



**Muscular Dystrophy
Support Centre**
inspiring independence

MDSC Service User Survey 2023

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, and therapeutic interventions, available at the MDSC headquarters and their four satellite therapy clinics.

Questionnaire distribution commenced in November 2023 and was terminated on the 15th of January, 2024. Distribution was electronic, via e-mail, and was transmitted to 568 addresses in the MDSC database. After data cleaning there were 193 entries available for analysis.

A descriptive mode of analysis was adopted. Question formats were single choice “radio button” variables, categorical variables (which included multiple choice questions and single choice questions) and open text questions. 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”. The “strongly agree” and “agree” options on these variables outweighed the other options by a large margin.

Among the principal findings 65% of the respondents stated that the MDSC therapists played the primary role in helping them manage their condition (as against 16% reporting their NHS consultant playing this role). In addition to this 89% of respondents were in agreement that our support helped keep their joints flexible, and 82% said it helped maintain muscle strength. 77% said our support prevented or reduced falls, and 73% indicated that their therapy helped them kept them out of hospital and reduced their reliance on other healthcare services. 76% said our support helped slow the deterioration of their condition, and 73% said that therapy support helped them manage pain. 77% said we had helped them understand and manage their condition, 75% stated that their motivation was improved and 76% indicated that the MDSC had assisted them to live well with MD. 75% said that our support – online and face to face - helped them maintain their emotional wellbeing, and 79% said our support helped them build their physical resilience.

Respondents clearly felt that the range of interventions from the MDSC were very valuable. Respondents were also able to input free text expressing, in their own words, their sentiments regarding the MDSC and its work. These comments were overwhelmingly positive, reinforcing the data derived from the quantitative questions.

It is apparent that in the view of those who responded through both quantitative and qualitative questions 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 2023

(1) Introduction

An annual survey of the MDC service users is made 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

Questionnaire distribution commenced in November 2023 and was terminated on the 15th of January, 2024. Distribution was electronic, via e-mail, and was transmitted to 568 addresses in the MDSC database. Questionnaire design was undertaken through the QuestionPro¹ package with the answers being stored in their database. Questionnaires were completed without the use of identifiers beyond asking which condition the respondent lived with. No attempt was made to screen for multiple responses from the same individual. Question formats were single choice “radio button” variables, categorical variables (which included multiple choice questions and single choice questions) and open text questions.

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

(3) Results

An initial examination of the database suggested the presence of a number of spurious case entries. The ‘logic’ of the questionnaire did not allow for any validation or screening process to be applied to the creation of new records. There was therefore the possibility that an individual respondent had, by accident or design, created more than one record. The dump from QuestionPro contained a total of 291 entries in the database. Among the system variables recorded by QuestionPro was the internet protocol (IP) address. The IP address is a unique identifier for a device that is connected to the Internet. On the assumption that each respondent to the questionnaire communicated via the same device those entries which showed the same IP address might therefore be assumed to be the same person making two or more new entries. The database was then reorganised and sorted on the IP address variable. Repeated IP addresses could now be easily identified and the multiple entries removed. Where two or more entries did exist for the same IP address the most complete entry was retained and the other entries

¹located at <www.questionpro.com>

deleted. At the end of this process 193 unique entries remained. Each of these entries represented a completed or partially completed questionnaire which had been submitted by a single individual.

Following the cleaning of the data 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 presentation of the analysis is arranged around two broad headings: (i) those questions relating to the respondents' opinions of the various therapeutic interventions offered by the MDSC; and (ii) those questions which relate to the background and other characteristics of the respondents.

A breakdown of the quantitative survey results is presented below in section one and section two of the Appendix with qualitative material located in section three.

(4) Discussion

To view the results in graphical form please see section one and section of the Appendix. The survey achieved a response rate of 34% of the number of e-mail addresses originally contacted.

Regarding the patterns of service usage respondents report that they access the face to face therapies quite intensively, predominantly every two weeks to every month (see Appendix, section 2, figure 4). The most favoured location for this is the facility in Coventry with ninety six out of 139 respondents attending here (Appendix, section 2, figure 5a and also figure 5b).

Turning firstly to the opinions of the respondents regarding the efficacy and health promotional benefits of MDSC therapies. The variables capturing this data are ordinal variables, arranged on a five-point scale ranging from "strongly agree" to "strongly disagree" with a sixth option of "not applicable/don't know". One option only from these can be selected by the respondents.

An examination of figure one in section one of the appendix clearly demonstrates the positive benefits respondents feel they gain. The "strongly agree" and "agree" options on these variables outweigh the other options by a large margin. Respondents clearly feel that these interventions are very valuable. It can be seen that the interventions are perceived as having a direct beneficial action on such physiological attributes as joint flexibility, muscle strength, pain management, walking ability, reduction in falls and also in reducing the need for hospital services. This is not to argue though that such a benefit could be objectively demonstrated through tests or measurements or other means. But what can be asserted is that if the respondents *feel* that such a benefit exists then it is real for them regardless of its objective demonstrability.

The dystrophic conditions encountered at the MDSC are unlikely to show any improvement over the long term. In general, these conditions will worsen gradually over time. However, looking at figure 2 (Appendix, section one), respondents feel strongly that the MDSC interventions are significantly reducing the speed at which their condition is deteriorating. Once

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

again, it is not possible to show by objective means a clear clinical reduction in the rate of deterioration. This sense of delayed deterioration is a subjective phenomenon, although none the less real for that.

In figures three to six respondents are presented with a series of statements to which they may indicate agreement or disagreement with the sentiment expressed. These sentiments cover a wide range of psychosocial parameters such as building emotional resilience, feeling in control, and maintaining motivation and independence. There are twenty-one statements here and forty-nine respondents provided answers. What is particularly noticeable is the relative paucity of negative opinions. In each instance no more than four respondents indicated disagreement with the statement, and then only when considering the statements “enables me to do more with family/friends” and “enables me to remain in employment.” Otherwise, the respondents were in agreement or strong agreement.

Feedback included that 65% of the respondents believe that the MDSC therapists play the primary role in helping them manage their condition (as against 16% reporting their NHS consultant playing this role).

Other key findings included that:

89% of respondents were in agreement that our support helped keep their joints flexible, and 82% said it helped maintain muscle strength.

77% said our support prevented or reduced falls, and 73% indicated that their therapy helped them kept them out of hospital and reduced their reliance on other healthcare services.

76% said our support helped slow the deterioration of their condition, and 73% said that therapy support helped them manage pain.

77% said we had helped them understand and manage their condition, 75% stated that their motivation was improved and 76% indicated that the MDSC assisted them to live well with MD.

75% said that our support – online and face to face - helps them maintain their emotional wellbeing, and 79% said our support helps them build their physical resilience.

In the main the respondents report that their presence in the Centre is physical, attending face to face sessions, with only a relative minority accessing ‘virtual’, or online, therapies. (as may be seen by comparing figure 14 with figure 16). There is also uncertainty regarding the benefit to wellbeing of the online therapies (see figure 17), with only physiotherapy, group physiotherapy and the drop-in exercise sessions receiving majorities in “strongly agree” and “agree” categories.

In addition to this quantitative information respondents were also able to input free text expressing, in their own words, their sentiments regarding the MDSC and its work. The

sentiments expressed are overwhelmingly positive and this material may be viewed in section three of the Appendix.

