

Healthcare Service Utilization for Children with Metabolic Disorders Diagnosed Through California Newborn Screening

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Background

California Follow-up System (SIS)

- Short-term follow-up for all screened positive cases:
 - Service Report data system to capture interval data covering the case referral, case management and confirmatory testing process by which a diagnosis is confirmed or ruled-out.
- Long term-follow-up for all diagnosed cases:
 - Annual Patient Summaries to track on-going case management and treatment for children through age 5

Long Term Follow-up Using Annual Patient Summaries

- Provides an aggregate profile of similar (rare) disorders, at similar ages, for the first five years of life.
- Build knowledge base describing the full spectrum of clinical outcomes associated with each disorder.
- Impact of newborn screening on the public's health:
 - Service utilization
 - Access to care
 - Health status

Long Term Follow-up Using Annual Patient Summaries

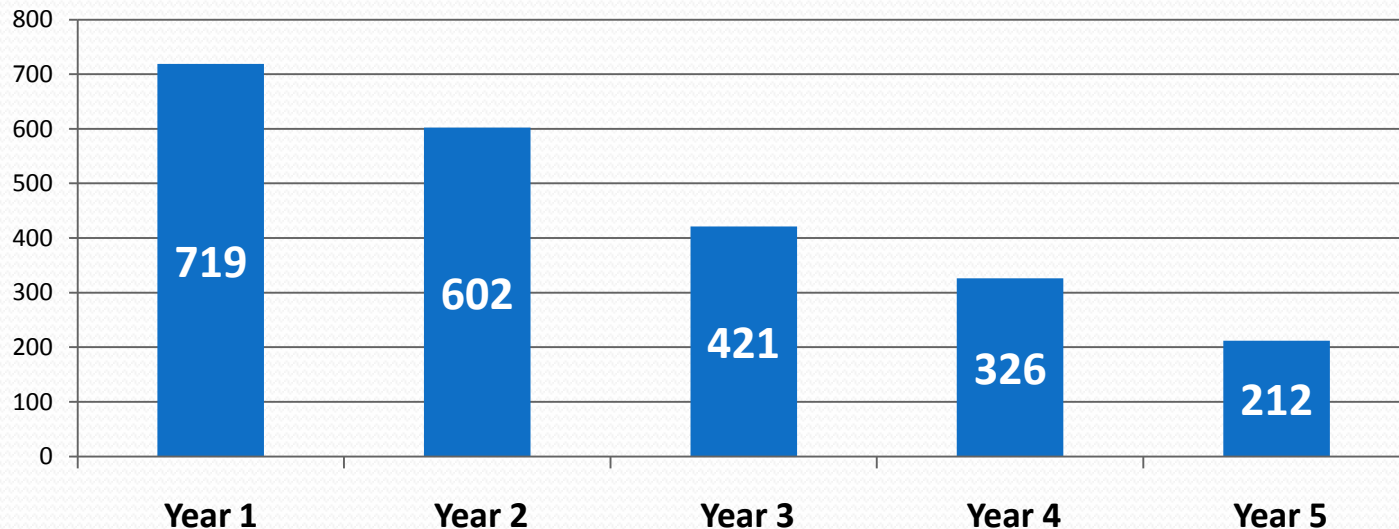
- Data captured (but not reviewed today)
 - Changes in diagnosis/new genotype data
 - Caregiver adherence/compliance with care
 - Anthropometric measurements to assess growth
 - Type of health care services provided
 - Symptoms/health problems/complications
 - Disorder related interventions
 - Clinician assessment of the development status of the child (cognitive, speech, physical growth, social emotional, gross and fine motor skills)

Long Term Follow-up Using Annual Patient Summaries

- Data captured (and reviewed today)
 - Follow-up status - is child still in care and if not, why?
 - Visits to follow-up care centers
 - Hospitalizations
 - Length of stay
 - Emergency department visits
 - Referrals for additional services

Total responses

- Between July 2005-October 2011:
 - 1,256 metabolic cases detected through NBS
- Since July 2007:
 - 2,280 MCAPS collected (1,082 individuals)



Patient Follow-up Status

	Active – patient being seen at center	Follow-up not deemed necessary	Lost to follow-up	Moved out of state	Patient died	Patient not seen	Refused follow-up	Patient transferred to another center
Year 1 (n=719)	81.6%	5.4%	4.5%	2.5%	0.8%	0.3%	3.1%	1.8%
Year 2 (n=602)	80.1%	6.6%	5.6%	2.8%	0.3%	1.7%	1.8%	1.0%
Year 3 (n=421)	81.7%	4.8%	5.7%	2.4%	0.5%	3.1%	0.5%	1.4%
Year 4 (n=326)	82.2%	6.4%	5.5%	1.2%	0.0%	2.8%	0.3%	1.5%
Year 5 (n=212)	74.5%	11.8%	3.8%	1.9%	0.0%	3.8%	1.4%	2.8%
All (n=2280)	80.7%	6.4%	5.1%	2.3%	0.4%	1.8%	1.7%	1.6%

