



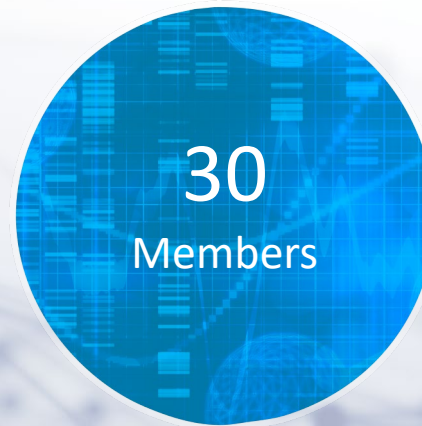
# Vivli

CENTER FOR GLOBAL CLINICAL RESEARCH DATA

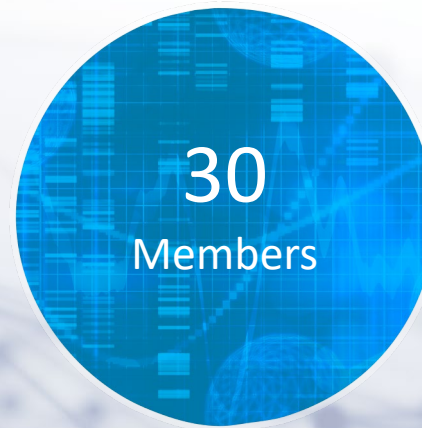
## Data Sharing of Rare Disease Data – A Case Study

PHUSE DT Winter 2021

# Vivli by the numbers ...TODAY

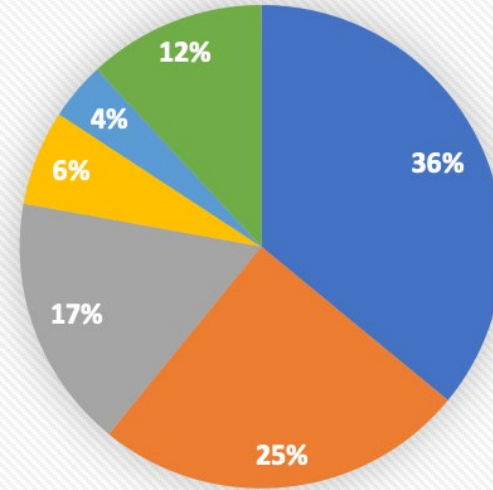


# Most of these data shared are Non-Rare studies from Major Programs





What types of secondary research are conducted through Vivli?



- New Research
- Participant Level Metanalysis
- Confirmatory Research
- Summary Level Meta Analysis
- Preliminary Research
- Other

# How Vivli works for a data requester

## SEARCH

**Search Vivli platform** for information about available studies.



## REQUEST

**Request** IPD Data sets.  
Each Data Request will be **reviewed** according to contributors' publicly stated requirements.



## ACCESS

Data from approved requests can be **accessed** in Vivli's secure research environment or **downloaded** with permission.



## ANALYZE

Use robust **analytical tools** to combine and analyze multiple data sets.



## DISSEMINATE

Completed **research results** will be assigned a DOI.  
Researchers may use the Vivli platform to meet their **publication** requirements.



# We have had a number of successes in data sharing

Today we will discuss one example in Duchenne and how in partnership we have succeeded in unlocking this data...