(6) Conclusion

The survey appears to have been well received by the MDSC service users and it achieved a substantial 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 managing their conditions and allowing them to achieve richer and more rewarding lives. For every question in the questionnaire which seeks an opinion as to 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 whatever means made available those users of the MDSC services who answered this survey offer support for, and much appreciation of, the work that the MDSC undertakes.

Appendix

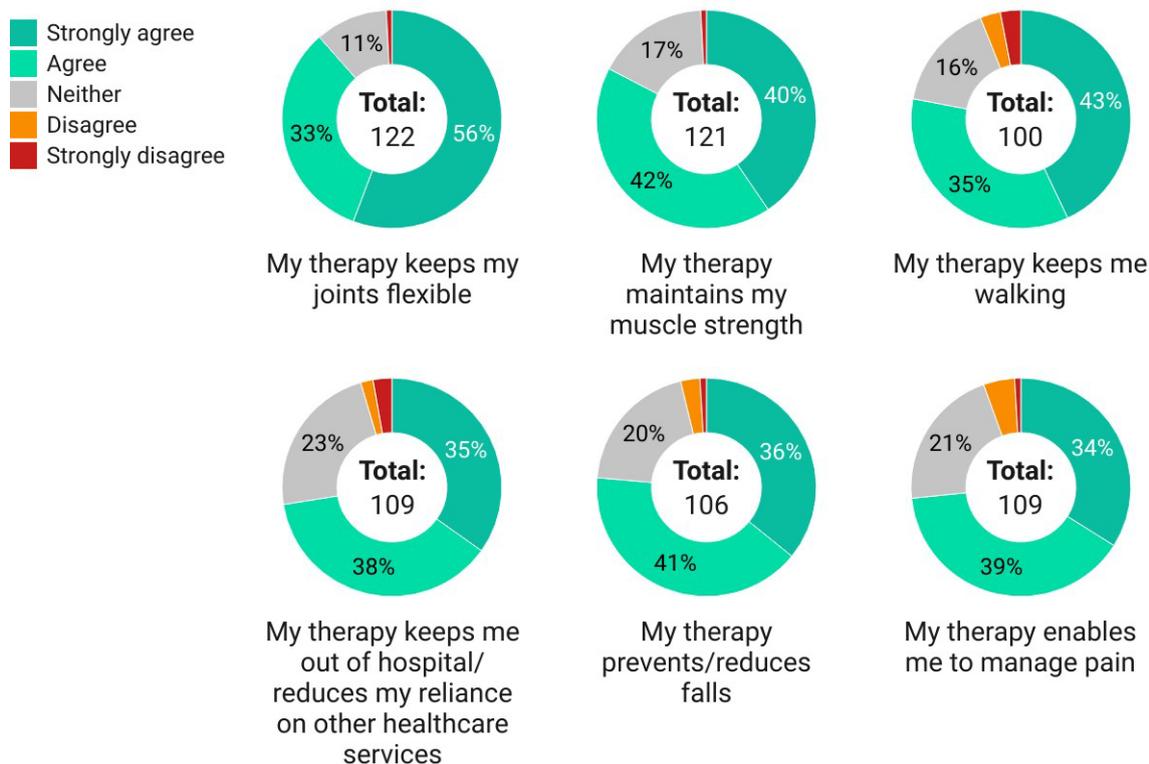
Results in detail

Section 1 - The user assessed impact.

This section presents results pertaining to the respondents' views regarding the impact of the various therapeutic interventions which they receive. To start with here is an assessment by respondents, across a variety of parameters, of the impact that the therapies have. 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.

Question 20 - The overall impact of MDSC therapies on my health.

APPENDIX SECTION 1 FIGURE 1



Total number of responses = 127. Statements marked as "non-applicable/don't know" excluded from these graphs. The total figure shown inside the doughnut is the number remaining after the "non-applicables" have been discounted.

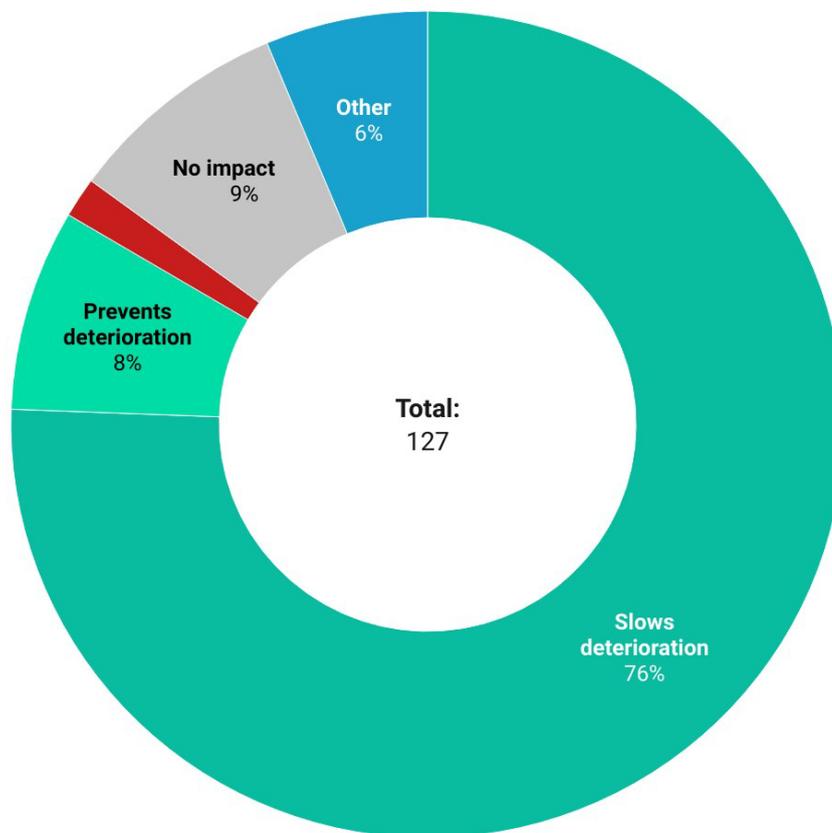
Created with Datawrapper

Above, we see an overall assessment by service users of the general impact therapies had on the respondents' condition. The question format used here (and on the other ordinal variables) was the 'radio button' format which permitted a single choice of response per question statement. The therapies in question here might be either face to face, online or both.

Question 21 - Which best describes the impact MDSC therapies have on the progression of your condition?

APPENDIX SECTION 1 FIGURE 2

■ Slows deterioration ■ Prevents deterioration ■ Speeds deterioration ■ No impact ■ Other



Number of responses = 127. Two respondents reported "speeds deterioration".

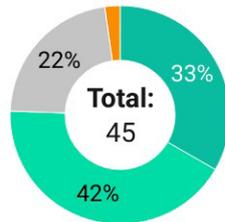
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Figure 2 continues the theme of the general, overall, impact that the various MDSC therapies have on the respondents' conditions. Preventing or slowing deterioration are the responses given by more than three quarters of the respondents.

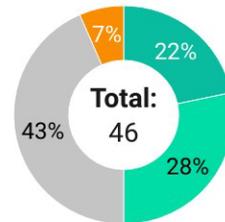
Investigation of the service users' feelings about the impact of the therapies more widely on their life was given in question 27, illustrated in figures three to six, where respondents expressed the extent to which they agreed or not with a series of statements. Forty-nine respondents provided answers to this question.

Question 27 (1) - Do you agree or disagree with the following statements?

