

Notes from Steering/Focus Group meeting – January 2025

Welcome

Attendees:

MDSC Staff: Nina Hanks, Sarah Ann Moore, Helen McCarroll

Attendees: Frank Sturzaker, Mark Thompson

Sarah welcomed everyone to the meeting.

Discussion: Developing the 2025 – 2029 Strategic Plan

Sarah presented to the group, briefly describing how the Charity has grown and changed over the period of the last 5-year strategic plan (Transforming Access to Therapies) and what work has taken place so far to design and develop a new 5-year strategic plan, explaining the important role of the Focus Group, and service user feedback from our annual surveys in ensuring that our new plan will be service-user led.

Sarah recapped that as a charity over the last 5 years we have:

- Doubled in size
- Grown our staff team
- Opened new satellite sites or moved to strategically better sites
- Relocated our HQ/ Centre to a larger independent space

Based on the work over the last year to develop a new strategic plan, she summarised key aims for the next 5 years as:

- To embed change, creating/ embedding processes to run all aspects of our Centre and satellites smoothly and sustainably for the future
- To continue to offer high quality services to our existing service users
- To carefully and sustainably grow – reaching more people with MD and offer more services

Sarah explained that both to better serve our existing service users and to accommodate growth, our plan will include:

- Looking for a new location for our Leicester satellite to accommodate demand and allow clinics to run on weekdays as well and the current Saturdays
- Looking at all our existing satellites to ensure that they are optimal in terms of accessibility and service user experience – trialling new sites where necessary (such as Movewell in Birmingham)
- Adding more core service capacity in Coventry and additional services at our satellite locations that are only providing physiotherapy at the moment (such as osteotherapy and complementary therapies)

- Facilitating service user access to online services - growing/ restoring other core services such as aquatic therapies in Coventry (the search for a hydrotherapy pool is ongoing), educational sessions, peer support groups and social activities. To facilitate this, the team are currently looking at taking on additional space in Coventry at Westwood Business Park.

In order to do the above, Sarah highlighted the importance of having good quality data and evidence of our impact – mentioning that the charity is continuing to look for a new clinical records system to help with this.

At this point Frank suggested Upshot as a system that might be beneficial.

Sarah moved on to share highlights from the recent Service User Survey. She explained that results included lots of great, positive feedback, but also some very constructive comments and suggestions for our services, including with regard to demand pressure and appointment availability and the impact of late cancellations.

Frank suggested that we should record our online sessions and make them available online for a certain period – a discussion was held re: the challenges of obtaining consent for attendees for this but that there are prerecorded sessions on the website and it would be good to try and add more.

Sarah asked how we can improve communication through the Centre regarding therapies and options available (such as online therapies or events). A discussion was held re: therapists providing information being the best way for SUs to find out about things. There may be signage in Centre etc. but Frank wants to know what is relevant to him, so a therapist telling him is what will make him most interested. He stated that this communication often it is not always timely enough.

Mark stated he has enjoyed the presentation/ discussion and agrees with the positive feedback in the recent survey. He said that negatives can always be found but he feels secure in the knowledge we are trying to address those.

He questioned whether we should move our satellite provision a little further afield into Oxfordshire/Gloucestershire etc as the provision in the Midlands seems quite good. He asked, from a strategic point, what is our ambition? Are we being too cautious? Sarah answered that the charity views itself as a regional Midlands charity and is not trying to become national – however by positioning itself in the right locations within the Midlands, it is possible to enable reach beyond those exact boundaries for those who need support from other geographies. The charity is also starting to really think about how it can help and support others to set up Centres in different parts of the UK.

Frank questioned why we would want to continue to grow and engage more service users when we can't meet the current demand for appointments. Sarah explained that ideologically we have a mission to help people with and affected with MD and we know that there is substantial unmet need in the community – so we have a responsibility to do both – we must focus on providing quality services to our existing service users, but longer term we also should find and help others who might be in need.

Mark agreed that there is a huge need for the MD Support Centre as the provision in the health sector seems to be declining rapidly, and he felt that limiting access to existing service users in order to reach more people affected by MD might be a necessary step.

He also suggested that working with research agencies into MD and having our service users involved in research would be a good idea. A discussion was held regarding this and Mark suggested that he has an evaluations team at work and that he might be able to engage the team in some pro bono work for us including data analysis and evaluation exports. He would be happy to facilitate a collaboration.

Sarah thanked attendees for listening to her presentation and for the valuable input and feedback. She reassured that all the feedback helps steer where we want to go as a charity and will be incorporated into the final plan.

The meeting was closed.