Partnering With Patient Organizations to Accelerate Research

Applying Insurance Claim Analysis to a Cohort of Rare Disease Patients From a Rare Disease Registry (Primary Ciliary Dyskinesia)

May 9, 2023

DATAVANT

Chan Zuckerberg Initiative

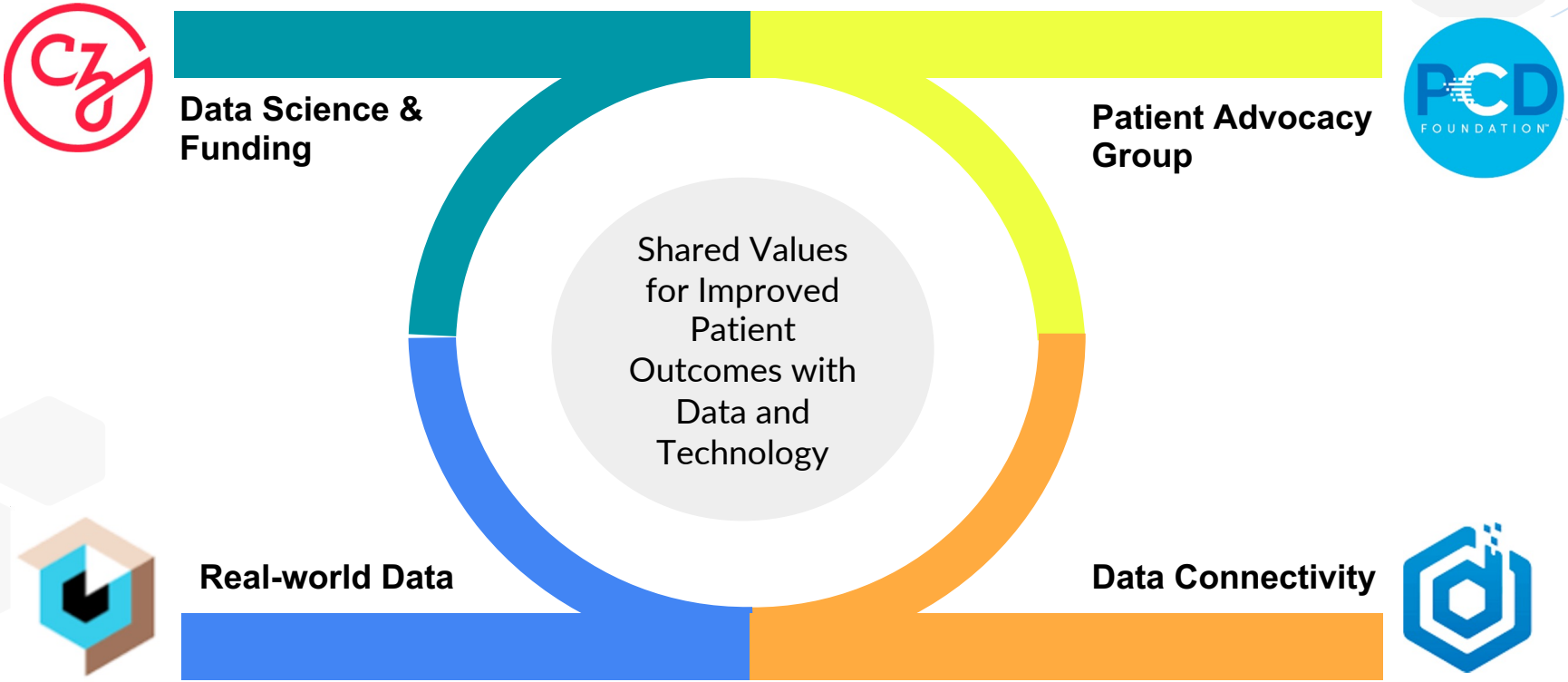
PCD FOUNDATION

komodo™ HEALTH

Conflicts of Interest

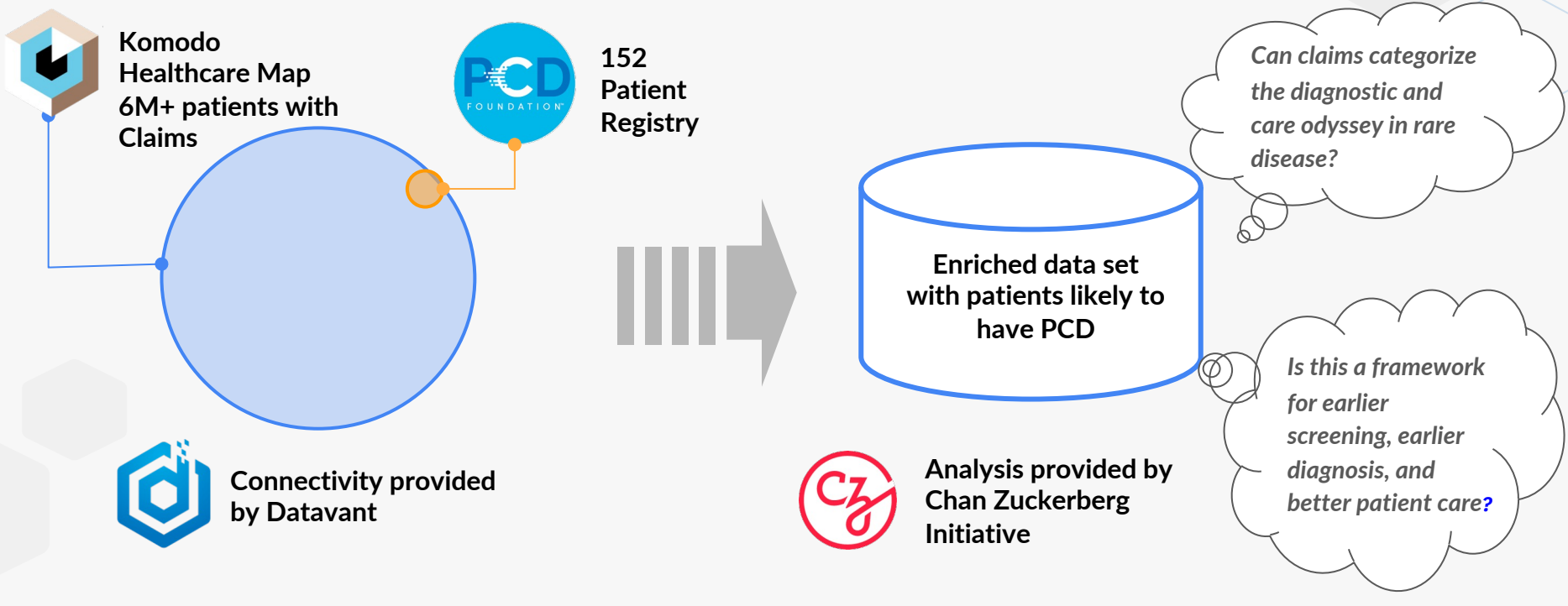
- None

Multi-stakeholder partnership demonstrates possibilities for rare disease research

