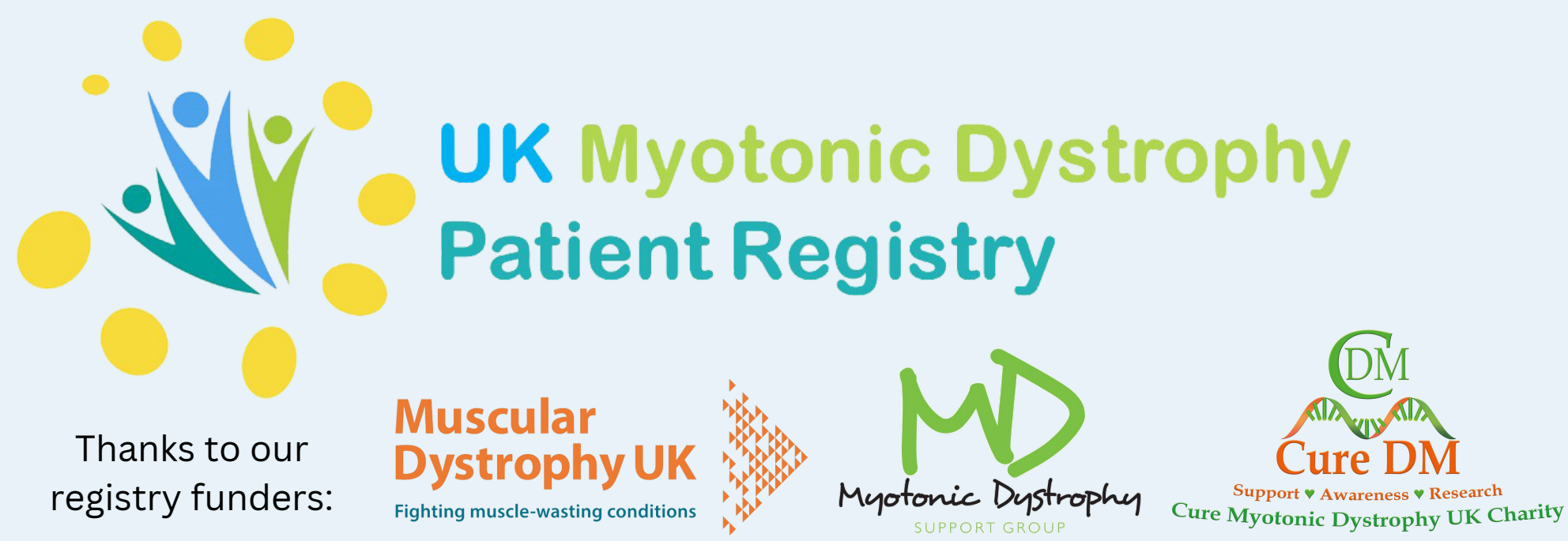


Identifying barriers and increasing patient enrolment in the UK Myotonic Dystrophy Registry.

Helen Walker¹, Chiara Marini-Bettolo¹, Emma-Jayne Ashley²

¹ The John Walton Muscular Dystrophy Research Centre, Translational and Clinical Research Institute, Newcastle University and Newcastle Hospitals NHS Foundation Trust, Newcastle upon Tyne, UK

² Cure Myotonic Dystrophy UK Charity, UK



Background

Patient registries collect information from individuals affected by specific conditions, such as myotonic dystrophy. They can contribute to natural history, support the creation of care standards, and aid development of new treatments or therapies by identifying participants for clinical trials. Registries play an important role in providing a link between community and research.