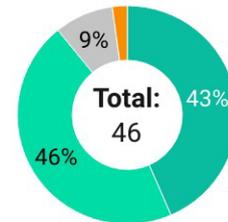
FIGURE 3



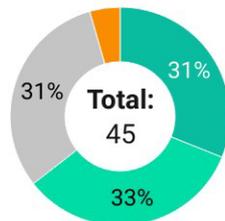
Helps my overall emotional and mental wellbeing



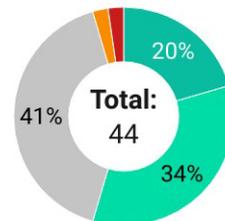
Helps me to connect with others



Gives me somewhere to readily turn to to discuss my muscle condition if needed



Helps me to avoid seeking GP or A&E care



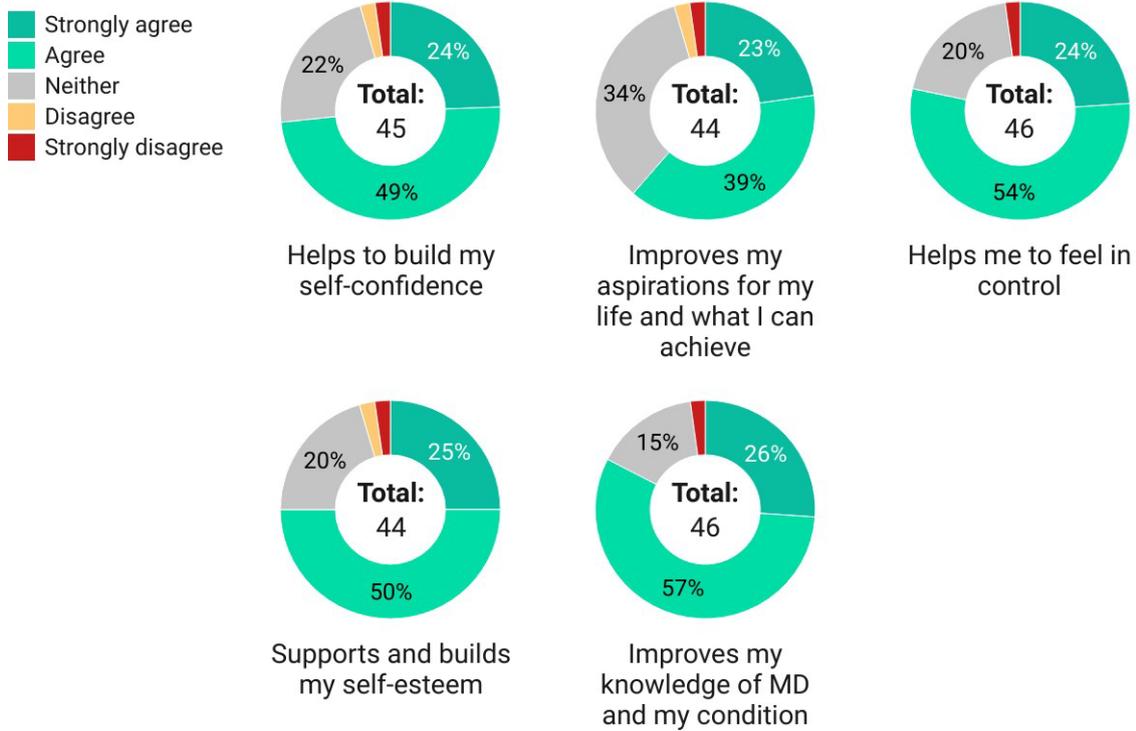
Helps provide social opportunities and community

Total number of responses to each question = 49. Statements marked as "non-applicable/don't know" excluded from these graphs. The total figure shown inside the doughnut is the number remaining after the "non-applicables" have been discounted.

Created with Datawrapper

Question 27 (2) - Do you agree or disagree with the following statements?

FIGURE 4

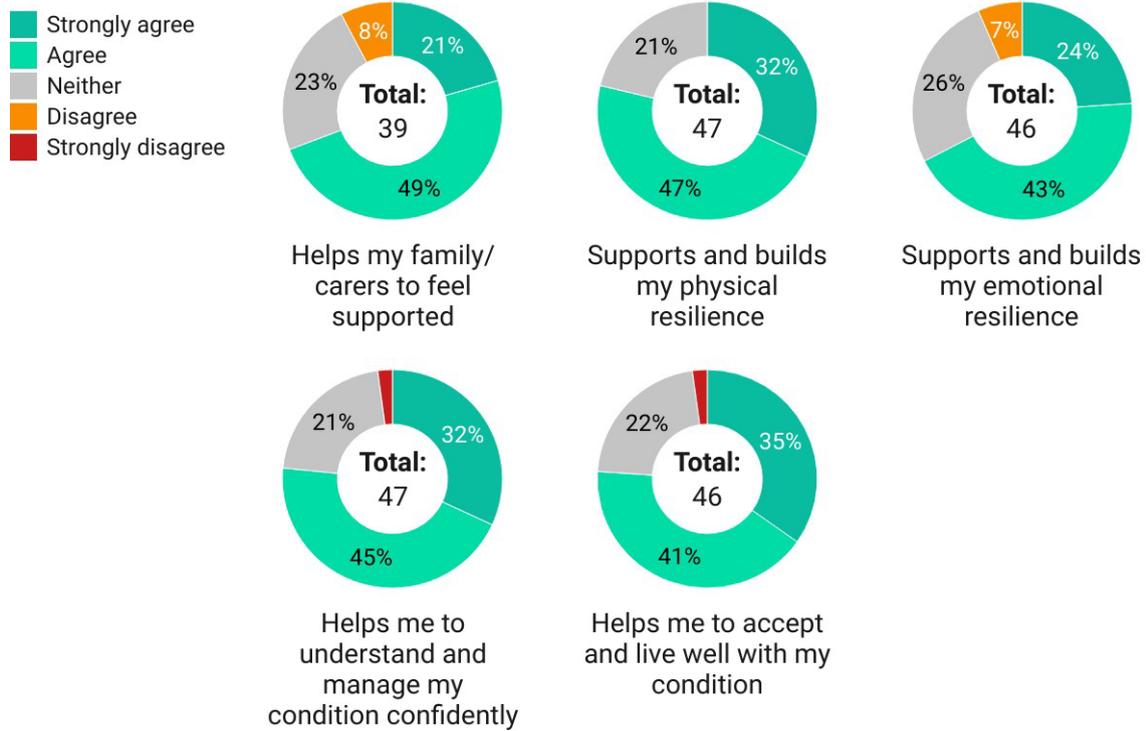


Total number of responses to each question = 49. Statements marked as "non-applicable/don't know" excluded from these graphs. The total figure shown inside the doughnut is the number remaining after the "non-applicables" have been discounted.

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Question 27 (3) - Do you agree or disagree with the following statements?

