

## MOVR DATA HUB SHOWS VALUE IN CLINICAL SETTINGS

After MDA launched a custom platform for data capture and analysis in 2019, MDA's neuroMuscular ObserVational Research (MOVR) Data Hub was poised to make an impact on the neuromuscular disease (NMD) research community. Now, with 46 active sites and more than 3,800 total participants, MOVR is reaching a critical mass of data.

Clinicians and researchers have been accessing MOVR's clinical data across multiple NMDs and using the Custom Visualization and Reporting Platform (VRP) to manipulate datasets into projects with advanced data governance. This gives them the opportunity to utilize MOVR data to provide insights that support clinical care and therapy development.

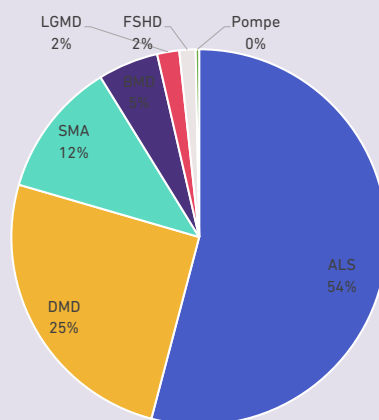
### MOVR Fast Facts:

Active sites: **46**

Total participants: **3,836**

Disease areas: **7**

Participants by disease area:



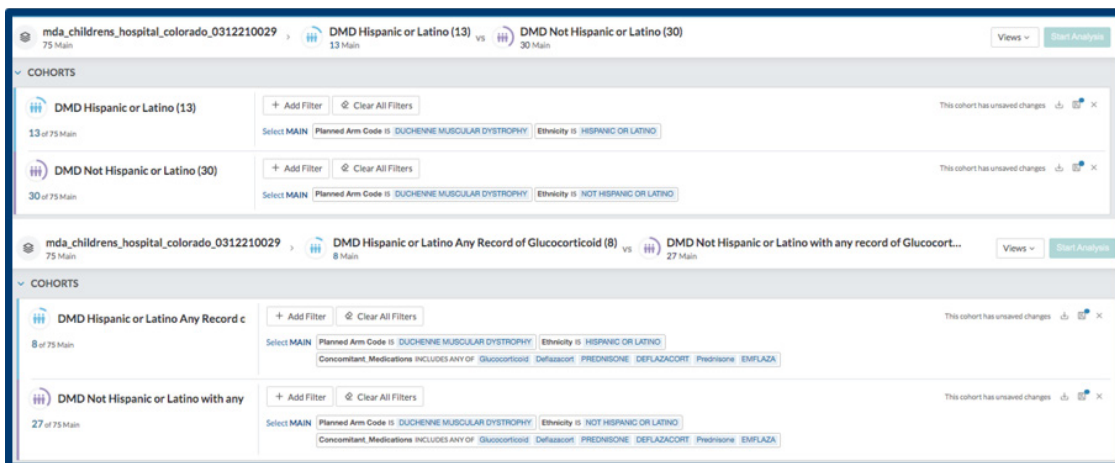
## First-use case

At the 2021 Virtual Clinical & Scientific Conference, two researchers presented first-use cases of MOVR data. One of those researchers was Susan Apkon, MD, chief of Pediatric Rehabilitation at Children's Hospital Colorado. She presented an opportunity for clinical quality improvement, identified through analysis of MOVR data.

"The COVID-19 pandemic has sadly highlighted what we already know: There are significant inequities in the current healthcare system, which negatively impacts the health of our patients who are Black, Hispanic, or Native American," Dr. Apkon said. "The inequities are long-standing and need to be addressed to improve the health of all our patients, including those with neuromuscular conditions."

Her team at Children's Colorado set out to understand the care they are providing to boys with **Duchenne muscular dystrophy (DMD)** and to ensure equitable care is delivered. This quality improvement work utilized the MOVR database and the VRP to compare their hospital's use of corticosteroids and cardiac medications in non-Hispanic and Hispanic boys.