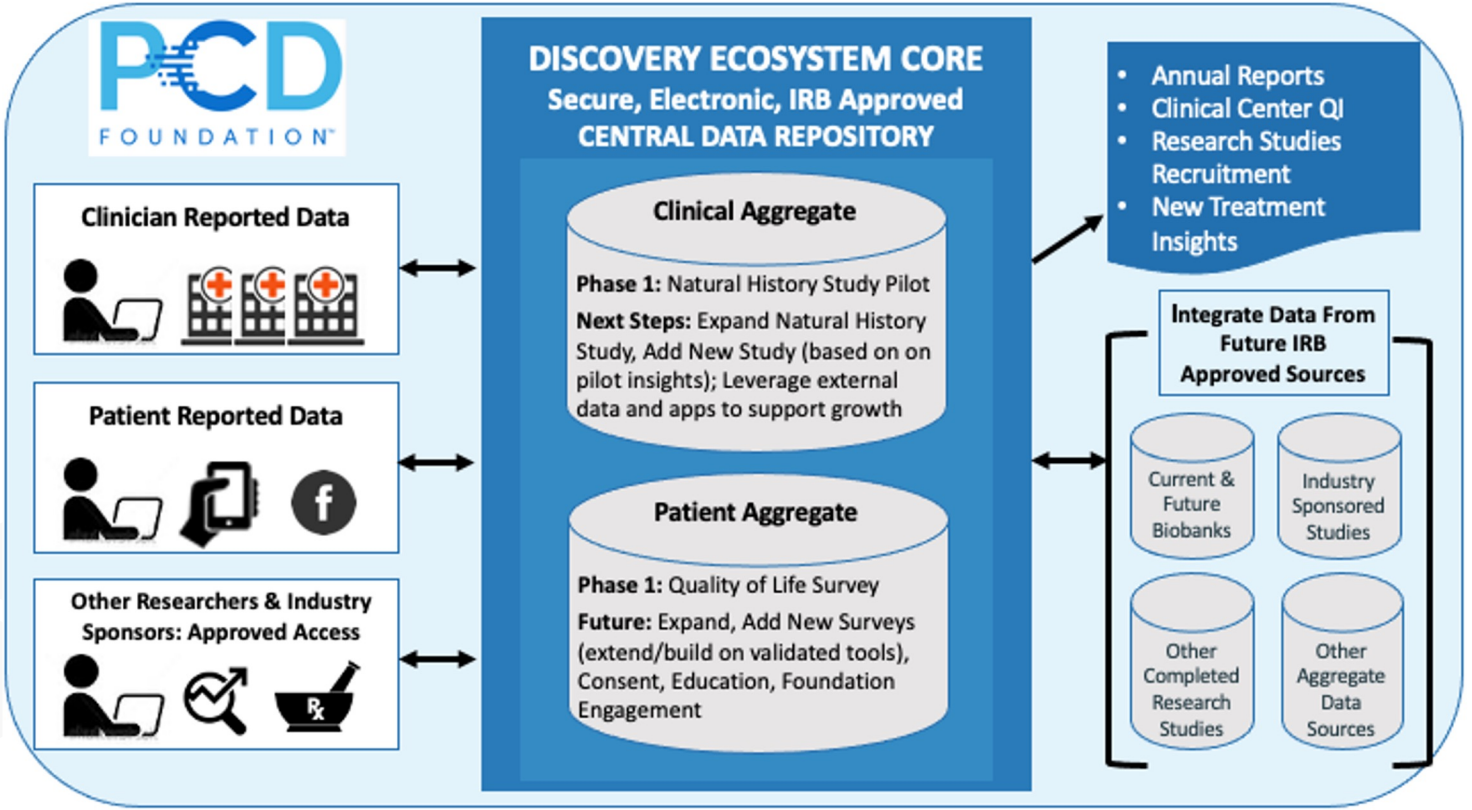


PROOF OF CONCEPT

Linking patient data from a rare disease registry to national claims for de-identified analysis