FIGURE 5

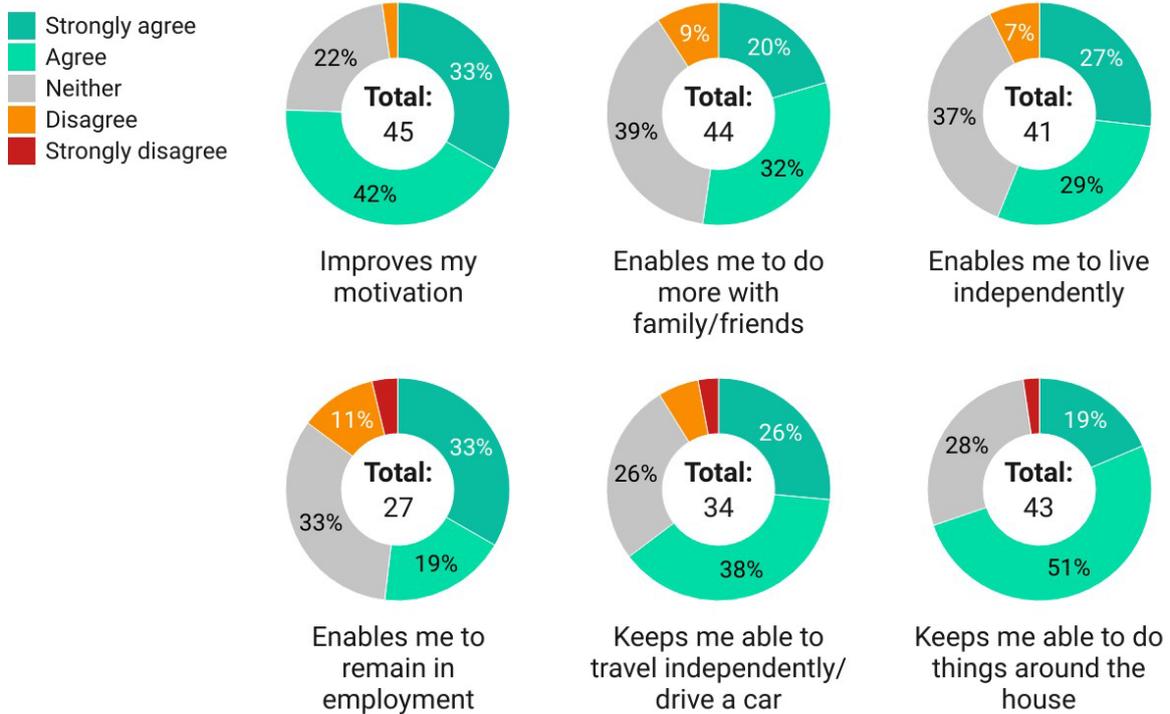


Total number of responses to each question = 49. Statements marked as "non-applicable/don't know" excluded from these graphs. The total figure shown inside the doughnut is the number remaining after the "non-applicables" have been discounted.

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Question 27 (4) - Do you agree or disagree with the following statements?

FIGURE 6



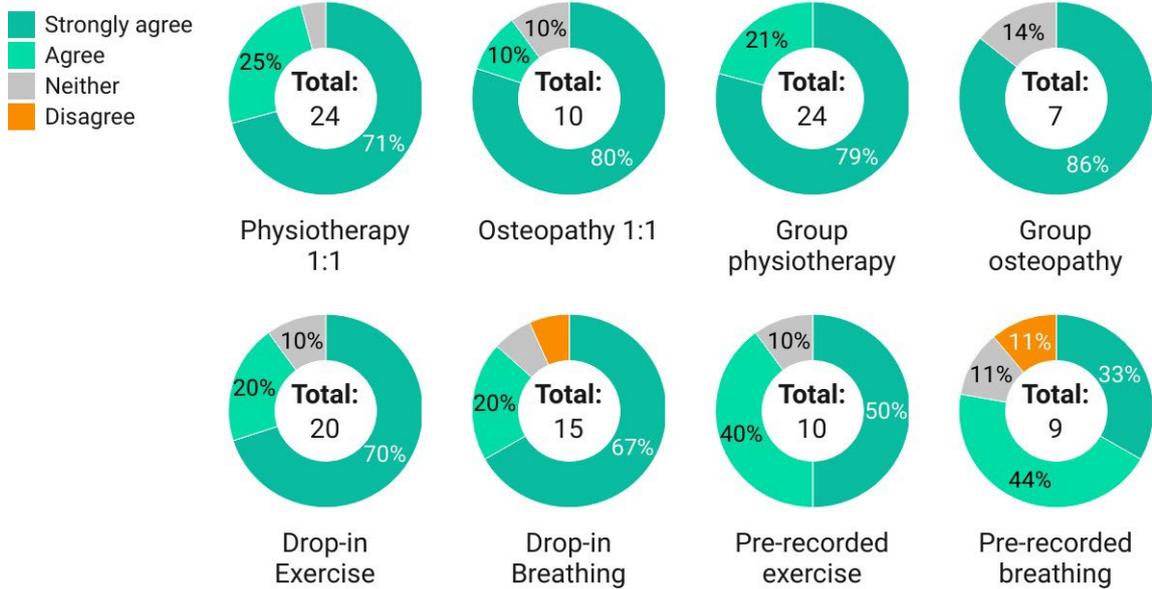
Total number of responses to each question = 49. Statements marked as "non-applicable/don't know" excluded from these graphs. The total figure shown inside the doughnut is the number remaining after the "non-applicables" have been discounted.

Created with Datawrapper

Question 17 allowed respondents to express an opinion regarding the benefits of the various online interventions that are offered.

Question 17 - "I find this online therapy to be of benefit to my wellbeing" - agree or disagree:

FIGURE 7



Total number of responses to each question = 31. Statements marked as "non-applicable/don't know" excluded from these graphs. The total figure shown inside the doughnut is the number remaining after the "non-applicables" have been discounted. No responses recorded for "strongly disagree".

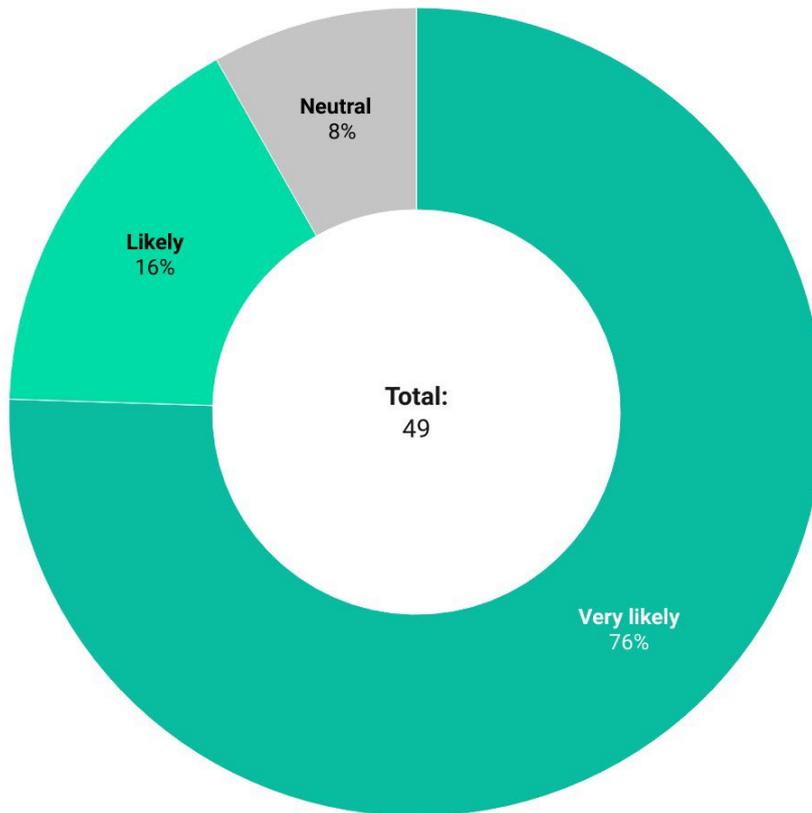
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That there were prominent levels of “don’t know, not applicable” answers for osteopathy, group osteopathy, pre-recorded exercise and pre-recorded breathing probably reflects the small numbers actually using these therapies and thus finding them relevant or applicable.