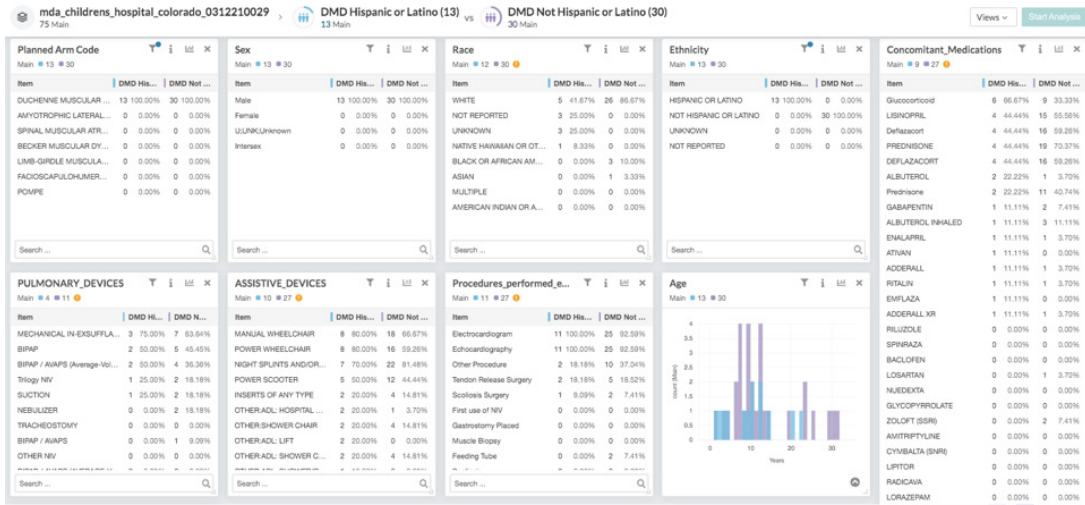
The results showed that 90% of non-Hispanic boys received corticosteroids at some time while under their care, compared to 61% of Hispanic boys. A similar difference was found when looking at cardiac medication use, with 57% of non-Hispanic boys on these medications compared to 31% of Hispanic boys.



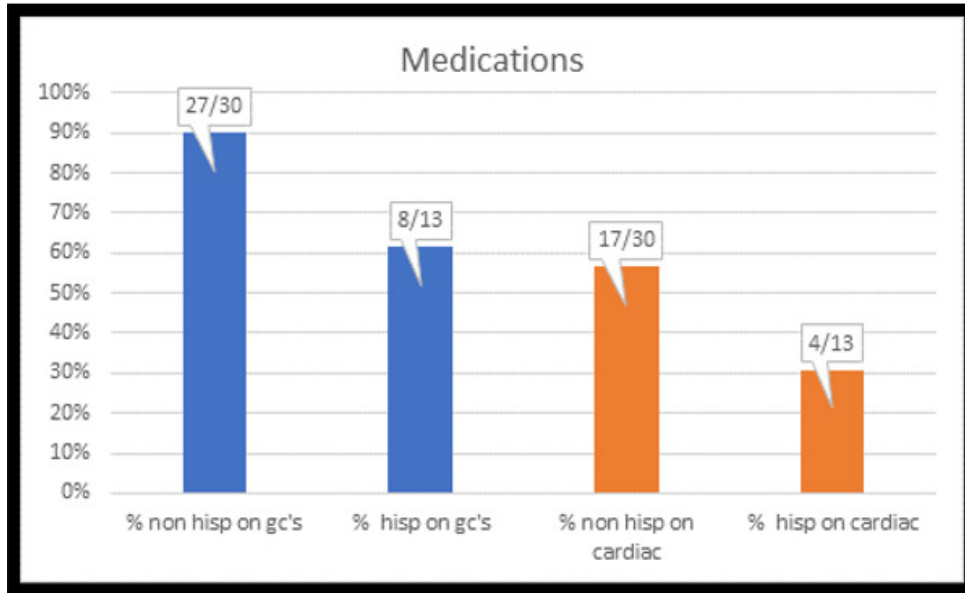
The MOVR VRP dashboard allows users to look at specific datasets. In this case, Dr. Apkon's team analyzed how many of their non-Hispanic and Hispanic patients received corticosteroids.

# PROGRAM SPOTLIGHT

June 2021



Using the VRP, Dr. Apkon's team utilized the MOVR dataset to look at multiple aspects of the care they provide to boys with DMD.



The MOVR data revealed a discrepancy in medications received by their non-Hispanic and Hispanic patients. Dr. Apkon's team can now evaluate their care practices with these populations to ensure equitable care.

Dr. Apkon recognized that, because only a portion of their patients enrolled in MOVR, the numbers may not represent their broader population, so the data needs to be validated.

“These results are a starting point for our team,” Dr. Apkon said. “They showed we have work we need to do.”

For example, while members of her team believe they discuss corticosteroid and cardiac medication use with all patients, they need to confirm this. In addition, if they find that members do discuss those medications with all families, they need to better understand why some families choose to start the medications while others do not.

“We want to assure that we are providing information in a way that is equitable and not just equal,” Dr. Apkon said. “We want to assure that we are presenting information in a culturally sensitive way to allow families to fully evaluate the risks and benefits of these medications and make the best decision for their son.”

Use of MOVR and the VRP allowed Dr. Apkon and her team to get a glimpse into that aspect of their care, and now the team has clear marching orders to ensure that they provide all patients with the highest level of care regardless of race or ethnicity.

## Partnership Opportunities

If you're interested in becoming a MOVR research partner, email [mdamovr@mdausa.org](mailto:mdamovr@mdausa.org). Learn more about MOVR at [mda.org/movr](https://mda.org/movr).