Primary Ciliary Dyskinesia Foundation



TRACK NATURAL HISTORY & CLINICAL OUTCOMES

IMPROVE AND INFORM CLINICAL PRACTICE & PATIENT CARE QUALITY

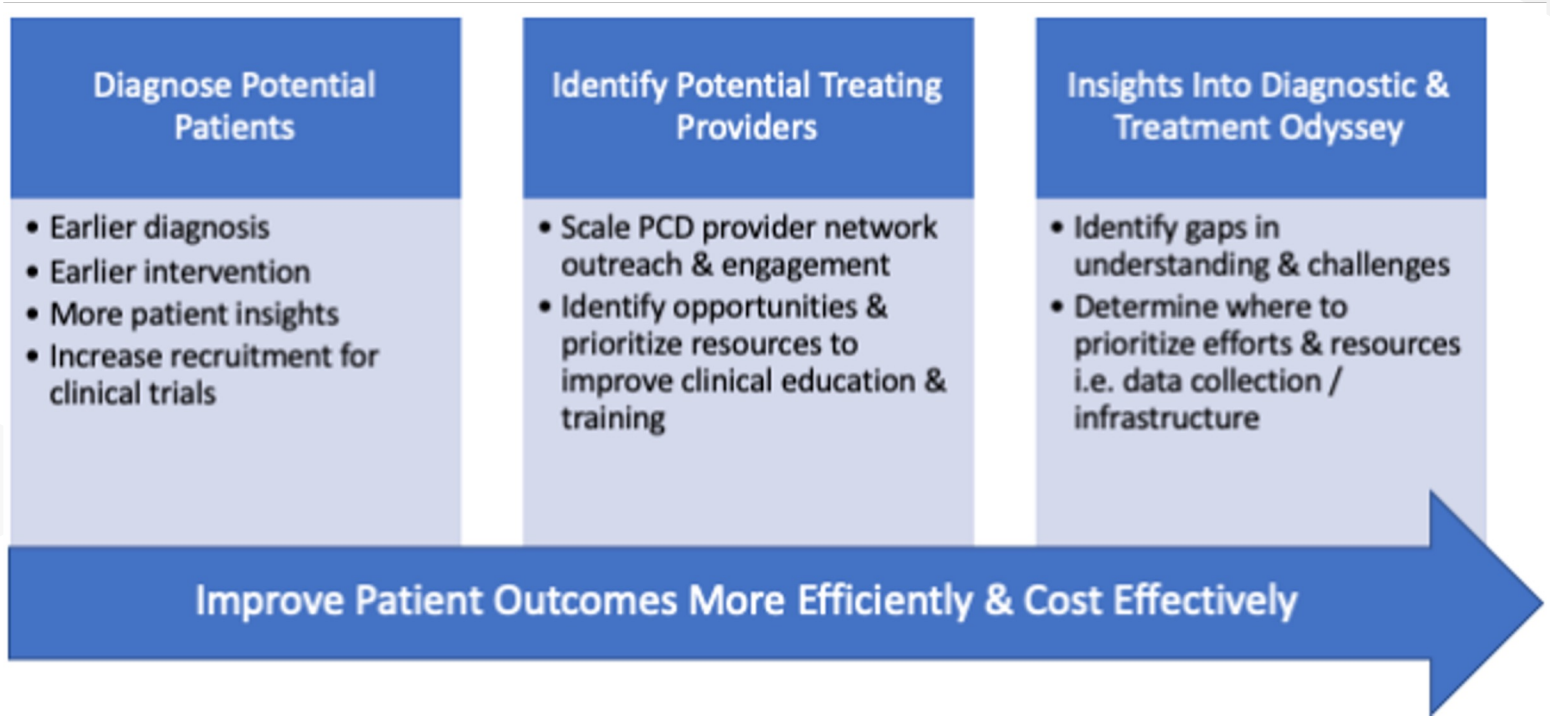
EXPAND EVIDENCE-BASE ON GENETIC, MOLECULAR & PHYSIOLOGICAL BASIS

PROVIDE FRAMEWORK FOR CLINICAL TRIALS &TREATMENT PIPELINE

INFORM STAKEHOLDER DECISION-MAKING VIA PATIENT INSIGHTS

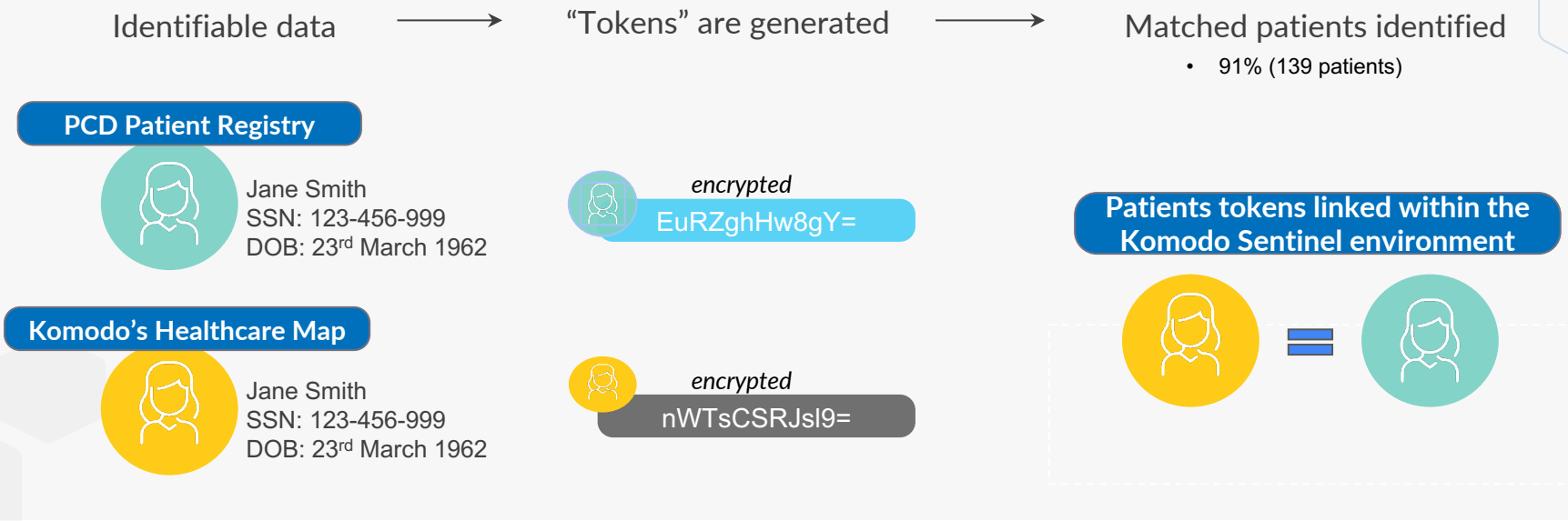
VISION

Claims Data and Partnerships: Catalysts for Impact



CONNECTIVITY SOLUTION

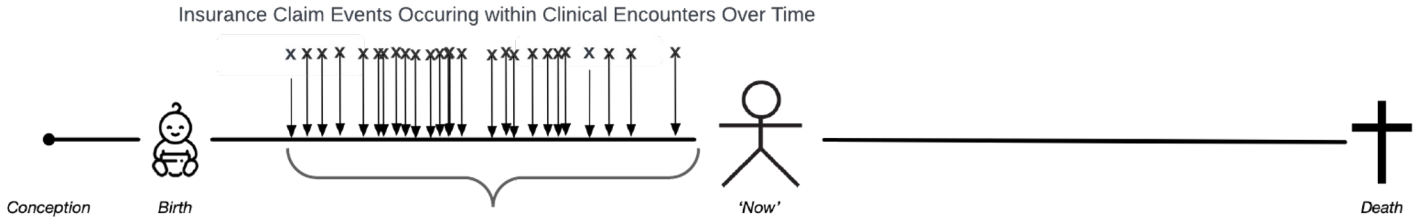
Privacy-preserving record linkage (PPRL) connected the data needed for our analysis



- Both parties used **Datavant Connectivity technology** to tokenize patient demographic information
- No Personally Identifiable Information (PII) was shared
- <1 month from ideation to analysis-ready combined data set

ANALYSIS

Mapping Patient Journey Data to Features for Screening



Komodo Data

Date	Code	Zip	Clinician
1.18.18	99283	125	000078
1.18.18	32851	125	000078
1.20.18	Q34.8	123	10009
...	...	...	...

