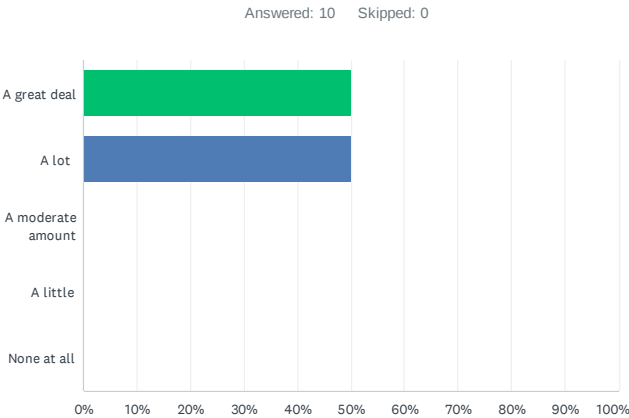


Return of Results Site Physician Survey

Q1 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.

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

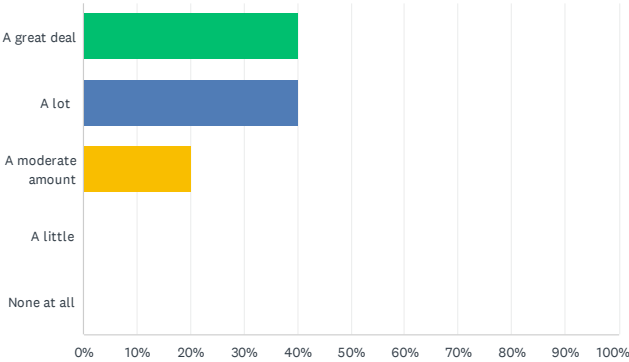


ANSWER CHOICES	RESPONSES	
A great deal	50.00%	5
A lot	50.00%	5
A moderate amount	0.00%	0
A little	0.00%	0
None at all	0.00%	0
TOTAL		10

Return of Results Site Physician Survey

Q2 How much importance do you believe families place on receiving their aggregate clinical trial results?

Answered: 10 Skipped: 0

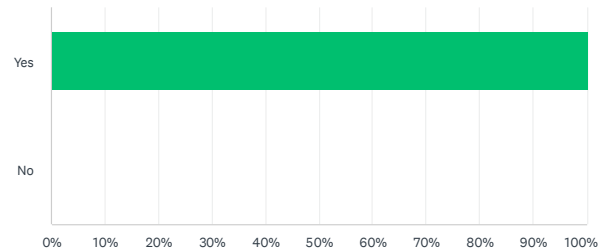


ANSWER CHOICES	RESPONSES	
A great deal	40.00%	4
A lot	40.00%	4
A moderate amount	20.00%	2
A little	0.00%	0
None at all	0.00%	0
TOTAL		10

Return of Results Site Physician Survey

Q3 Do you think a parent/guardian should receive their child's individual clinical trial data if the parent requests it?

Answered: 10 Skipped: 0

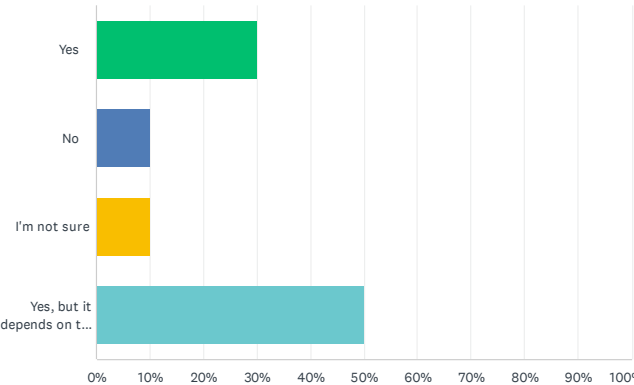


ANSWER CHOICES	RESPONSES	
Yes	100.00%	10
No	0.00%	0
TOTAL		10

Return of Results Site Physician Survey

Q4 Do you agree with the concept of a Sponsor returning individual clinical trial data directly to trial participants?

Answered: 10 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	30.00%	3
No	10.00%	1
I'm not sure	10.00%	1
Yes, but it depends on the circumstances	50.00%	5
Total Respondents: 10		

Return of Results Site Physician Survey

Q5 If you don't agree with the concept of a company returning clinical trial data to participants, can you list your concerns?

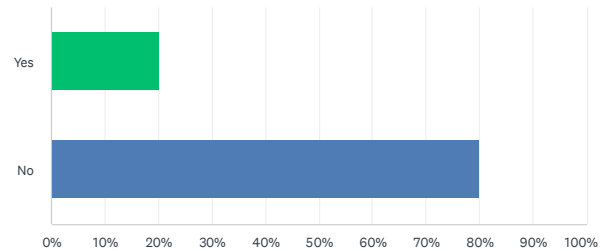
Answered: 8 Skipped: 2

#	RESPONSES	DATE
1	after trial is finished, data should be shared	6/21/2021 9:42 AM
2	What's meant by 'clinical trial data'? I don't think getting e.g. ECG, echo or MRI data is very useful and even some of the functional or strength measurements don't mean much to a family. It's a nice option for a family to see clinical trial data, but it would probably be more meaningful to provide them through a healthcare professional, either a doctor or a physiotherapist.	6/21/2021 3:55 AM
3	Has to go through PI, SI and/or site staff	6/21/2021 2:12 AM
4	Interpreting the data and put the individual data in the context of the study results and of a progressive disease might not be easy for all families and can create some false judgement and/or anxiety. It creates some "inequality" as proactive and well informed families are more likely to ask for the data	6/21/2021 1:48 AM
5	Not to disagree with this objective, but to raise the concern that the PI/treating physician for the participant could be blind-sided by the parent contacting the office and requesting an urgent discussion with the physician over an abnormal lab result. How to educate parents on labs/biomarkers/tests that are predicted to be abnormal (due to having DMD)? The poster does not go into this in any detail.	6/20/2021 7:46 PM
6	None	6/20/2021 7:28 PM
7	I agree, but it needs to be done in a thoughtful manner, properly contextualized.	6/4/2021 10:55 AM
8	at the end of the trial, all data should be returned to families. However, on a week by week basis during the trial, I don't favor providing results to individual families.	6/3/2021 2:49 PM

Return of Results Site Physician Survey

Q6 Are you aware of additional questions/comments/concerns from parents/guardians directed to you/your team following return of their data from ReveraGen?

Answered: 10 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	20.00%	2
No	80.00%	8
TOTAL		10

Return of Results Site Physician Survey

Q7 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.

Answered: 7 Skipped: 3

#	RESPONSES	DATE
1	Families have heard that data are supposed to be provided, but aren't certain how and when.	6/21/2021 3:55 AM
2	This is still hypothetical but the interpretation of the results, language barrier, cosequences for future therapies sould be explained by the local physician	6/21/2021 2:53 AM
3	Does not apply.	6/21/2021 2:12 AM
4	It does not apply to a specific situation however it would be important that the clinician is also provided with exactly the same report to be able to answer the questions appropriately	6/21/2021 1:48 AM
5	as above - I anticipate parents will become alarmed over reviewing the labs/test results and where something unexpected comes to their attention. They often lack in context and are unable to sort out what is typical for DMD or a non-significant drug effect.	6/20/2021 7:46 PM
6	N/a	6/20/2021 7:28 PM
7	N/A	6/4/2021 12:07 AM

Return of Results Site Physician Survey

Q8 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

Answered: 1 Skipped: 9