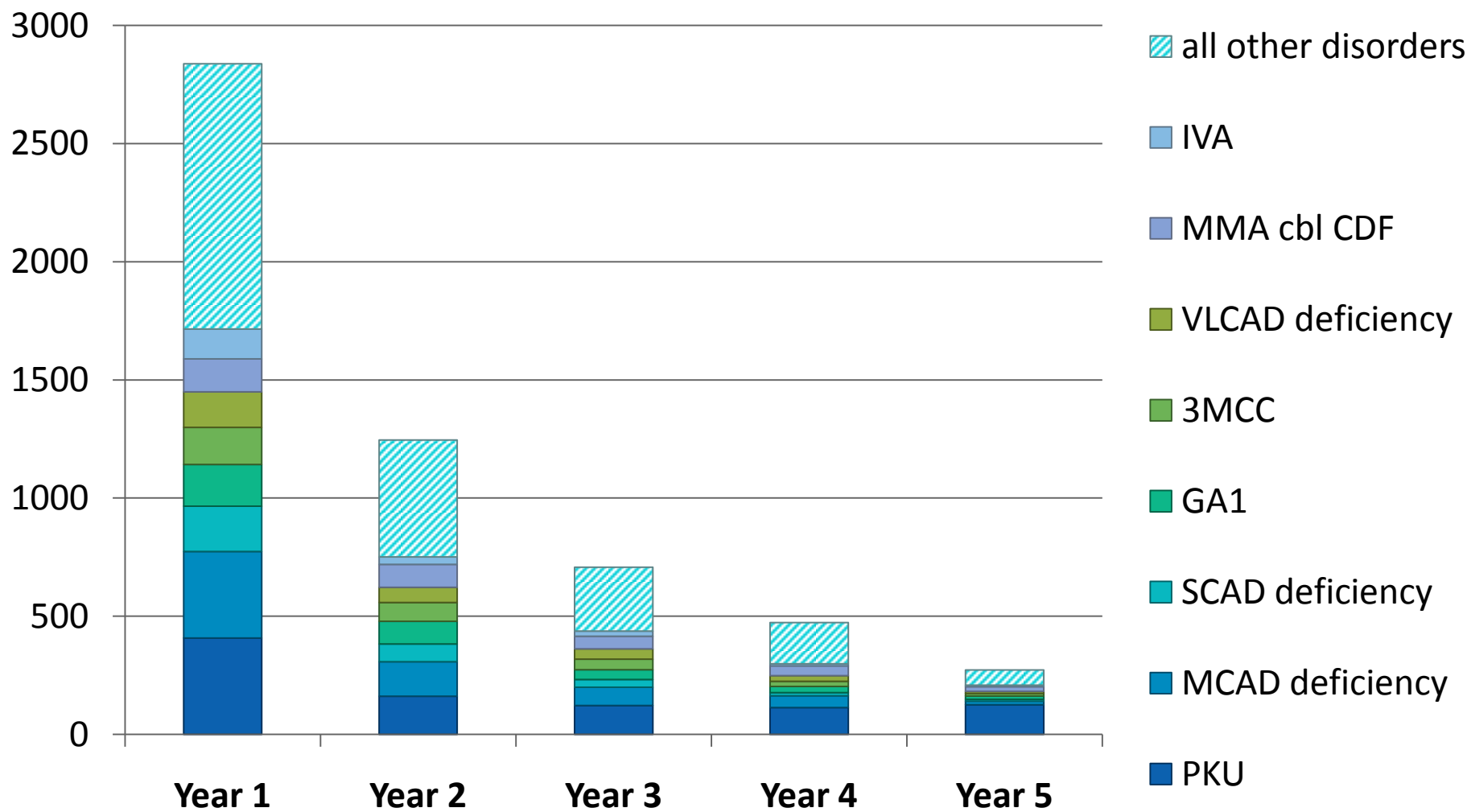
Cumulative Patient Follow-up Status

- As of the most recent report received:
- 66.5% of cases were reported to be under active follow-up with a metabolic center.
- For 145 (13.4%) of cases further follow-up was deemed unnecessary
- 4.9% of cases moved out of state
- Ten cases (<1%) died during the LTFU
- 14.5% had parents that refused follow-up or were otherwise lost to follow-up at various ages.