Aims

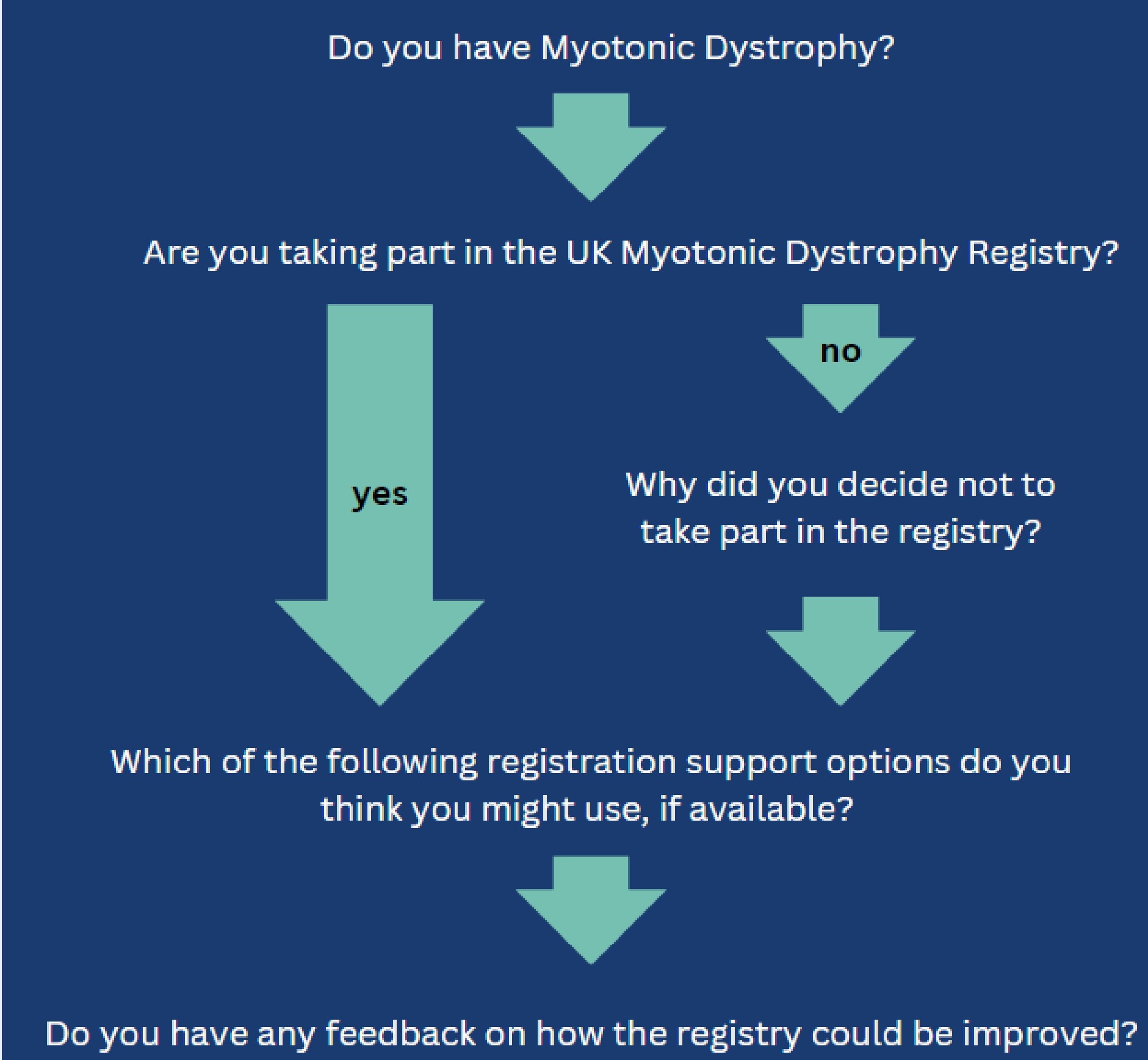
The JWMDRC developed an online, anonymised survey, with the aims of identifying patient perceived barriers to joining the UK DM patient registry, and to understand what additional support could be provided.



Method

Participants were invited to complete a survey about their experiences with the UK DM Patient Registry, with the opportunity to provide comments and feedback. The survey was disseminated to the existing registry participants via email, and to the wider DM community via social media through UK DM charities. The registry engagement survey launched 23rd August 2022 and remains open to continue to collect ongoing data.

