulation - the knowledge and physical therapy has been excellent

No

Filled in on behalf of my husband. Tried physio for a few months but took nearly a week to recover - gave up. Does not like perfumed products or people touching him - aromatherapy. Too far to travel to main base. No help from professionals, have a very supportive wife who was a nurse. Would like more support locally -mentally and physical. GP not interested at all.

improvements regarding lymphatic drainage, reducing stiffness/tightness within the muscle, and stretching the muscles.

Definitely my shoulders, neck, hips & legs are sustaining good movement without this treatment I would have gone down hill physically as well as mentally

Section1, final question - “Have you engaged in any of the online classes led by MDSC therapists (e.g. seated or standing classes, yoga, pilates, breathwork, and / or pre-recorded classes available on the MDSC website)?” - is a “yes/no” binary format filter question that directs respondents to either section two (for those who are online users) or section three (for non-users). An open text question, which follows immediately on from the above, allows respondents answering “no” to explain, if they wish, why they do not use the online services.

Given the therapy and home exercises I do, I haven't generally felt the need to try these courses. Also, as they are held during the day during working hours it would be difficult to attend as I already have time out of work to attend in-person therapy sessions.

Prefer face to face.

Work ft

Too busy

I have a lot to manage in my life due to multiple health issues and although I intend to join them, I have been unable to get round to them as of yet

Prefer face to face appointments

Fitting it in

Haven’t appealed to myself

I’ve not had the time and when I did try an online class my laptop was breached therefore out of action for a few weeks. However I plan to access the courses in the future!

I work and the online sessions are when I'm there

I am not really into online therapies

Still working full time so don’t really have the time

Would like to use them, just been busy with work and not got round to booking onto one yet

Had forgotten they were availabe

I prefer one to one therapy

I was not aware that they are any classes online.

Unfortunately I have been busy when these have been run

did some in lockdown but not since. I attend two seated exercise classes a week in person so dont need to do any online ones.

Trying to follow through with exercises on my own.

I will be joining the breathing class and others in time.

I was going to but it coincided with a previous engagement and I haven't seen any others since.

Didn't know about the classes

Timing with work is difficult.

I am not really sure about using on line support. Prefer face to face.

Generally time factors but I do hope to in future

I didn't know about them

Lack of time

Been too busy

May try some later on but a little busy at the moment. Would definitely want to try the wellbeing classes as breathing exercises do appeal to me.

Don't think they will help with my condition

I'm not sure I need them and it has never been suggested by a therapist.

The timings have never really been suitable or I definitely would.

Do not do zoom or similar calls

Due to my work commitments running a dancing school

Section 3, final question. And finally, if you have any comments or suggestions you wish to make about the services and support the MDSC provides please enter them here.

I have been visiting the Centre now for around a year and the physical support, treatment and benefits have been fantastic. Until I started using the Centre my physio support (at the JR hospital in Oxford) was very infrequent, so being able to see high quality and specialised physiotherapists every few weeks has been great. Just having the centre and it's wonderful staff there and ready to help in any way possible is incredibly comforting, and what I really feel is supported. In terms of my condition, I know that I am getting the best out of myself with your support and guidance, and for that I am very grateful. I haven't yet made much use of the more social / community side of the centre but expect to do so in the future. Thank you for all that you do - and please keep doing it!

My answers to the online therapies cannot be viewed as accurate as I haven't attended that many. The therapy received is fantastic and I feel very lucky to have access to such a wonderful team of therapists. The support given by therapists, admin, volunteers and other services users is completely uplifting. The centre facilitates the sharing of information and useful advice.

None I can think of at the moment but please keep up all the good work and thanks for all your hard work.

Due to my Asperger Syndrome I have not made use of the other services available but hope that I can in the future

The support centre make me feel like I'm part of the family and have always made me feel welcomed and appreciated

MDSC provides a professional, welcoming and very friendly service. And its facilities are first class (I attend your Coventry palace!).

I feel so fortunate to have been able to access this service. The support has been invaluable.

I do hope that you continue to provide physiotherapy at the Birmingham Bournville hub. I note that MDSC are piloting new services at Birmingham Uni taking account of more equipment. I strongly prefer one to one hands on therapy rather than anything equipment based. I also think it important to be able to express a choice of having a female therapist. As I felt more comfortable having therapy with a female therapist. The Bournville hub is very good with lots of parking, a cafe and comfortable seating in the communal area and it's very accessible with good road and transport links.

No

More staff, more beds

Before being referred I was struggling through with pain management, and coming here has really helped me to move away from entirely relying on pain killers (which aren't always effective) and therapies have actually tackled the issue rather than covering it up. You all do such amazing work, and I can't thank you enough for the work you do.

For the love of all that is holy, please choose calmer and more relaxing music in the centre!! I attended an appointment today and it was like a rave. Awful. We're coming for professional therapy services, not a disco. I understand that you can't appeal to everybody's musical taste, but try to find something generic and calming. Apart from that, I love my appointments. They've helped my posture, improved my core stability and improved my physical well-being.

