Registries play an important role in providing development of new treatments or therapies registry funders: registry participants via email, and charities. The registry engagement survey launched 23rd August 2022

Registry enrolment and longitudinal participation could be This data and feedback will be used by the registry curator and steering committee to implement new strategies and improve awareness of the registry in clinicians. These strategies will increase the quality and quantity of data available to support DM research.

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.

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.

Registry Participation Responses

<table>
<thead>
<tr>
<th>Do you have DM?</th>
<th>Are you taking part in the registry?</th>
<th>Level of participation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes 100%</td>
<td>52%</td>
<td>Registered as patient: 79%</td>
</tr>
<tr>
<td>No</td>
<td>48%</td>
<td>Doesn’t update data annually but does receive emails: 21%</td>
</tr>
</tbody>
</table>

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, FAQ, 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