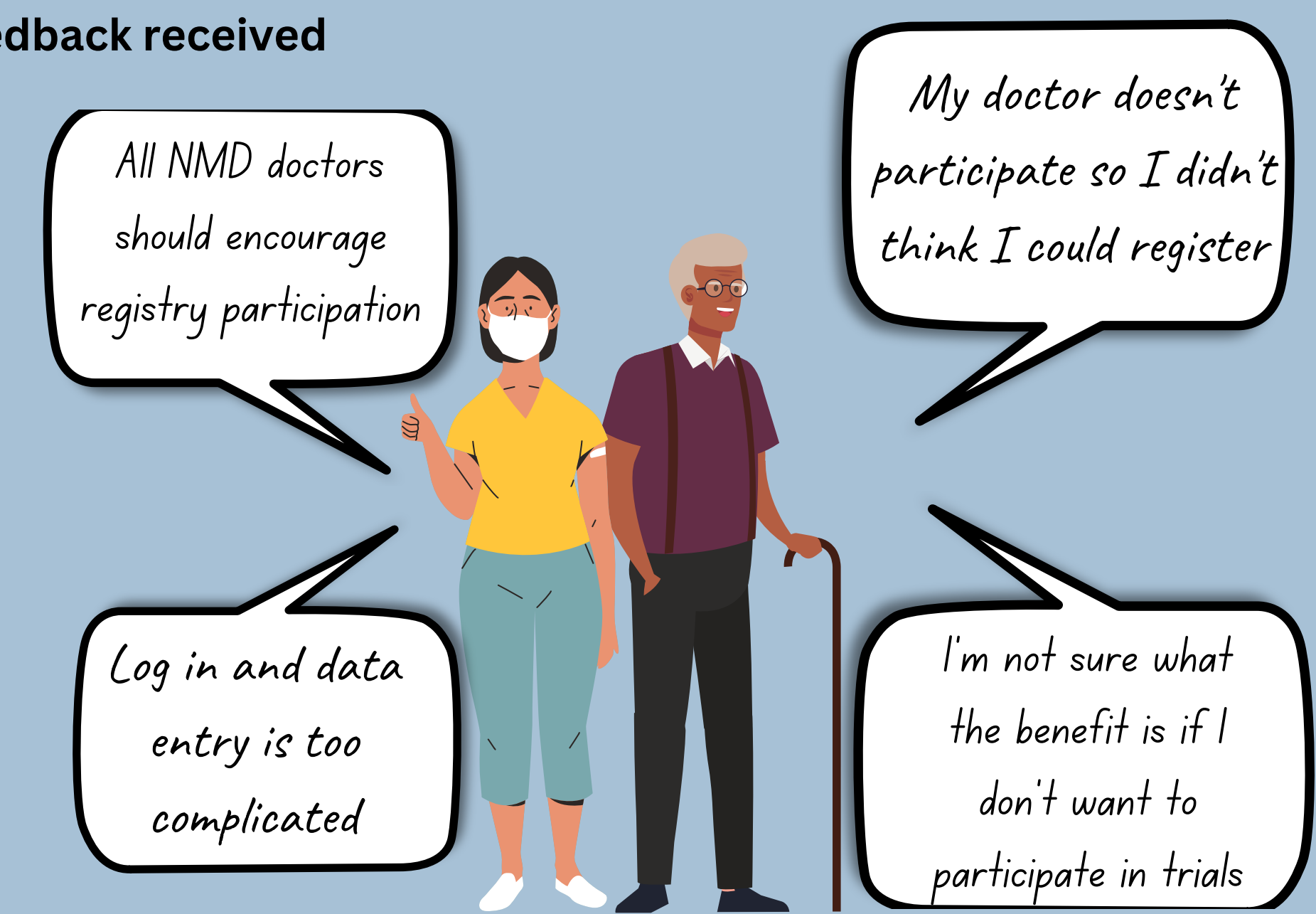
The Survey



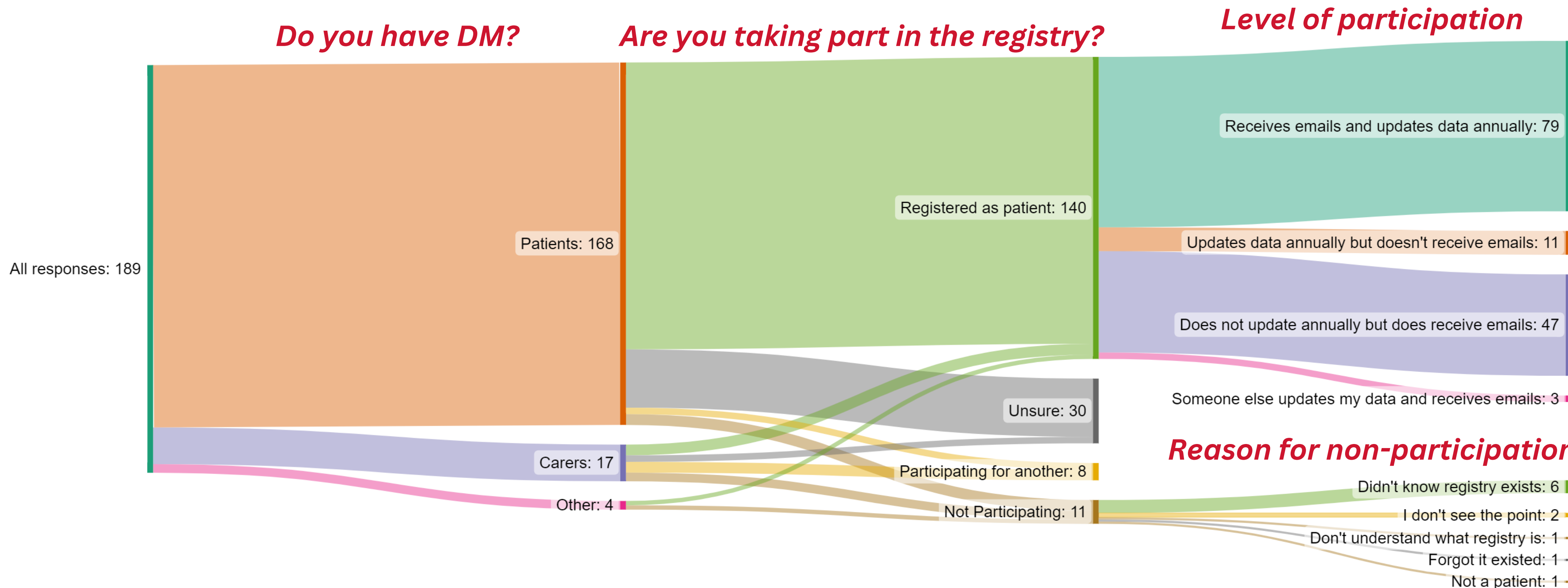
Results

To date the survey has received 189 individual responses, of which 168 have a diagnosis of myotonic dystrophy and 17 are caregivers. 78% currently participate in the registry. Of those participating, 60% reported logging in annually to update data. 11 respondents stated they are not enrolled with reasons including most not knowing of the registry, not understanding what the registry is, or 'not seeing the point'. The most popular registration support options suggested was clinicians passing on contact details directly to the curator.

Other comments and feedback received



Registry Participation Responses



The following non-participation answer options were included but not selected by any respondents:

- I don't have a computer
- It's too much effort
- It looks too complicated
- I have concerns about privacy

The registry is grateful for the assistance and encouragement from CureDM with this project, in addition to their financial support of the registry.

Conclusion: Difficulties within the patient community in understanding or accessing the registry were identified. This data and feedback will be used by the registry curator and steering committee to implement new strategies and create better resources for the patient community. Registry enrolment and longitudinal participation could be increased by facilitating direct contact between the patient and registry curator, however this requires closer links with neuromuscular clinics and health networks to improve awareness of the registry in clinicians. These strategies will increase the quality and quantity of data available to support DM research.

Registration support preferences



Strategies to Increase Patient Awareness and Engagement

- Ensure all clinicians are aware of and are promoting the registry
- Develop an online 'expression of interest' form for patients to make initial contact
- Highlight existing registration support options (user guide, curator contact info)
- One-to-one curator support may be possible with funding for additional capacity
- Increase accessibility of patient resources, e.g. videos, print at home options
- Update existing resources to better explain exactly what a registry is (and is not), the benefits of participating, and how data is used to facilitate research.

Strategies to Increase Clinician Awareness and Engagement

- Highlight existing registration support options (user guide, FAQ, curator contact info)
- Acknowledge participating doctors on registry website, in publications etc.
- Empower patients to ask doctors to participate directly
- Promote use of registry data in research to clinicians and students
- Develop and send out clinic packs, to include 'patient contact permission forms' to be completed by patients during clinic visits with their neuromuscular specialist