Enjoying being part of the new Adapting to Change service user led group. Sorry to hear that the France led "Breathing and More" is reducing to monthly although especially as I often miss it due to work. As and when I finish working I had been thinking I would attend regularly and it would have been part of structuring my week.

Relying on online classes I am absolutely gutted you have decided to reduce the offer of these. Honestly these were a lifeline and will have a detrimental effect in all areas. Very disappointed in this decision and very saddened. If anything online classes should be increasing. If it wasn't broken why try and fix it? Maybe we need another pandemic for you to see sense

More social activities for service users.

What can you say when MDSC support from everyone has changed your life for the better, from finishing work, into what I think will be a good retirement. Thank you all.

MDSC has provided me with an opportunity to have various therapies and a place where I can go which understands my difficulties and provides a central body that I can rely on for support, therapy, social gatherings and general peace of mind with my condition. I have also made a lot of friends there and have involved myself in many fund-raising activities which I enjoy and it gives me a chance of being able to help the MDSC in return for the service they have given me over the years I have been a member. The MDSC plays a very important part in my life and I am very grateful to them for all they have done for me and continue to do for me.

Keep doing what you're doing because I am finally accepting my condition at 55yrs age having been diagnosed as having MD 40yrs ago. I have always hidden it thinking I was the only one with MD until I joined your service and saw other service users.

I think the services provided by the MDSC are marvellous. All the staff are very friendly and knowledgeable. The fact that they tailor the sessions to my needs and apply no pressure at all is very accommodating. The only reason I haven't ticked the strongly agree box is due to lack of effort on my part,

The service provided is dedicated to my needs and has a big positive impact on my health. I am enjoying all sessions I attend

Before I used to get every fortnight session and at the moment I am not getting regular physio sessions and I am going bad

Just so grateful that you are there, the support has been all round not just physical support. Thank you

I visit Dan at Murray Hall for physio and he's been a great help, with a wealth of information and suggestions to aid me with my condition. When I first started, about a year ago, I was seen every 2 weeks, which I felt very beneficial. However as time has gone on, it's been virtually impossible to get fortnightly appointments, there's none available. I don't know if that's because more service users have been taken on, or if there's another reason. But I feel I don't get the full benefit of a physio session if I have to wait 7 weeks between appointments. I feel like our hard work is undone with such a length of time missed.

Overall of the MDSC and everyone I have engaged with have been kind, understanding, helpful and a joy to interact with and the therapists are professional and very knowledgeable in what they do and the general conversation is always good too not just about my condition but anything in general. The sessions that I have have helped in many ways mostly improving my overall mobility and providing me with knowledge to do some exercises at home inbetween sessions which all helps to keep me mobile I can't them all enough.

I feel the help and support I receive from MDSC has been brilliant there always there for you if you have any concerns and all the staff are so helpful and caring

Without the MDSC there is really no help or guidance, with the NHS offering very little support, and local doctors knowledge of MD is mainly what they read before the appointment and the outcome is normally of little use. Without the MDSC there is nothing and if your condition is not serious you would fade into oblivion. The only suggestion would be a closer relationship to the NHS and definitely a government funded programme. Without the MDSC nearly all would need the NHS and this would add to their already long list.

Keep doing what you do so well. Thank you for all your support you give the service users that is unavailable anywhere else.

This support service is essential to me and my partner. It has made an incredible difference to my quality of life and mental wellbeing

A huge thank you to all the staff for their brilliant support and expertise.

I've had the privilege of seeing so many of the physios since attending and I think they are all brilliant! The support staff I've interacted with too are always kind, professional and so helpful. You all do Incredible work and are so supportive and encouraging. I've received way more support and help from my physio (mainly Dan F) on how to manage my condition than any doctor/consultant. He is always looking to find out more, chase up the QE due to cancelled appointments and is just generally fantastic (and very funny). Thank you for providing such great care, it really has had a huge impact on my life.

Keep up the good work I couldn't cope without you!!! No one understands me and my family like you do

The survey is really important but I feel that a lot more meaningful information could be gleaned from reviewing if the person replying is wheelchair bound or otherwise - this would allow more targeted reviews of the therapies and classes outcomes - equally a lot of my responses were 'not applicable' due to the services not being offered / available at a satellite - asking questions around this aspect would assist the MDSC in looking at gaps in offerings

and targeting future investment requests and engaging with NHS commissioners more effectively - I would dearly love to participate and potentially benefit from complementary therapies , osteopathy and equipment aid therapies but I cannot benefit as I cannot get to Coventry - the survey responses of many may not give a more accurate reflection of outcomes because of similar barriers - I am somewhat surprised this level of detail is not being captured

Need actual help locally - Loros Leicester, monthly coffee mornings, counselling, practical help with aids.

MDSC provided an excellent service which gives consistent, long term, good quality help and guidance

Online sessions to be on time, sometimes I have waited up to 20 minutes for a session to start

More Service user's social nights

I am most impressed on every level with MDSC. At this moment i have no suggestions

Section 4 Supplementary Tables

In this section are located tables showing the full numerical breakdown of the respondents to questions reported in section one.

