

2020 was dominated by COVID-19 and for the MSDA this implicated that we worked on the Global Data Sharing Initiative ([GDSI](#)) since mid-March. In this initiative, the MSDA and MS International Federation (MSIF) teamed up to give answers to the most urgent questions people with MS and their care-givers were struggling with during the pandemic. We learned a lot from this global data project and therefore 2020 was an inspiring year for the MSDA that recently celebrated its first birthday. The lessons learned of 2020 were discussed during four break-out sessions, and will be taken into account to define our ambitions and to move forward.

#### **Topics discussed:**

- Data harmonization and data quality
- Stakeholder outreach & engagement
- How to grow our collaborative global data ecosystem?
- Other research topics and activities

#### **What did we learn/noticed in 2020?:**

- Due to the GDSI, sites were enabled to build up local registries to collect data.
- The core dataset was well chosen and sufficient to answer the urgent questions on MS and COVID-19.
- Goals are important for data collection design.
- Early widespread publication is important to allow early adoption of the core dataset.
- Diversity on where data is coming from: e.g. still limited engagement in Middle-East and North- Africa.
- Due to the time pressure (we had to act as quick as possible) there were challenges with the quality of the data and harmonisation.
- Providing near-real-time feedback to quality-issues helps improving the local processes for multidata upload.
- Not everything was done right from the beginning, but we managed to adapt.
- Listening to people and adapting the model through their feedback, did not impose a single data platform. Instead, different ways to share data were accepted (inclusive (google docs) and transparent approach).
- Not all data partners were familiar with the software to run the federated scripts, but the MSDA guided and helped a lot to make it feasible.
- Data campaign and MSDA's data harmonisation effort are needed, creating a stronger data-driven and scientifically-driven narrative for decision makers.
- Number of patient-driven data is much larger than clinician-driven. There might be a link between the two. Future: link between patients and contribution to disease registry would be a major advantage to have. It would provide a tremendous strength.
- In times of crisis it was possible to get everyone aligned and acting quickly, working in a collaborative way.
- Future MSDA projects should be unique as well.
- Legal processes should be in place to speed things up.
- We cannot over-burden people and expect to downgrade all their day-to-day activities, because of the project.
- The partners showed tremendous trust and goodwill, building on years of work by MSIF and Progressive MS Alliance.

- Many patients with MS do not speak English: translation of the survey for patients has been a challenge.
- We could not have as much interaction with stakeholders as we would have liked (e.g. no formal consortium was created).
- Multi-stakeholder approach is the best approach.
- The patient community is vital.
- We should listen to the perspective of allied healthcare professionals (nurses, assistants, managers, front line staff).
- More biopharma involved, perhaps more medium term
- Digital technology companies, e.g. data collection, connect data silos, greater interoperability