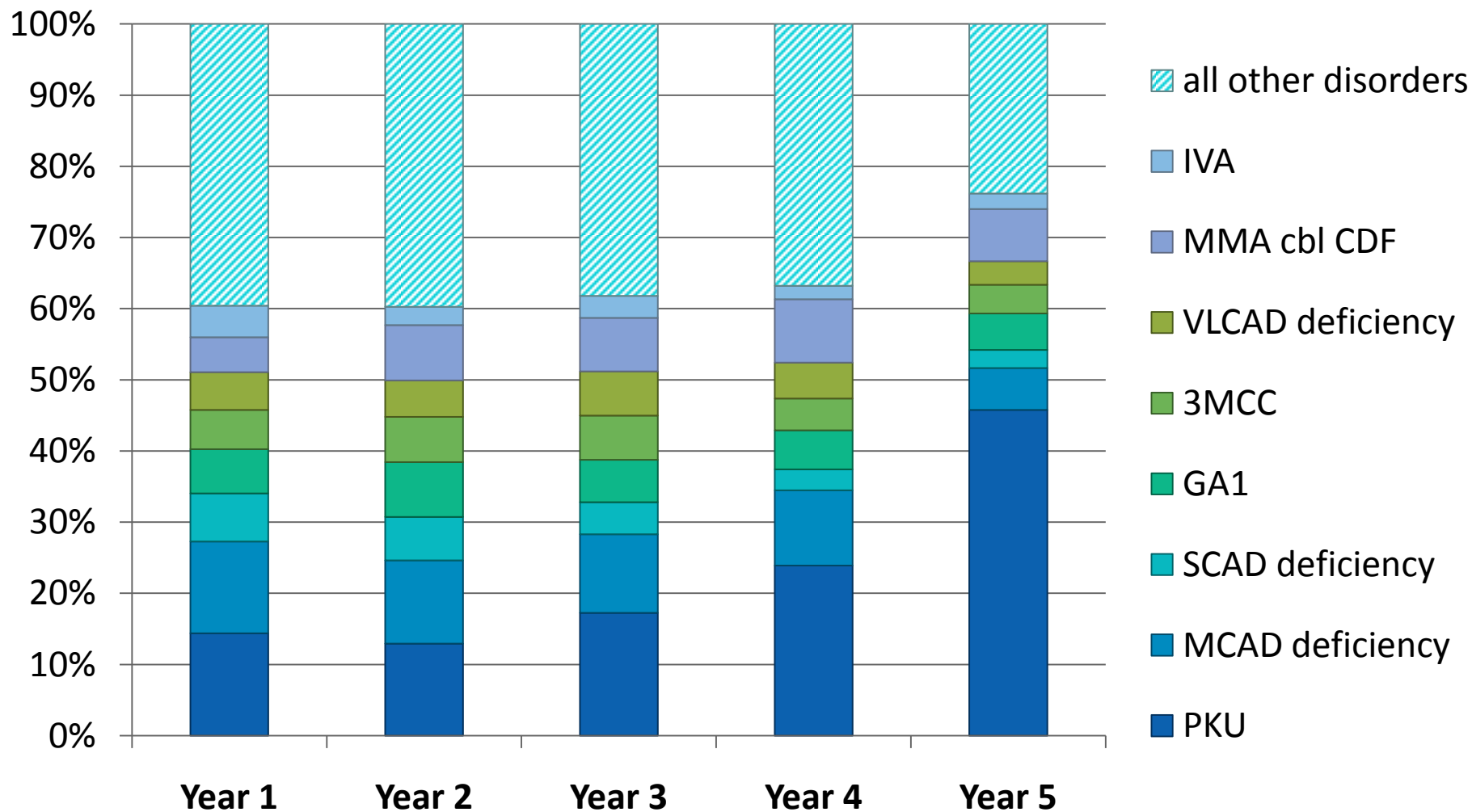
Count of Clinic Visits Among Referrals to Metabolic Specialty Follow-up Centers

		25%ile	50%ile	75%ile	95%ile
Year 1	n = 719	2	3	5	10
Year 2	n = 602	1	2	3	5
Year 3	n = 421	1	1	2	4
Year 4	n = 326	1	1	2	4
Year 5	n = 212	0	1	2	4

