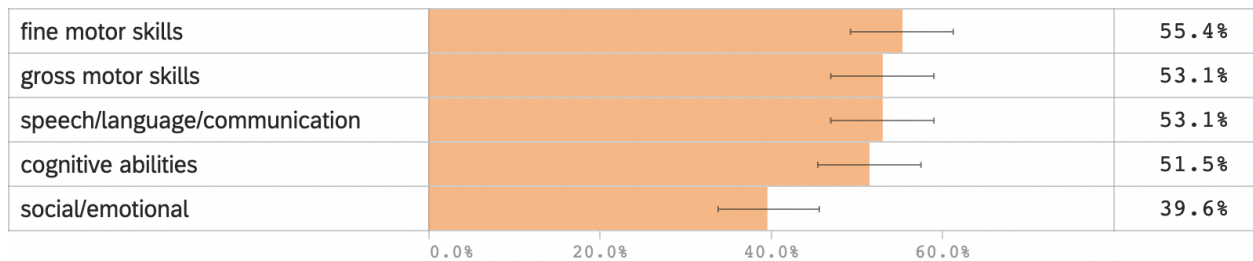


Collective Voices in Gut1 Deficiency Project Survey – Report

The Glut1 Deficiency Collective Voices Project was designed to have a better understanding of the patient and family experience across a broad range of areas. The goals for the survey were to better define the range of symptoms, identify gaps in treatment and patient care, identify the gaps in knowledge and understanding of this disease, better understand disease burdens, identify the most important components of a future natural history study, develop and prioritize a patient-led strategic research plan, and to develop better and more effective clinical trials for potential future treatments.

This time we are reporting the section about **Development**.

1. Do you experience challenges in any of the following areas of development?



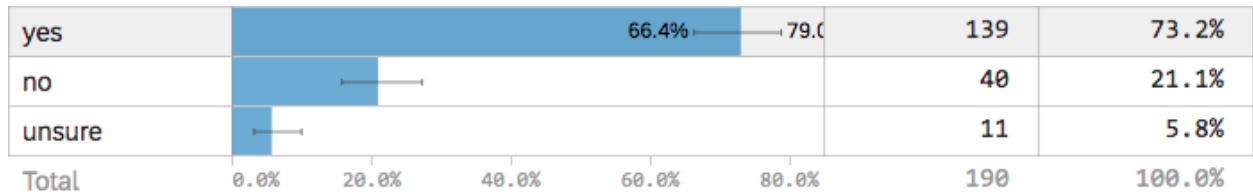
Of the developmental areas listed above, roughly half of the respondents reported having experienced challenges in fine motor skills, gross motor skills, speech/language/communication, or cognitive abilities. Slightly less respondents, about 40%, report social/emotional challenges.

2. Did you meet all developmental milestones on time in the following areas?

	social/emotional	cognitive	physical/movement	speech/language/com...
Yes	36.8%	21.1%	20.5%	20.0%
No	52.6%	69.5%	75.3%	73.7%
Unsure	10.5%	9.5%	4.2%	6.3%
Total	100.0%	100.0%	100.0%	100.0%

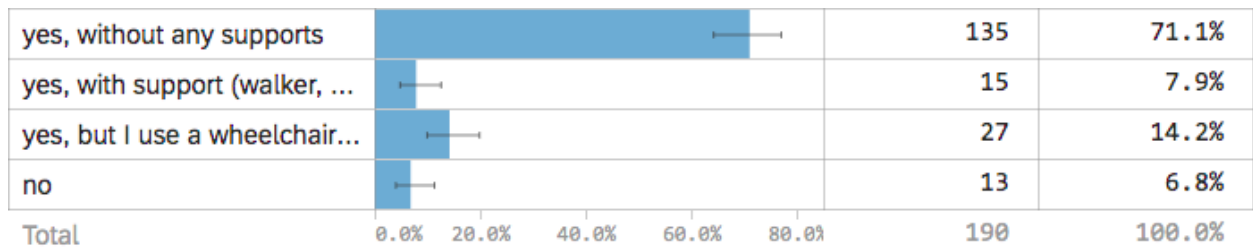
Similarly, the majority of respondents reported not having met developmental milestones. The highest percentage of being physical/movement followed by speech/language/communication, followed by cognitive at 69.5% and finally social/emotional at 52.6%.

3. Did you receive early intervention services (typically ages 0-5)?



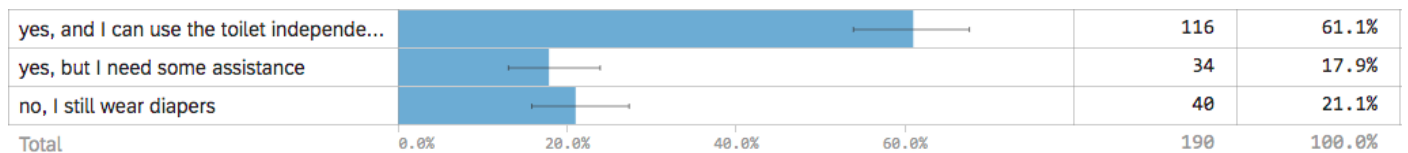
The majority of our respondents (73.2%) did receive early intervention services. Despite this, the majority of participants did not meet cognitive, physical/movement, or speech/language/communication milestones on time.