Question 28 - How likely are you to recommend us to friends and family?

FIGURE 8

Very likely Likely Neutral



Total number of responses = 49. Five point scale used ("very likely" to "very unlikely"); the "unlikely" and "very unlikely" options attracted no responses.

Created with Datawrapper

It can be seen in figure 8 that of the respondents who answered this question the majority would recommend the MDSC to others.

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.

Section 2 Respondent characteristics

This section presents results regarding various aspects of the respondents' background.

Which condition are you living with?

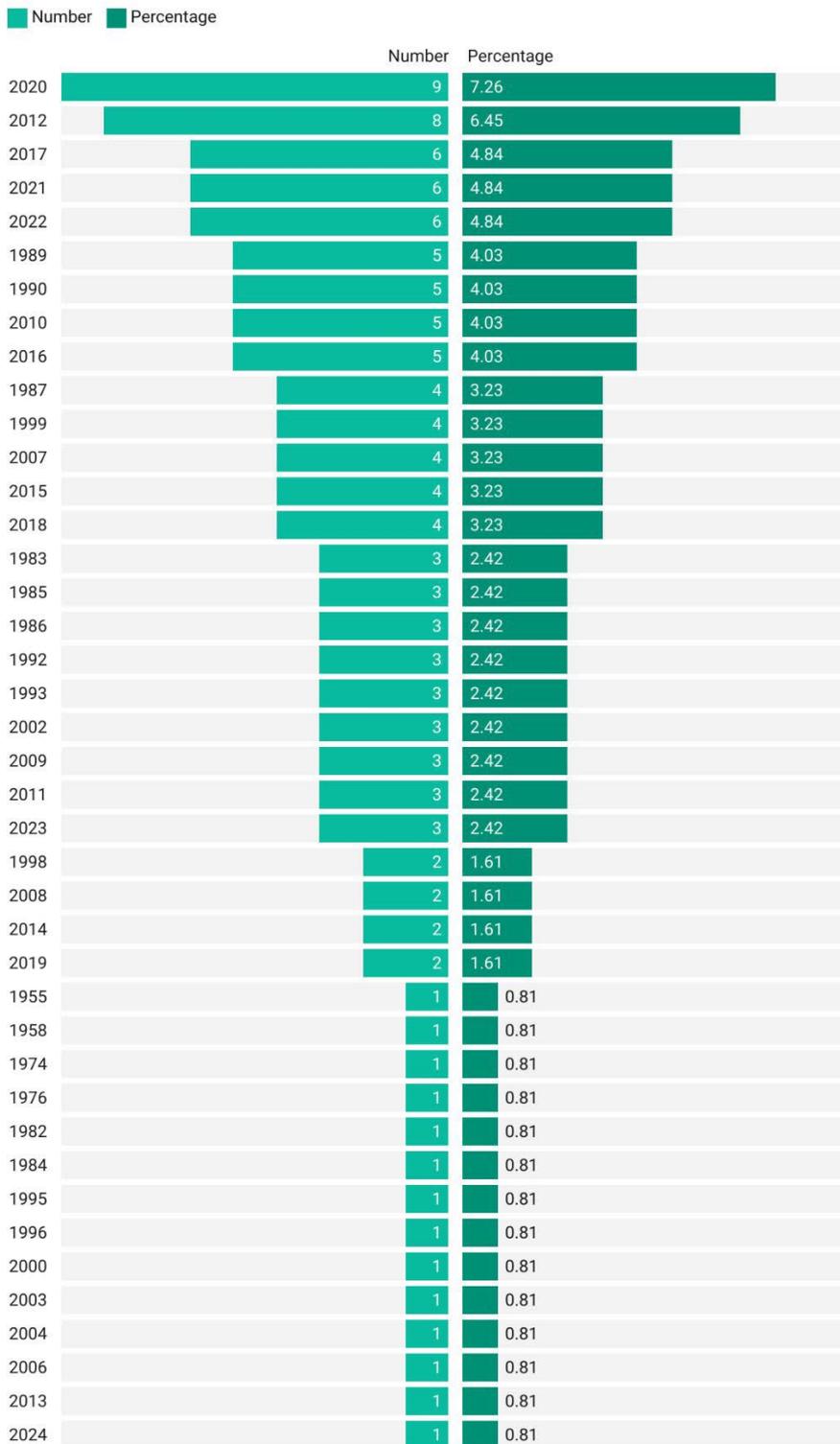
APPENDIX SECTION 2 FIGURE 1

Condition	Number	Percentage
Fascioscapulohumeral (FSH)	40	23
Charcot-Marie Tooth (CMT)	23	13
Limb-Girdle Muscular Dystrophy	22	13
Inclusion Body Myositis	18	11
Becker Muscular Dystrophy	10	6
Myotonic	15	9
Other	9	5
Spinal Muscular Atrophy (SMA)	8	5
Myofibrillar Myopathy	6	4
Duchenne Muscular Dystrophy	4	2
Prefer not to say	3	2
Pompe Disease	2	1
Merosin deficient congenital Muscular Dystrophy	2	1
Congenital Myotonic Dystrophy	2	1
Bethlem Myopathy	2	1
Ullrich MD	1	1
Mitochondrial Muscle Disorder	1	1
Mitochondrial DNA Disease	1	1
Emery-Dreifuss	1	1
Distal Hereditary Motor Neuropathy	1	1
Total	171	100

Created with Datawrapper

Question 3 - In what year were you diagnosed with your condition?

APPENDIX SECTION 2 FIGURE 2

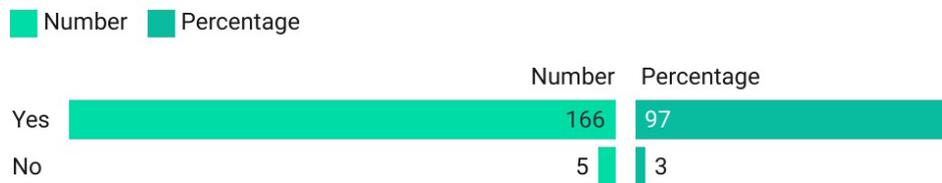


Total responses = 124.

Created with Datawrapper

Question 4 - Are you aware that MDSC is an independent self-funded charity and that individual support is critical to its running?

APPENDIX SECTION 2 FIGURE 3



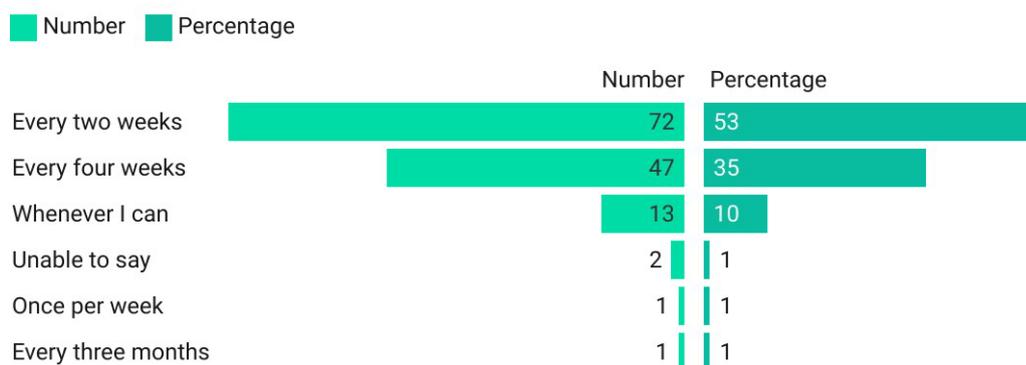
Total number of responses = 171.