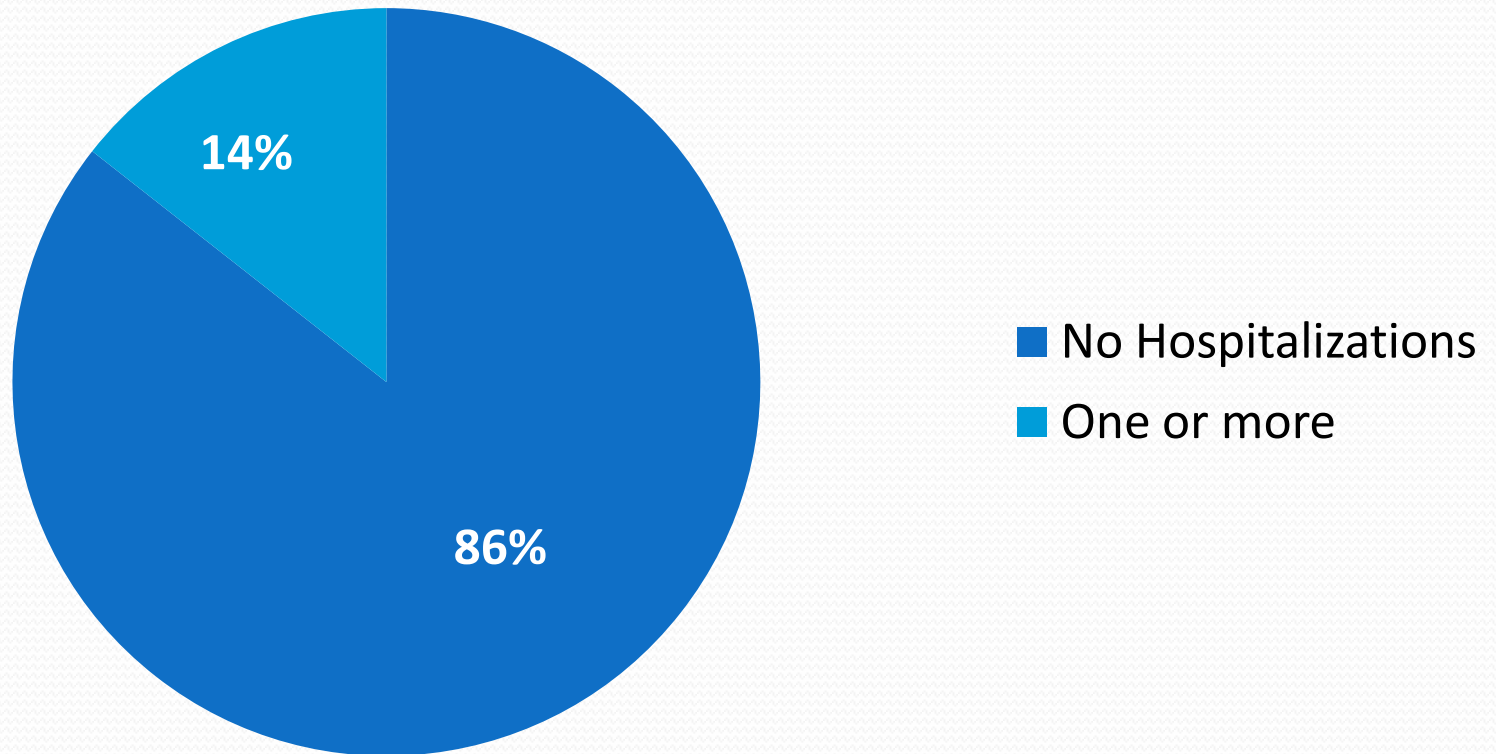
Contribution of disorder types to total count of clinic visits



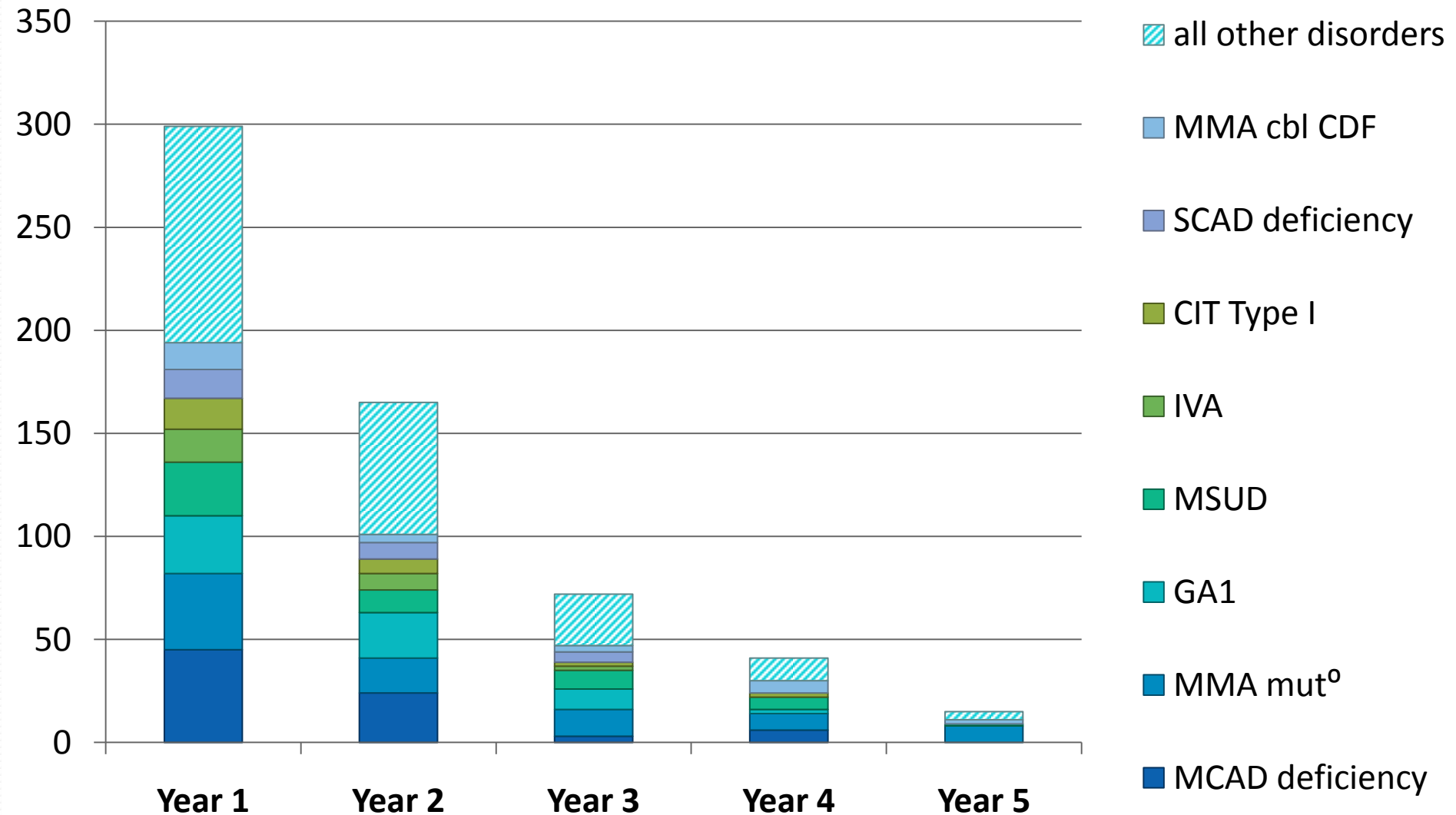
Contribution of disorder types to total count of clinic visits



