ReveraGen BioPharma

Return of Results Site Physician Survey

1. ReveraGen received a Bioethics supplement from the NIH to study a process of returning individual clinical trial data to patient families. We are returning data to study participants after the database is locked, the clinical study report written, and top-line results announced.

One of the vamorolone clinical trial participants recently requested their data.

We want to understand this issue from a physician perspective- thank you for completing this anonymous survey and answering the following questions.

How much importance do you believe families place on receiving their son's individual clinical trial results?

- ◯ A great deal
- ◯ A little
- ◯ A lot
- ◯ None at all
- ◯ A moderate amount

2. How much importance do you believe families place on receiving their aggregate clinical trial results?

- ◯ A great deal
- ◯ A little
- ◯ A lot
- ◯ None at all
- ◯ A moderate amount

3. Do you think a parent/guardian should receive their child's individual clinical trial data if the parent requests it?

- ◯ Yes
- ◯ No

4. Do you agree with the concept of a Sponsor returning individual clinical trial data directly to trial participants?

- ☐ Yes
- ☐ No
- ☐ I'm not sure
- ☐ Yes, but it depends on the circumstances

5. If you don't agree with the concept of a company returning clinical trial data to participants, can you list your concerns?

6. Are you aware of additional questions/comments/concerns from parents/guardians directed to you/your team following return of their data from ReveraGen?

- ◯ Yes
- ◯ No

7. If your team received questions/concerns from parents/guardians about the returned data, can you elaborate on what types of questions/concerns they had?
This question may be skipped if it does not apply.

8. Do you have any feedback for ReveraGen on this process?
This question may be skipped.

Thank you for completing our survey!

With best wishes from the ReveraGen team