Created with Datawrapper

The majority of the respondents appear well informed as to the Centre's charitable status and principal source of funds.

Question 8 - How often do you attend face-to-face therapies at the MDSC?

APPENDIX SECTION 2 FIGURE 4

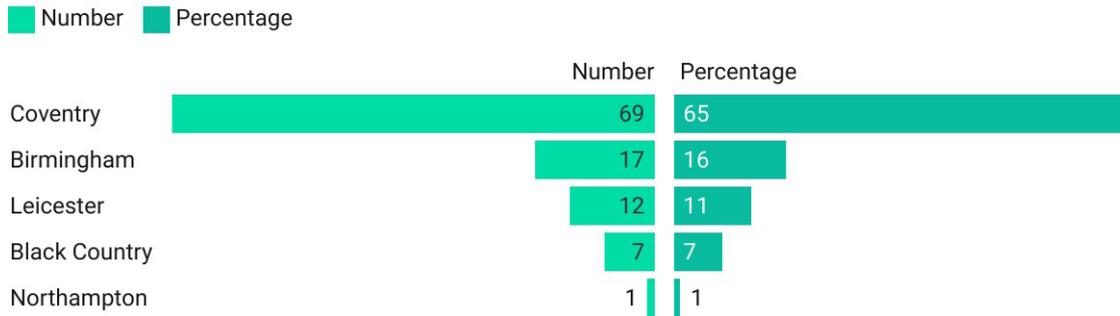


Total number of responses = 136.

Created with Datawrapper

Question 9 - Which MDSC location do you use (single site attendance)?

APPENDIX SECTION 2 FIGURE 5A

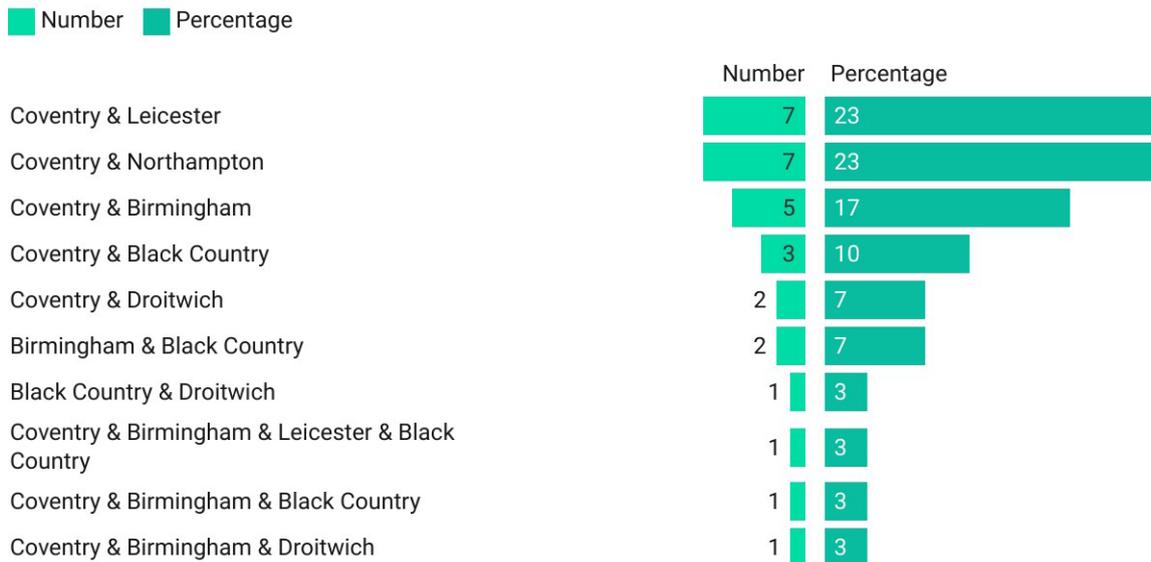


Total number of respondents attending a single site = 106.

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Question 9 - Which MDSC locations do you use (multi-site attendance)?

APPENDIX SECTION 2 FIGURE 5B



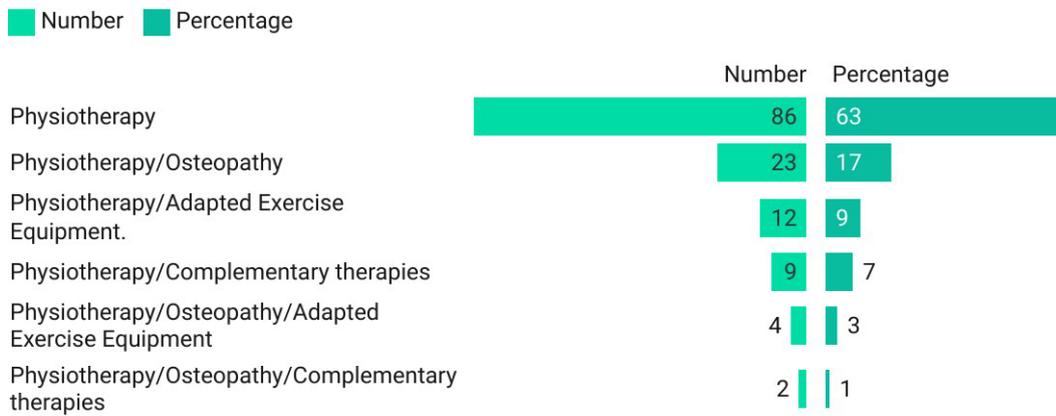
Total number of respondents attending multiple sites = 30.

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One hundred and thirty-six respondents answered the question regarding which site attended. The MDSC has headquarters in Coventry and five satellite operations in Leicester, Birmingham, Black Country, Northampton and Droitwich. One hundred and six respondents attended a single site, twenty-seven attended two sites, two attended three sites and one respondent attended four sites.

Question 10 - Which face-to-face therapies do you access?

APPENDIX SECTION 2 FIGURE 6



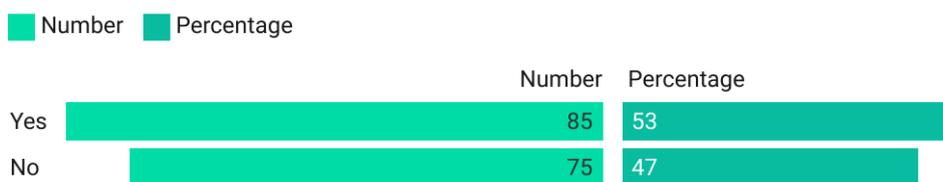
Total number of responses = 136.

Created with Datawrapper

As can be seen from figure six above approximately two-thirds of the respondents make use of physiotherapy as a single therapy, while the remainder utilise physiotherapy in combination with other therapeutic interventions.

Question 11 - Are there face-to-face therapies that you haven't tried/not currently using?