Section 1, question 2

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

Therapy	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	N/A	Total
Physiotherapy	69	34	5	0	2	4	114
Osteopathy	30	14	2	0	1	62	109
Complementary therapies	14	11	2	0	1	80	108
Use of adapted exercise equipment	30	19	6	0	0	53	108

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Section 1, question 3

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

Therapy	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	N/A	Total
Physiotherapy	39	43	13	4	2	5	106
Osteopathy	15	20	8	1	1	61	106
Complementary therapies	11	9	7	0	1	78	106
Use of adapted exercise equipment	22	21	7	1	1	54	106

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Section 1, question 4

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

Therapy	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	N/A	Total
Physiotherapy	37	35	19	6	2	4	103
Osteopathy	14	20	7	0	2	60	103
Complementary therapies	11	6	9	0	2	75	103
Use of adapted exercise equipment	25	17	6	1	2	52	103

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Section 1, question 5

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

Therapy	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	N/A	Total
Physiotherapy	39	40	13	1	2	3	98
Osteopathy	19	18	4	0	2	55	98
Complementary therapies	10	6	8	0	2	72	98
Use of adapted exercise equipment	16	19	8	1	2	52	98

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Section 1, question 6

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

Therapy	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	N/A	Total
Physiotherapy	24	37	20	6	2	8	97
Osteopathy	13	17	10	1	2	54	97
Complementary therapies	9	4	9	2	2	71	97
Use of adapted exercise equipment	13	16	13	2	2	51	97

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Section 1, question 7

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

Therapy	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	N/A	Total
Physiotherapy	34	38	15	1	1	5	94
Osteopathy	15	20	4	0	0	55	94
Complementary therapies	8	6	9	0	0	71	94
Use of adapted exercise equipment	13	23	9	0	0	49	94

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Section 1, question 8

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

Therapy	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	N/A	Total
Physiotherapy	21	34	18	3	2	13	91
Osteopathy	7	15	10	1	1	57	91
Complementary therapies	5	8	7	0	0	71	91
Use of adapted exercise equipment	7	20	8	1	1	54	91

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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)?"

Therapy	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	N/A	Total
Physiotherapy	27	38	15	3	1	7	91
Osteopathy	13	19	2	2	0	55	91
Complementary therapies	9	4	8	0	0	70	91
Use of adapted exercise equipment	13	17	7	1	0	53	91

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Section 1, question 10

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

Therapy	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	N/A	Total
Physiotherapy	20	32	14	2	1	22	91
Osteopathy	15	14	4	0	0	58	91
Complementary therapies	8	10	5	0	0	68	91
Use of adapted exercise equipment	9	8	16	2	0	56	91

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Section 1, question 11

"To what extent would you agree that the MDSC support you have received 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	Total
36	29	12	0	2	12	91

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Section 1, question 12

"To what extent would you agree that MDSC support, by helping you understand and manage your condition better, has made you feel more confident and in control?"

Strongly agree	Agree	Neutral	Disagree	Strongly disagree	N/A	Total
53	27	7	0	1	2	90

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Section 1, question 13

"Viewed overall, would you agree or disagree that the MDSC support you have benefited from has helped you to stay in work?"

Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Unable to say	N/A	Total
20	10	12	2	3	0	43	90

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Section 1, question 14

"Viewed overall, would you agree or disagree that the MDSC support 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	Total
39	34	9	2	2	1	2	89

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Section 1, question 15

Viewed overall, would you say that with the MDSC services your condition is ...

Very much improved	Much improved	Moderately improved	Slightly improved	Not at all improved	Unable to say	Total
13	22	22	16	5	12	90

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Section 1, question 16

Which statement do you think would best describe the general impact the MDSC's services 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
16	55	5	1	10	87

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Section 2, question 1

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

Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Total
10	14	6	0	0	30

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Section 2, question 2

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

Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Total
9	10	11	0	0	30

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Section 2, question 3

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

Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Total
9	13	7	0	0	29

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Section 2, question 4

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

Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Total
5	12	11	1	0	29

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Section 2, question 5

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

Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Total
6	13	10	0	0	29

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Section 2, question 6

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

Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Total
5	6	17	1	0	29

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Section 2, question 7

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

Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Total
12	13	4	0	0	29

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Section 3, question 1

Viewed overall, would you agree or disagree that the MDSC support you have benefited from has helped you to connect with others?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree	N/A	Total
23	26	14	2	1	12	78

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Section 3, question 2

Viewed overall, would you agree or disagree that the MDSC support you have benefited from has given you a community to feel part of?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree	N/A	Total
22	30	13	3	1	9	78

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Section 3, question 3

Viewed overall, would you agree or disagree that the MDSC support you have benefited from has helped your family and/or carers to feel supported?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree	N/A	Total
21	27	12	1	1	16	78

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Section 3, question 4

Viewed overall, would you agree or disagree that the MDSC support you have benefited from has helped you to accept and live well with your condition?

Strongly agree	Agree	Neutral	Disagree	Strongly disagree	N/A	Total
26	38	9	1	1	3	78

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