

# Notes from Steering/Focus Group meeting – December 2023

## Annual Service User Survey Feedback and Ideas for the Charity's Future Strategy

### Welcome

Attendees:

*MDSC Staff: Sarah Ann Moore, Helen Hone*

*Attendees: Diana Wright, Mark Thompson, Nick Randle, Bhavesh Tailor, Emily Bonner*

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:

- Feedback on the ongoing SU Survey
- The Group's ideas for the Charity's upcoming review of its Strategy
- Any other topics or ideas that the group would like to share/ discuss!

### Discussion: SU Survey

Members of the group were asked for feedback regarding the SU annual survey that is currently running. Sarah explained that the survey is running until mid-January 2024 and the Charity is seeking from SUs information regarding their experience of the Centre and the therapies that it provides in order to evidence the impact that the Charity is having on its SUs. This information helps the Charity to better design its services and also to secure funding from external funders. Results will therefore be shared (and acted upon) in the new year.

Please see the link to the survey here: <https://bit.ly/MDSCsurvey2023>

Sarah asked if group members had seen/ completed the survey and if so, could give some feedback on length, content and accessibility.

- Nick confirmed he completed the survey, but experienced difficulty doing so on a mobile phone (iPhone on safari, connectivity might have been the issue). He accessed the survey through the email link
- Diana completed the survey on her phone (Android) and had no problems. Accessed via Facebook link
- Emily followed link on Email and completed on iPhone without problem
- Diana pointed out that there was one question that she was not sure how to answer as the suggested answer did not fit her circumstances. She suggested more free form writing boxes so that an appropriate answer can be given. She says she preferred this

year's survey to previous ones – aside from the one question mentioned it was asking the right questions and was good in terms of length

- Emily agreed that there was one question where she had to force an answer even though it did not quite fit her circumstances, but could not recall which question it was
- Nick was happy with both length and content. It was easier to tackle and no repeats or similar questions as in prior years. He confirmed that he also would use more free form writing boxes for feedback or more detail if available
- One group member suggested running smaller, more frequent surveys throughout the year, however another pointed out that data collection and analysis might be much harder that way
- Bhavesh confirmed that he had completed the survey and found that some questions similar, but that overall, he found completing the survey useful as it provided details of the different services that the Centre provides and therefore how he can look after himself better.

Sarah asked for recommendations for future surveys and also how to engage more SUs to take part:

- Diana suggests that communications need to explain/ emphasise clearly how the data is used and how it benefits the Charity and its services i.e. it helps the Charity to secure funds via trust grants and NHS contributions
- Publishing results afterwards is helpful – including how the Centre translates that feedback into action (i.e. You said it, we listened and here is how we acted). All agreed that feedback would be beneficial
- Bhavesh questioned whether it would be possible to start a SU WhatsApp group that links could be shared too as some SUs might be more familiar/ inclined to use WhatsApp rather than social media/ email

### **Discussion: Ideas for the Charity's Strategy**

Sarah moves on to the next point of the agenda around the Charity's future planning, explaining the Charity has a 5-year TATT (Transforming Access to Therapies) strategy and plan, and the Charity is currently in year 4. The organisation is therefore in the process of reviewing the plan, thinking about how to complete the final years, and shaping the Charity for the next 5 years and beyond. Sarah explains that the trustees are that the core mission and aims of the Charity remain unchanged, so they are looking to develop a refreshed strategy that continues to focus on:

- Growing MDSC capacity and services to support more people with MD
- Focussing on service user needs
- Securing operational and financial sustainability

Sarah asks the group what they would like to see included in the Charity's next strategy and what everyone would like to see from MDSC in the future.

- Diana explains that at times waiting periods for more appointments are too long. Waits of 3-4 weeks are not great, especially after a cancellation. She says she understands that cancellations are unavoidable, but more service provision would be great, especially as there is cost involved to the SU (for example, where a cancellation is MDSC driven and an SU has to pay a carer but cannot get their appointment)
- Nick agrees that the current 2 appointment rule is not great and suggests being able to book recurring appointments for a longer period of time (ideally a whole year) would be better
- Bhavesh agrees that getting an appointment in Leicester can be difficult at present.

All discussed and agreed that cancellations (both SU and Centre driven) are very challenging for all. The group acknowledged the measures that the Centre have put in place to try to manage cancellations better, including the DNA Policy and recruiting additional cover for some clinics.

- Mark suggests that the Charity should expanding further to the south with satellites as the demand seems high. He is also suggesting starting to charge for some activities or adopting a “pay it forward/ pay what you can” system - making clear to SUs the real cost of therapy

Other ideas raised by the group included:

- A buddy system for more specialised support, i.e. matching people with the same condition or at the same stage in their journey
- Condition specific socials/Wellness Hubs or sessions that are not based on medical advances or drug trials like some of the big MDUK events, but instead focussing on sharing of peer lived-experience
- More communication is needed around SU social/ engagement events, and accessibility needs to be considered to make events available for all in terms of timings (work schedules), venues and themes. Maintaining the mixture of online and in person events was welcomed
- Dinners - all who attended the Charity’s 10<sup>th</sup> anniversary celebrations in 2023 agreed that the events were successful, enjoyable, and well organised. The accessibility of the Open Day and the Birmingham/ Black Country dinner venue (Saphari) and quality of food was praised. All enjoyed the opportunity to socialise with other service users and MDSC team members

### **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.