APPENDIX SECTION 2 FIGURE 7



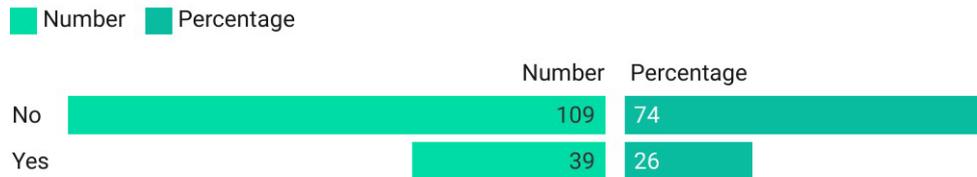
Total number of responses = 160.

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Question 14 on the survey asked respondents to indicate whether they were already online therapy users. Thirty nine out of 148 respondents answered “yes”.

Question 14 - Do you access our online therapy services for your condition?

APPENDIX SECTION 2 FIGURE 8



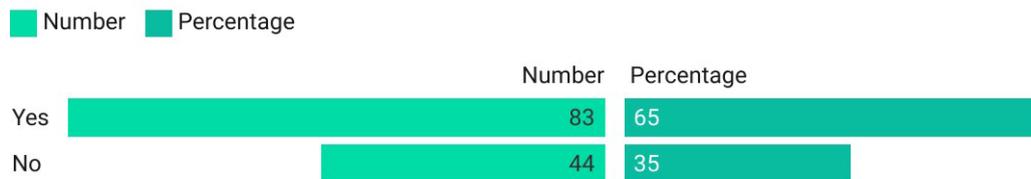
Total number of responses = 148.

Created with Datawrapper

Online therapies are less popular than face-to-face therapies.

Question 18 - Are you interested in accessing online therapy services or support in the future?

APPENDIX SECTION 2 FIGURE 9



Total number of responses = 127.

Created with Datawrapper

There is substantial interest in gaining access to online therapies. Of the 109 people who said, in answer to question 14, that they didn't use online therapy fifty-five of these respondents went on to answer "yes" to question 18.

Question 16 - Which online therapies do you access?

APPENDIX SECTION 2 FIGURE 10

■ Number ■ Percentage



Total number of responses = 31.

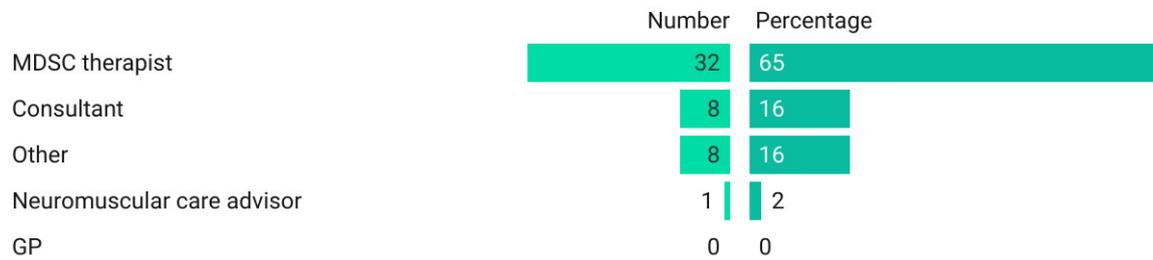
Created with Datawrapper

It can be seen in figure 10 that of the online therapies available it is the physiotherapies that are predominantly the popular choices whereas osteopathy, whether group or individual, is much less so.

Question 26 - Which professional do you feel plays the primary role in helping you manage your condition?

APPENDIX SECTION 2 FIGURE 11

■ Number ■ Percentage



Total number of responses = 49.

Created with Datawrapper

As illustrated in figure 11, above, the respondents view the MDSC therapists as playing a pivotal role in the management of their condition. The other health professionals appear to be rated as of secondary importance only.

Section 3 - Qualitative and textual data

Question 34 Do you have any thoughts on how we might improve physical access or service user experience in our main centre and/or satellite clinics?

No they are excellent.

All generally accessible.

None.

Nothing at the moment.

No not at the moment.

At his moment in time I cannot suggest anything but if I have an idea I will share with you I am extremely happy with the support from MDSC A million thanks to you all

I think the main centre in Coventry is amazing.

At the moment I cannot see anyway that Bourneville can be improved. It certainly offers me a great support service meeting all my needs. Thank you to all.

More services available at satellite clinics

Turn off the radio and make the environment calmer and more relaxing!

Too far to travel to Coventry on a regular basis. Prefer more local base.

So far it's working for me but i would point out if there is not working for me and if there is room for improvement and would recommend others to say if something can be done to improve things.

Perfect experience for me thank you.

Having a PA that can't drive and very sketch taxi services make it difficult to attend sometimes, maybe forging links with a good local taxi firm (Coventry) would be useful.

No, I feel access is very good currently.

Not actual physical access but an online booking system would make arranging appointments easier for those of us who work and struggle to call during opening hours.

None - you already make it so easy.

Access is good.

A larger, more private space at Bourneville would be good, but it isn't a necessity... just a nice to have!

Can't think of anything at this time

Easier access to booking ahead therapies. Main centre is easily accessible. Make GPs aware of service and availability.

I think you are doing a great job anyway.

A monthly subscription to enable use of equipment.

No think the clinic runs very well.

The main issue, which no longer is an issue, was the old premises. The Westwood location is perfect for location, accessibility, and space.

Question 35 How has being an MDSC service user improved your health and well-being?

Good.

Keeps me supple and walking.

Difficult to say. I think it has helped with some aspects of my mobility.

Helped me socialise and meet people.

Keep me going.

Mental and physical resilience and support from someone who cares.

Showed the way to keep healthy.

Social and confidence.

By keeping me flexible and sometimes pain free thus helps me cope with all aspects of my life without you I would not be physically the person I am today.

It's kept me physically more able not only to cope with my condition but emotionally and mentally it has made me stronger, more upright and keeps my pain under control.

I believe MDSC has helped with the coming to terms with my condition and feel as though I am in expert hands which hopefully will slow my progression of my disease.

Given me a source of contact.

By connecting me to other people who are living a shared experience whether that's by directly having a neuromuscular condition or caring for someone with one.

More aware of the condition.

Improved my pain management and confidence.

I like the physio as they understand my condition and generally look forward to attend as the centre is doing a great job for me and others with muscular condition

Enabled me to access physio in a comfortable safe environment and building a relationship with staff helps my emotional wellbeing.

Definitely made me more aware of my posture and I have been given strength building exercises. I believe it has helped me to maintain current levels of fitness and hopefully slowed progression of muscle wasting. Lots of positivity from the therapists boosting mental health. Overall great experience. Thank you.

Very Much thanks.

It has not.

Made me more able to deal with this condition.

I've not had physio for almost 20 years so it's aided my joint mobility.

I have been able to maintain and improve my physical condition and mobility with the ongoing support of the MDSC. It has taught be strategies for self-management and made me feel far more in control of my condition and had a massively positive impact on my life

I am able to do more activities due to physio sessions keeping my muscles stretched.

It helps reduce pain.

Motivation, and realism - given me the information I need and the support to try and live the best life i possibly can

I cannot tell you the impact Dan has made on our lives. He is so positive and is like a font of all knowledge when I ask him about any worries he is able to put my mind at feast. I have a Zen moment whenever I have seen him and his therapy has such an impact on my well being both physically and mentally. He is a breath of fresh air that helps us so much.

