

DMD Hub Central Recruitment Pilot Project

Survey Responses Summary – Participants

45 responses received

Survey Responses - Participants

- The breakdown of the **age of the person** that the survey was either completed on behalf of or by, was:
5% aged 0-3, 28% aged 4-7, 52% aged 8-13, 10% aged 14-17 5% aged 18+
- The most popular **device used to access the project platform** were **Smartphone (62%)**, Computer (desktop/laptop) (33%) and Tablet was only 4%.
- **97%** said that it was **easy to log in** to the project platform.
- It took most people (29%) between **11 and 20 minutes to complete the questionnaire** when they first registered. 18% took between 1-10 minutes, 20% took between 21-30 minutes, 11% said it took over 30 minutes to complete whilst 22% were unsure as to how long it took them.
- **98%** had **no problems understanding the questions** they were asked in the questionnaire.
- **98%** had **no problems providing answers** to all of the questions they were asked.
- **80%** stated that they had **no problems in finding an explanation on the project website** or from the coordination team, if they were unsure of what information is being asked for in the project questionnaire. 16% who replied, found this question not applicable.
- Nobody replied to say they had any difficulties entering their answers in the online questionnaire.
- **40%** said that they would be happy to be contacted to request that they **review and update** their information on the project platform **every three months**, **35%** said **every six months**, 23% said monthly and 2% said annually.



Survey Responses - Participants

- If additional methods of contact became available (other than e-mail) in regards to participation on the project, **30% said e-mail** (with other methods of contact) would be their preference, 26% said text message, 19% said e-mail only, 13% by platform app notifications & 12% would like to be contacted by letter.
- When asked if there was the possibility of developing the project platform further, how would you most like to interact with the project - most people **(35%) were happy with the current platform**. However, **34%** of responses said they **would like to use an app** to interact with the project and 29% said that they would like to see an improved version of the current platform and 2% said they would like a paper version of the questionnaire made available.
- When asked about revisiting the project website to enter new information/update their details, **72% of respondents said that they find it easy to navigate around the website** to review all of their information/enter new information. 9% said that it could be improved and others stated that they had not yet had to do this and so it was not applicable.
- **98%** said that if the DMD Hub Central Recruitment Pilot Project was to be extended past the 31st March 2023 that **they would you continue to participate**, with 2% unsure.
- **14%** said that they have **engaged with pharmaceutical companies currently using patient referral systems** to facilitate recruitment to clinical research studies in the UK (e.g. Sarepta Ally).
- **65% strongly agreed/agreed to the statement that they feel more included/more engaged in the recruitment process** around DMD clinical research studies, having signed up to participate in the DMD Hub Central Recruitment Pilot Project. 26% were neutral to this statement and 9% disagreed.
- **71% strongly agreed/agreed to the statement that they feel the establishment of the DMD Hub Central Recruitment Pilot Project is helping make the process for recruitment to clinical research studies in the UK fairer**. 27% were neutral to this statement and 2% disagreed.
- **96% strongly agreed/agreed** that they would recommend other families to sign up to the DMD Hub Central Recruitment Pilot Project.



DMD Hub Central Recruitment Pilot Project

Survey Responses Summary – Clinics

19 responses received

Survey Responses - Clinics

- One out of nineteen sites responded to say that they were unaware of the DMD Hub Central Recruitment Pilot Project. Note: *This was a misunderstanding by the site.*
- **73%** said that they would **have enough knowledge** of the DMD Hub Central Recruitment Pilot Project **to use it to help with recruitment** to a clinical research study at their centre. Those that answered No, said that this was because they are not a trial centre/do not plan to run trials any time soon.
- **94%** said that they **have enough knowledge** of the DMD Hub Central Recruitment Pilot Project **to recommend patients to register.**
- **74%** said that **they discuss the CRD in clinic** with individual patients and 42% provide the flyer in clinic to patients. Sites are also sending the flyer out by post to patients, sending the flyer/website link in emails, promoting it when speaking to patients on the telephone, also by making the flyer available in a clinical setting.
- **100%** think **the community would benefit** from the DMD Hub Central Recruitment Pilot Project becoming open-ended.
- **89%** think that **their centre would benefit** if the DMD Hub Central Recruitment Pilot Project became an open-ended.
- **67% plan to utilise the DMD Hub Central Recruitment Pilot Project** for upcoming clinical research studies in DMD. Those that said they had no plans, were due to no research studies due to take place at their centre or that they are not currently able to run trials due to resources/service demands and clinical pressure.

Survey Responses - Clinics

- **72%** said that it would be **feasible to implement a process** whereby patients with DMD are registered on the DMD Hub Central Recruitment Pilot Project **at time of diagnosis**.
- All but one respondent said that it was straight forward for their site to follow up with the local clinic of a patient that was referred to them from the DMD Hub Central Recruitment Pilot Project. The issue that this site faced was made aware to us and helped in making adjustments to the processes used when referring participants to trial sites. It was an important case in highlighting the nuances involved with this project and its coordination.
- **56%** think that the process currently implemented to obtain **genetic reports** for patients who can't provide a copy themselves **is sustainable**.
- **100% were satisfied** that their request to the DMD Hub Central Recruitment Pilot Project to **request patients for referrals** was dealt with in a **timely manner**.
- **100% were satisfied** that with their request to the DMD Hub Central Recruitment Pilot Project, they **received all of the information that they required** to enable them to make an informed decision about screening the patient.