

Notes from Steering/Focus Group meeting – June 2024

Annual Service User Survey Results Discussion

Welcome

Attendees:

MDSC Staff: Sarah Ann Moore

Attendees: Richard Wilson, Maurice Cooper

Sarah welcomed everyone to the meeting and invited introductions. She described the history of the Steering/Focus Group and its key role in enabling the mission and culture of the Charity to continue to be led by service users.

She introduced the topics and agenda for the meeting, being:

- Reporting of the 2023 Service User (SU) Survey Results
- Discussion regarding the findings and any other ideas/ recommendations from attendees
- Any other topics or ideas that the group would like to share/ discuss!

Discussion: SU Survey

Sarah explained that the Charity recently collated and reported the results of its 2023 Annual Service User Survey and is in the process of refreshing its strategy for the next 5 years, so wants to make sure that service user feedback and ideas (from the Survey or otherwise) are incorporated in its plans for the future.

Sarah briefly summarised key themes of the feedback received from the survey, explaining how SU responses about how their therapy improved their mobility, strength, pain control and overall quality of life were vital for the Charity to demonstrate its impact to funders and help secure funding to keep running its services. She described some of the SU suggestions made in the survey for service improvement/ development which included:

- Making more services available at satellite clinic locations
- Selecting music to make the environment in Centre calmer and more relaxing
- Forging links with local taxi firms to help service users to get to us
- Implementing online booking for appointments
- Considering a monthly subscription to enable use of equipment

She then invited the attendees to discuss those suggestions and share any other ideas or feedback that they had.

Both Richard and Maurice thought that all of the SU suggestions seemed sensible and that they would support them, except perhaps the idea of a monthly subscription fee their understanding was that the Charity's intention was to remain free at point of use, and this

would conflict with that. Sarah agreed but noted that MS Centres do have a paid subscription or “membership” model, so that might be the context for the suggestion.

Richard has a research background and would be keen to see the Charity make more of research links and opportunities. He suggested that MDSC could make use of its physiotherapy student placement students and relationships with local universities to get them to do research for us. Sarah agreed and noted that now the Charity has 3 employed physios it is more able to offer student placements and this year we will have placements from the universities of Coventry, Birmingham and Northampton. Richard and Sarah also discussed the potential for Occupational Therapy placements as an opportunity. All agreed that MDSC has a critical mass of SUs with rare conditions that should be of value to researchers.

Maurice shared that he would like to see the Charity host and support more social events and interaction. He described how difficult it can be for someone with MD to “get back out there” after the recent pandemic, and the significant impact that this has had on the social lives of himself and others. He now finds it difficult to go to cinemas and concerts etc. activities that he enjoys, and is keen to find a community of peers to share such experiences with. He noted that he recently attended the in person coffee morning at the Black Country satellite but that there were only a couple of SUs who joined which was disappointing. Sarah agreed and confirmed that the Charity has been trying to host more in person social events in the main Centre and all satellite locations but that building interest and attendance takes time. The Birmingham satellite coffee morning has run a few times now and has better attendance, the Tipton one is newer but hopefully numbers will increase.

Maurice said he would be keen to see SU peer support/ social groups grow out of the events that MDSC hosts. All agreed. He discussed his interest in peer support and that he is planning to volunteer with MDUK to provide peer support. Sarah shared details of a new Adapting to Change peer support group that is being set up by MDSC SUs (supported by some of the Charity’s therapists). This has grown out of the successful session at the last Open Day re: mobility transitions. The aim is to provide an opportunity for SUs to learn from each other about all the transitions that their journeys with MD have involved, how they have managed that, what equipment or tools have helped them etc. It is hoped that this will be the first of SU led peer groups.

To register for the Adapting to Change group (which can be attended in person or online) follow this link: <https://bit.ly/MDSCAdaptingtoChange>

Next steps and Close

Sarah thanked all attendees for their time, participation, and ideas.

All attendees consented for their comments to be shared in meeting notes to be posted on the Charity’s website.

Sarah then closed the meeting.