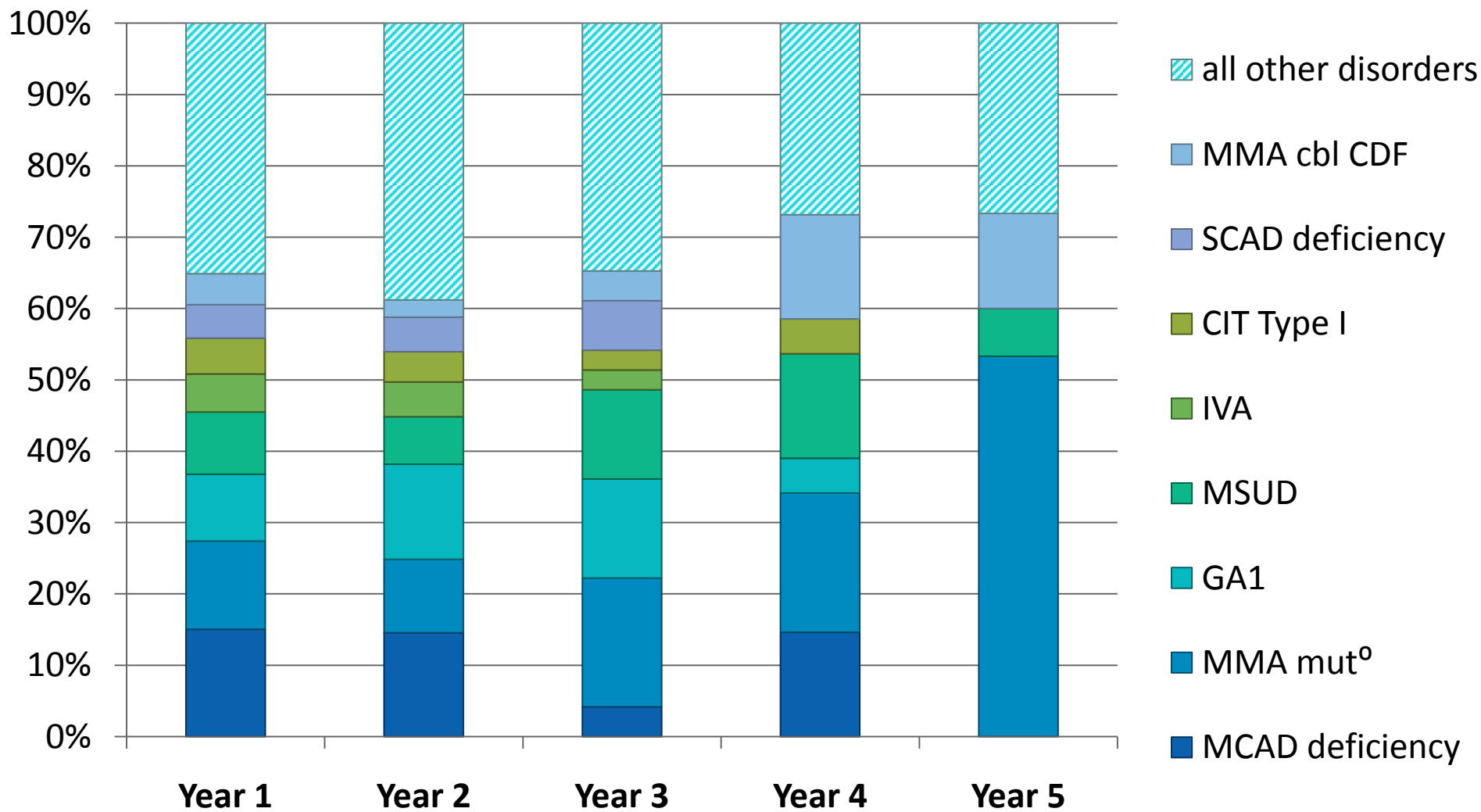
Hospitalizations (n=592)