4. Do you walk independently?



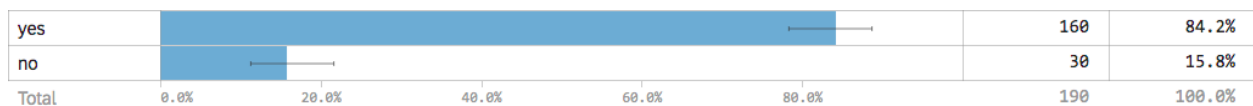
The majority of our respondents (71.1%) walk independently without any support. 14.2% report walking independently but use a wheelchair or other support when they need to walk long distances.

5. Are you toilet trained?



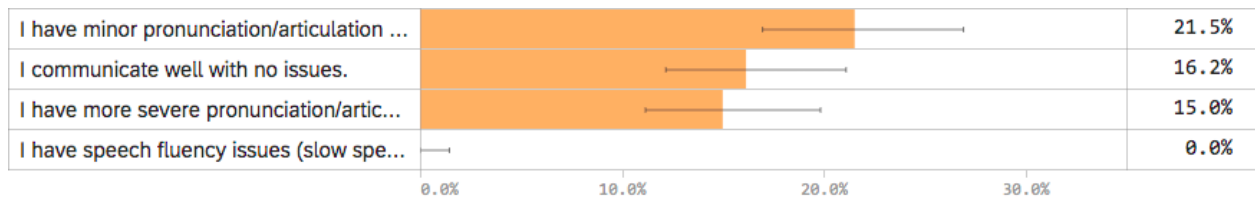
61.1% of our patients report being able to use the toilet independently. The rest either need some assistance or still wear diapers.

6. Are you able to speak using your own voice to communicate?



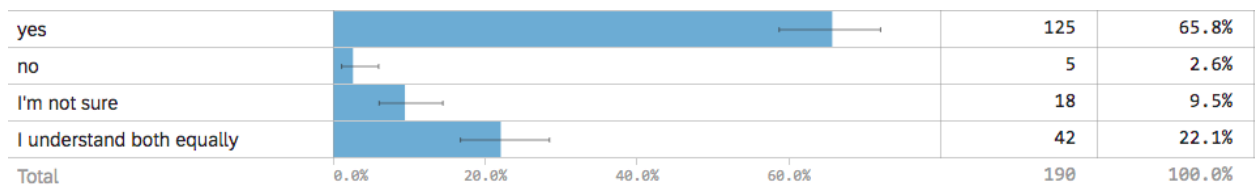
Most patients (84.2%) report being able to speak using their own voice to communicate.

7. How would you best characterize your speaking skills?



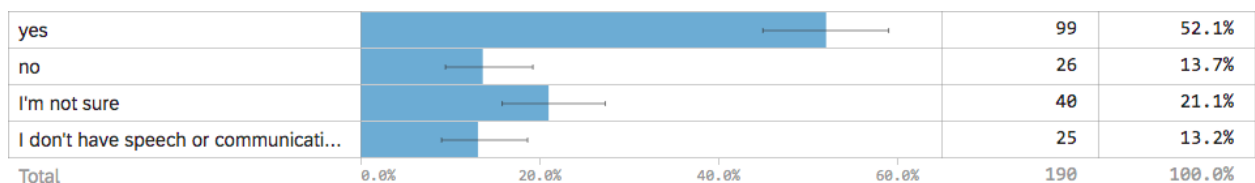
The respondents report a wide range of speaking skills. 22% feel that they have minor pronunciation/articulation issues but do not feel that they are not difficult to understand. 16% feel that they communicate well with no issues and 15% feel that they have speech fluency issues.

8. Are you able to understand language spoken by others better than you can express it yourself?



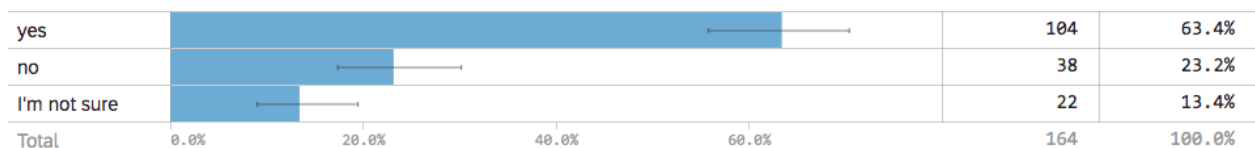
Consistent with what has been commonly expressed by Glut1 patients, most respondents report their receptive language to be better than their expressive language.

9. Do you feel your speech difficulties make you appear less capable or less intelligent than you really are?



Despite 37% of patients reporting minor or no communication issues, 52% feel that their speech difficulties make them appear less capable or less intelligent than they really are.

10. Do you get frustrated by communication challenges?



Further emphasizing this, 63% report getting frustrated by their communication challenges.