It's really helped me understand how to treat various issues. I really value having a full hour to discuss everything and get treatment - I feel listened to, taken seriously and encouraged to seek improvements in my movements and pain levels.

It's helped with my stability and movement.

Improved mental health.

Improved my understanding of my condition and has helped to keep me mobile.

It has kept me mobile and eased some of my pain.

Helped maintain flexibility and brill for building confidence.

Exercises shown to me have really helped me.

Exercises recommended do help me.

Enabled me to manage pain and discomfort.

Sometimes this is more of a personal struggle with decline rather than any services provider.

It certainly contributes!!

Feel more mobile and flexible.

Feel more confident.

It has provided me with a chance to meet others with my condition and to feel part of a community determined to make changes for the better.

Question 36 - Is there any other feedback that you would like to provide regarding any aspect of the Charity and its work?

Fantastic

It is excellent.

Fantastic work by volunteers and officers and staff . Exceptional people.

The work you do is amazing and I'm lucky to benefit from it.

Please keep up the superb support and we will try as much as we can to support you in any small way that we can as a family.

I think this is phenomenal set up and we try as a family to support this charity as much as we are able as we are extremely lucky to have this wonderful facility our sincere and grateful thanks as this means the world to us not only to me but my family.

Just to say a massive thank you to everyone at Coventry and Bournville as you provide a fantastic service.

Maybe encourage members to raise awareness of the service

GP not interested at all, never mentioned on checkups etc, once a year consultant appointment, feel that we are left in limbo and left to get on with it. Feel very envious with MND people, they seem to have won the jackpot with help and support.

I cannot express what wonderful work the charity does to help myself and others.

Massive appreciation of the work the charity does and the knowledge it spreads about the condition. Great to have a centre of expertise that thoroughly understands all of the users' challenges, providing the right support in a friendly environment

Thank you for all your help.

Thank you for all your amazing work, it is much appreciated!

MDSC is an invaluable service that has absolutely improved my ability to manage day to day with my disability.

Thank you for all of the work you do and I feel privileged to be part of the group. Unable to see specialist until June 2024 so I have many questions.

Having printed detailed exercise instructions with pictorial representations to amplify the instructions.

Just keep doing what you are doing - I don't know where i would be now if i hadn't been referred to MDSC 2 years ago

Dan is amazing!!! His positiveness and support is priceless to both me and my husband. Nobody understands the quirks we experience like he does. It's made a huge impact on our lives seeing Dan. Not sure what we would do without our visits.

I'm so grateful to have access to your amazing charity. It has made a huge difference - to know I can talk to a therapist (Dan in particular) about any aspect of my health, on a regular and on-going basis, helps me to feel in control, and builds my confidence. Thank you!

I think that the physiotherapists are really good, friendly, professional and knowledgeable. The rest of the staff at the centre are friendly, understanding and helpful. The charity is amazing and everyone there is a star.

Keep up good work.

Enables users to stay active.

I realize I haven't been for a while but I still believe you are doing a positive thing and you help so many people. I hope you keep going.

The growth in 10 years has been incredible and the challenges have been significant due to outside factors e.g. covid, cost of living. The management/staff are fantastic.

What a wonderful organisation it is.

I wish I had had the opportunity to access this service sooner as I believe it would have supported me as my condition progressed to the stage where I am no longer able to stand.

Section 4 Supplementary Tables

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

Question 20 - Which of the following best describes the general impact MDSC therapies have on the progression of your condition?

APPENDIX SECTION 4 FIGURE 1

	Strongly agree	Agree	Neither	Disagree	Strongly disagree	N/A, Don't know	Total
My therapy keeps my joints flexible	68	40	13	0	1	5	127
My therapy maintains my muscle strength	49	51	20	0	1	6	127
My therapy keeps me walking	43	35	16	3	3	27	127
My therapy keeps me out of hospital/ reduces my reliance on other healthcare services	38	41	25	2	3	18	127
My therapy prevents/reduces falls	38	43	21	3	1	21	127
My therapy enables me to manage pain	37	43	23	5	1	18	127

Source data for figure one of Appendix section one.

Created with Datawrapper

Question 27 - The overall impact of MDSC therapies on my health

APPENDIX SECTION 4 FIGURE 2

	Strongly agree	Agree	Neither	Disagree	Strongly disagree	N/A, Don't know	Total
Helps my overall emotional and mental wellbeing	15	19	10	1	0	4	49
Helps me to connect with others	10	13	20	3	0	3	49
Gives me somewhere to readily turn to to discuss my muscle condition if needed	20	21	4	1	0	3	49
Helps me to avoid seeking GP or A&E care	14	15	14	2	0	4	49
Helps provide social opportunities and community	9	15	18	1	1	5	49

Source data for figure three of Appendix section one.

Created with Datawrapper

Question 27 - The overall impact of MDSC therapies on my health

APPENDIX SECTION 4 FIGURE 3

	Strongly agree	Agree	Neither	Disagree	Strongly disagree	N/A, Don't know	
Helps to build my self-confidence	11	22	10	1	1	4	49
Improves my aspirations for my life and what I can achieve	10	17	15	1	1	5	49
Helps me to feel in control	11	25	9	0	1	3	49
Supports and builds my self-esteem	11	22	9	1	1	5	49
Improves my knowledge of MD and my condition	12	26	7	0	1	3	49

Source data for figure four of Appendix section one.

Created with Datawrapper

Question 27 - The overall impact of MDSC therapies on my health

APPENDIX SECTION 4 FIGURE 4

	Strongly agree	Agree	Neither	Disagree	Strongly disagree	N/A, Don't know	Total
Helps my family/ carers to feel supported	8	19	9	3	0	10	49
Supports and builds my physical resilience	15	22	10	0	0	2	49
Supports and builds my emotional resilience	11	20	12	3	0	3	49
Helps me to understand and manage my condition confidently	15	21	10	0	1	2	49
Helps me to accept and live well with my condition	16	19	10	0	1	3	49

Source data for figure 5 of Appendix section one.

Created with Datawrapper

Question 27 - The overall impact of MDSC therapies on my health

APPENDIX SECTION 4 FIGURE 5

	Strongly agree	Agree	Neither	Disagree	Strongly disagree	N/A, Don't know	Total
Improves my motivation	15	19	10	1	0	4	49
Enables me to do more with family/friends	9	14	17	4	0	5	49
Enables me to live independently	11	12	15	3	0	8	49
Enables me to remain in employment	9	5	9	3	1	22	49
Keeps me able to travel independently/ drive a car	9	13	9	2	1	15	49
Keeps me able to do things around the house	8	22	12	0	1	6	49

Source data for figure six of Appendix section one.

Created with Datawrapper

Question 17 - "I find this online therapy to be of benefit to my wellbeing" - agree or disagree:

APPENDIX SECTION 4 FIGURE 6

	Strongly agree	Agree	Neither	Disagree	Strongly disagree	Don't know, N/A	Total
Physiotherapy 1:1	17	6	1	0	0	7	31
Osteopathy 1:1	8	1	1	0	0	21	31
Group physiotherapy	19	5	0	0	0	7	31
Group osteopathy	6	0	1	0	0	24	31
Drop-in Exercise	14	4	2	0	0	11	31
Drop-in Breathing	10	3	1	1	0	16	31
Pre-recorded exercise	5	4	1	0	0	21	31
Pre-recorded breathing	3	4	1	1	0	22	31

Source data for figure seven of Appendix section one.

Created with Datawrapper