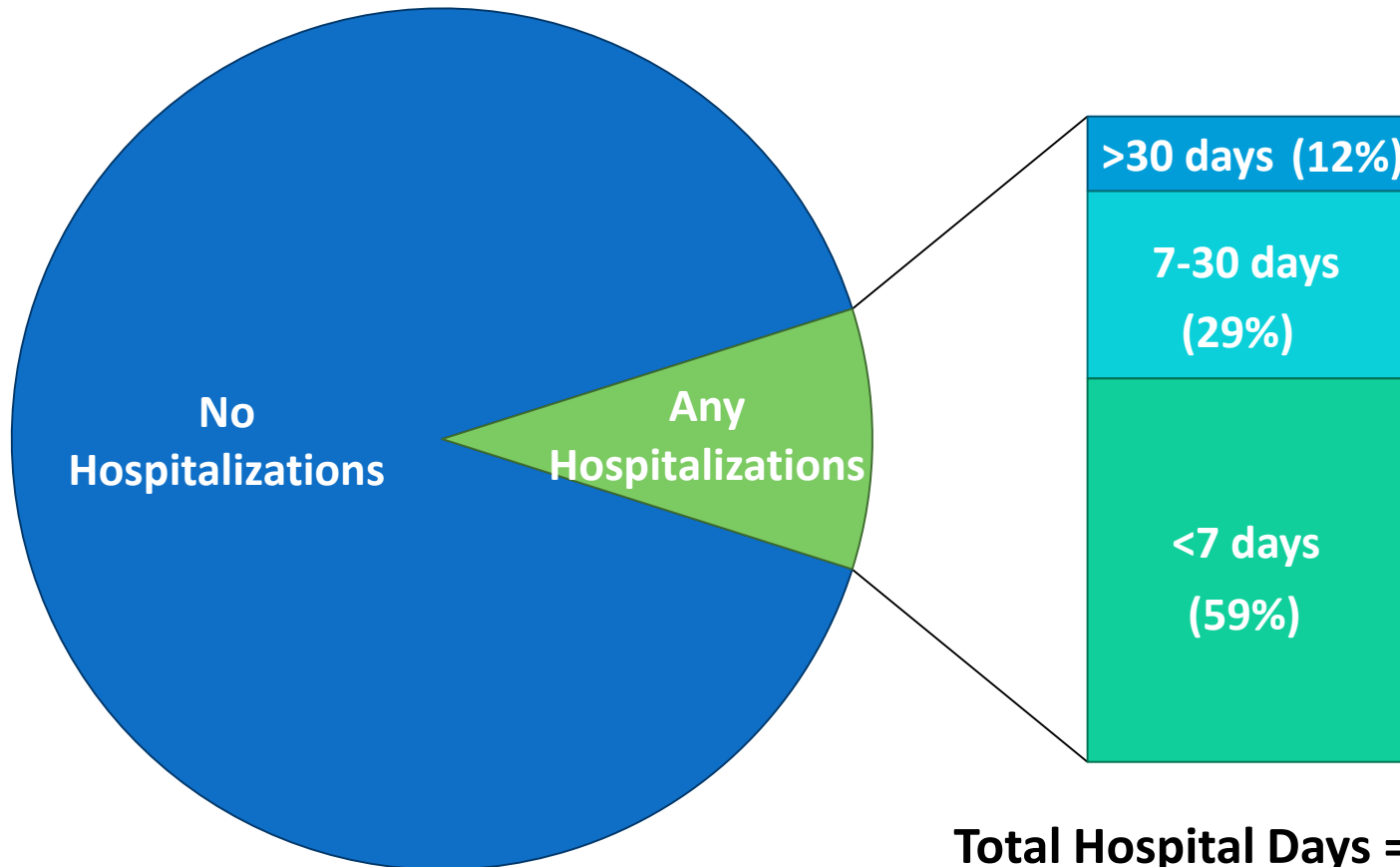
Contribution of disorder types to total hospitalizations



