



Summit Data Sharing Policy

V.1, Effective March 2018

VISION

We view drug development as a partnership with physicians, researchers, patients and their families, all of whom contribute to furthering our science for the betterment of the community. With this in mind, we are committed to responsibly sharing clinical data with these partners while protecting patient privacy, regulatory submissions, publication opportunities and intellectual property rights. In particular, we wish to honor the collaboration our patients and caregivers undertook by participating in our clinical trials by providing them with study-level summaries of the trial results.

SCOPE

This policy applies to all Summit-sponsored DMD clinical trials and addresses the sharing of results with clinical trial participants and their caregivers. The policy covers which data will be shared, when it will be shared and how it will be shared.

PURPOSE

It is our intent to provide patients access to study-level summaries of the clinical trials in which they participated through their study sites at an appropriate timepoint after completion of the trial.

WHAT

- Study-level summaries will comprise a layperson overview of the clinical trial outcomes as are discussed/published in the primary manuscript. These results will minimally include the primary and key secondary endpoints and any pertinent safety data related to routine care (eg. vitals, echocardiograms).

WHEN

- Study-level summaries will be provided to the study sites after the primary manuscript has been published.
- For the primary manuscript to be published, the following must be true:
 - The clinical trial is complete (not inclusive of any extension phase)
 - The main clinical study report is finalized

HOW

- Study-level summaries issued and authorized by Summit will be provided in writing to every study site. Physicians will be responsible for disseminating these summaries to the patients who participated in the trial at their site and remained enrolled at the conclusion of the study.
- For all DMD clinical trials, a summary of this policy will be included in all informed consent forms going forward.