Contribution of disorder types to total hospitalizations



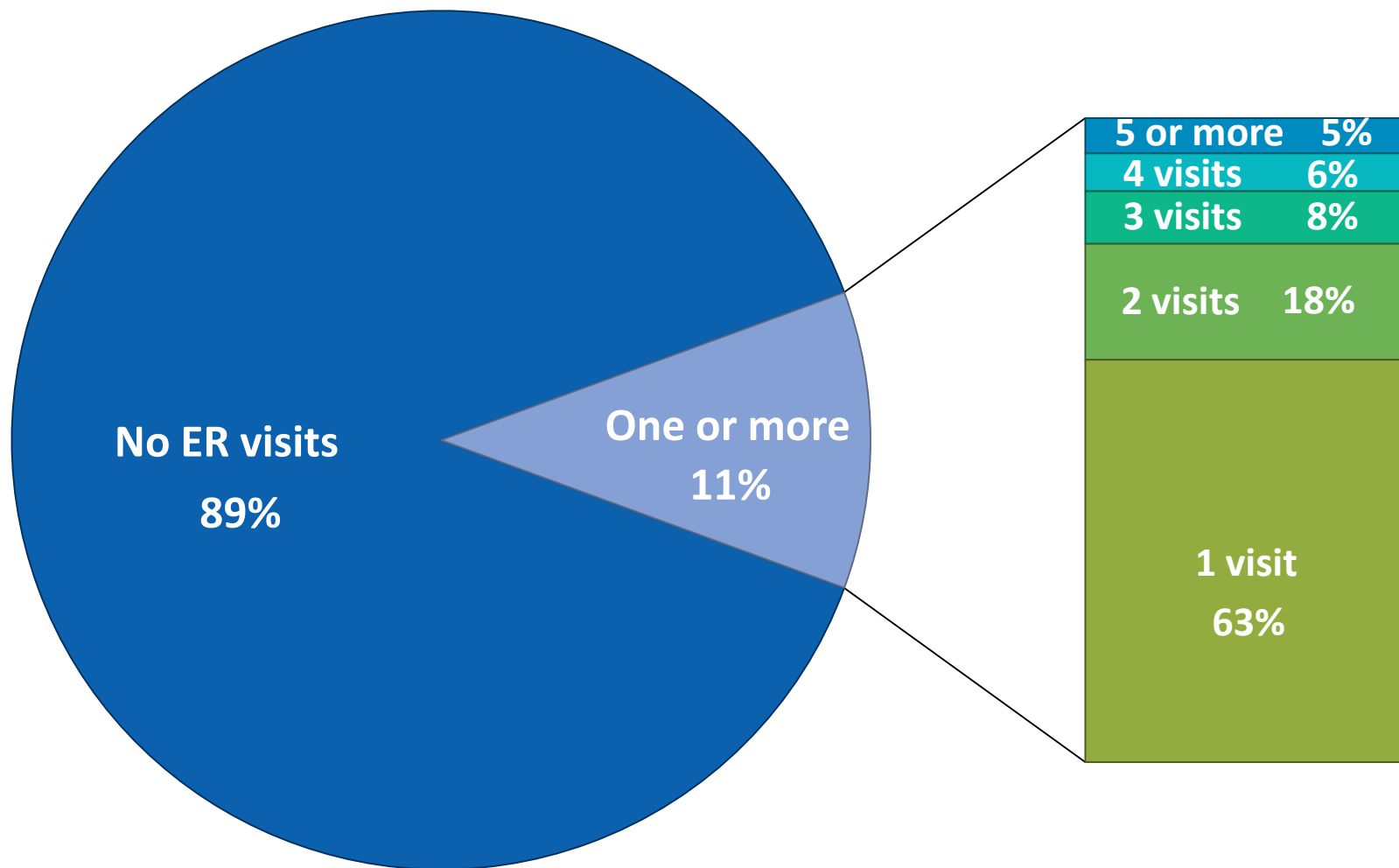
Hospitalizations and Length of Stay



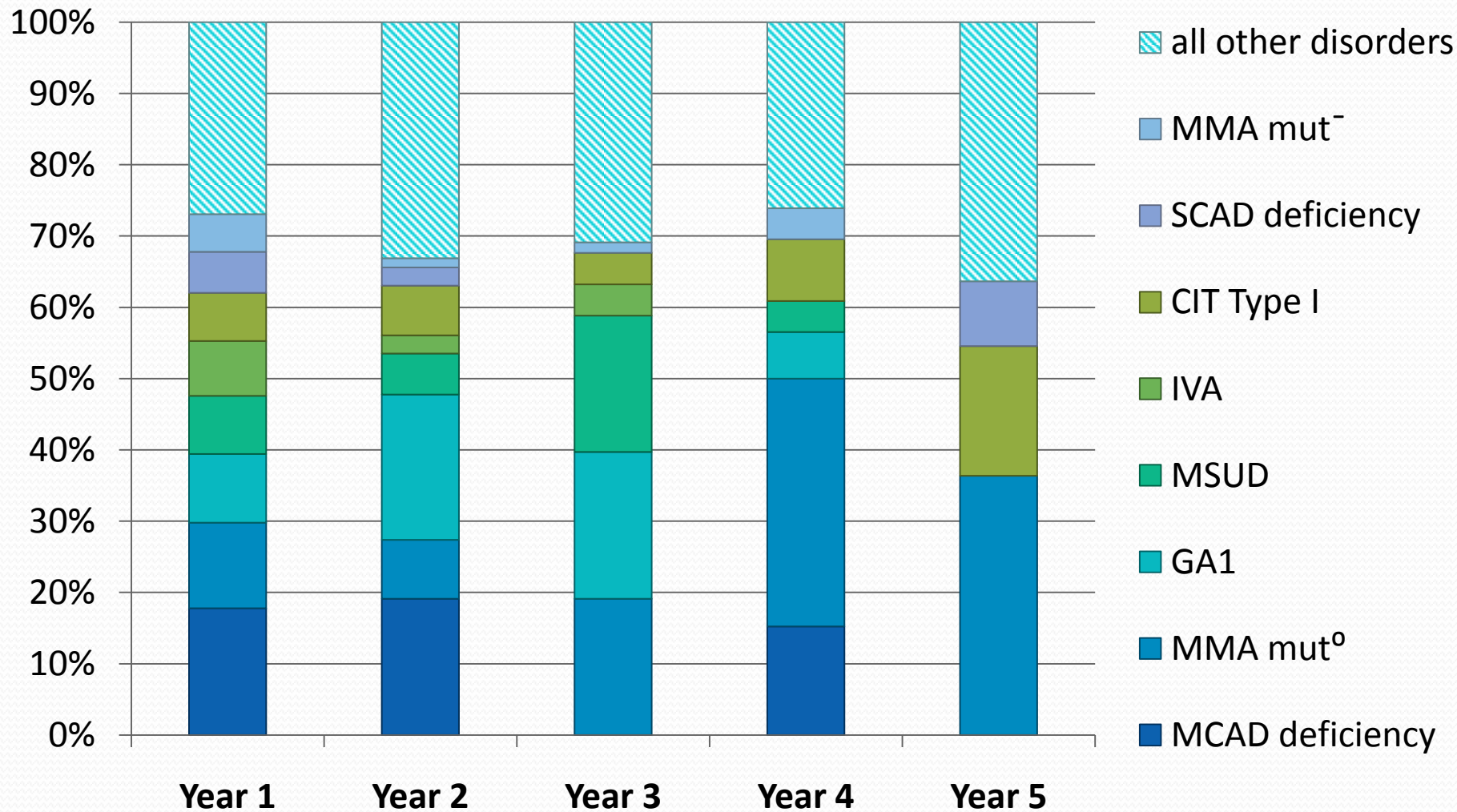
Hospital Length of Stay Among Referrals to Metabolic Specialty Follow-up Centers

		25%ile	50%ile	75%ile	95%ile
Year 1	n = 110	4	7.5	26	88
Year 2	n = 67	2	4	10	20
Year 3	n = 27	2	3	9	44
Year 4	n = 19	2	3	4	22
Year 5	n = 3	3	5	9	9

ER visits (n=490)



Contribution of disorder types to Emergency Department Visits



Assessments and Referrals for Additional Services Among 726 Cases

Type	%
Provider review of milestones	49.6
Developmental assessment using standardized instrument	4.3
Referred or receiving ongoing physical/occupational therapy	8.7
Referred or receiving ongoing speech therapy	6.6

Why does this matter?

- Because more kids are now getting diagnosed with disorders, preventative health service utilization for genetic disorders would be expected to increase
- Due to earlier diagnosis, the hope is that ER and hospitalization use decreases with better disease management.
- But we won't really know if this is happening if we don't follow-up!

Future Steps

- Continue to slice and dice the data to answer public health/clinical outcomes questions
- Improve data quality
 - Better capture hospitalization information – validate with hospital discharge data?
- Find out what issues people want to know most about.....

Acknowledgements

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 - Harbor/UCLA Medical Center
- Kaiser Permanente-Northern California
- Kaiser Permanente- Southern California
 - LAC/USC Medical Center
- Stanford University Medical Center
- Sutter Memorial Hospital, Sacramento
 - UC Davis Medical Center
 - UC San Francisco Medical Center
 - UCLA Medical Center

**and CDC Cooperative Agreement
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