- De-identified patient records
- 2016-2022
- Visit / Encounter data
- 30,000+ possible codes:
  - Diagnoses
  - Procedures
  - Drug Prescriptions
- Focus on Pediatric Data (age <= 18)
- Demographics (ZIP3 only)
- Provider information

Feature Representation

Patient ID	DOB	F1	F2	...	F70
zz1987321asdaef	1.1.2014	0.1	625.0	...	0.0

- Each patient = 1 row with 68 feature variables
  - 28 Features based on Diagnosis codes
  - 28 Features based on Procedure codes
  - 12 Features based on Drug Prescription descriptions

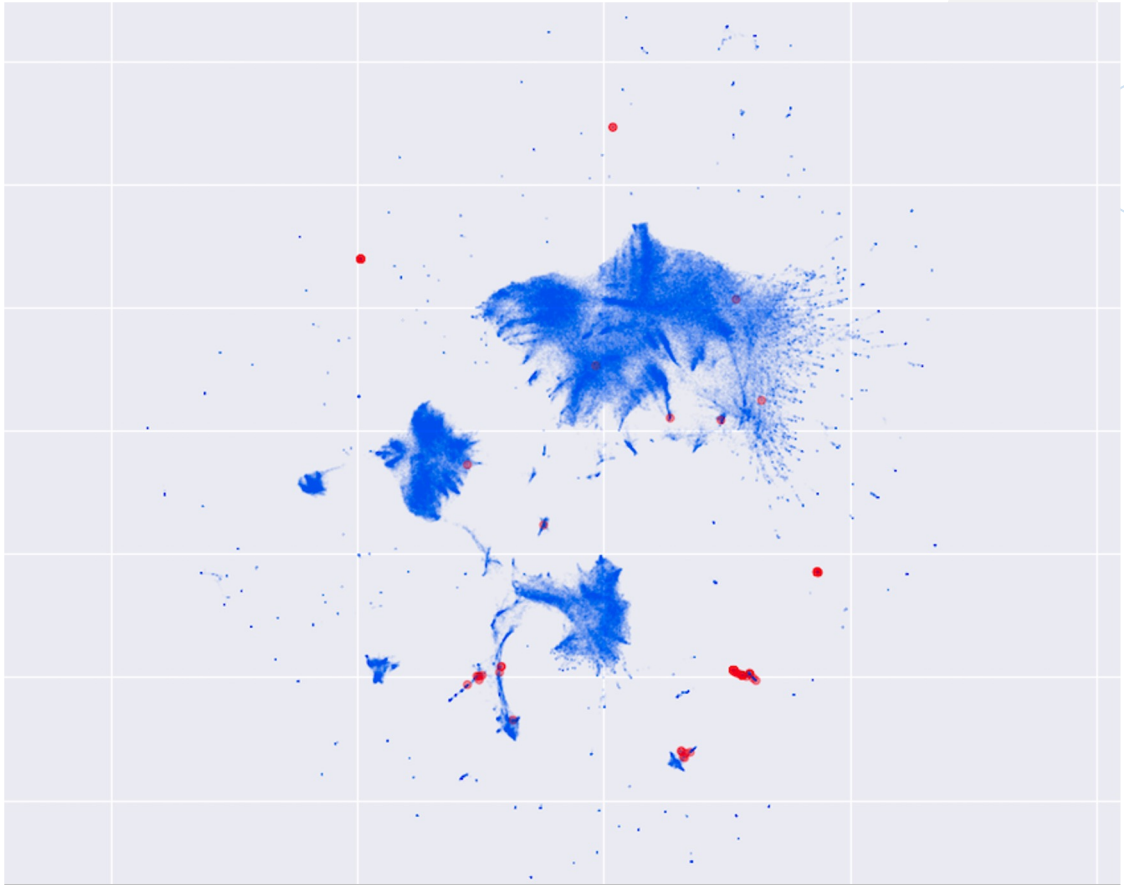
ICD10 / CPT / Drug Coding Reference for Primary Ciliary Dyskinesia

ANALYSIS

PCD Feature-Space Map of Patients

~500K randomly sampled pediatric patients clustered by local similarities in feature space (X/Y axes not meaningful)

- Blue Dots - All patients with Claims
- Red Circles - All patients in PCDF Registry



ANALYSIS

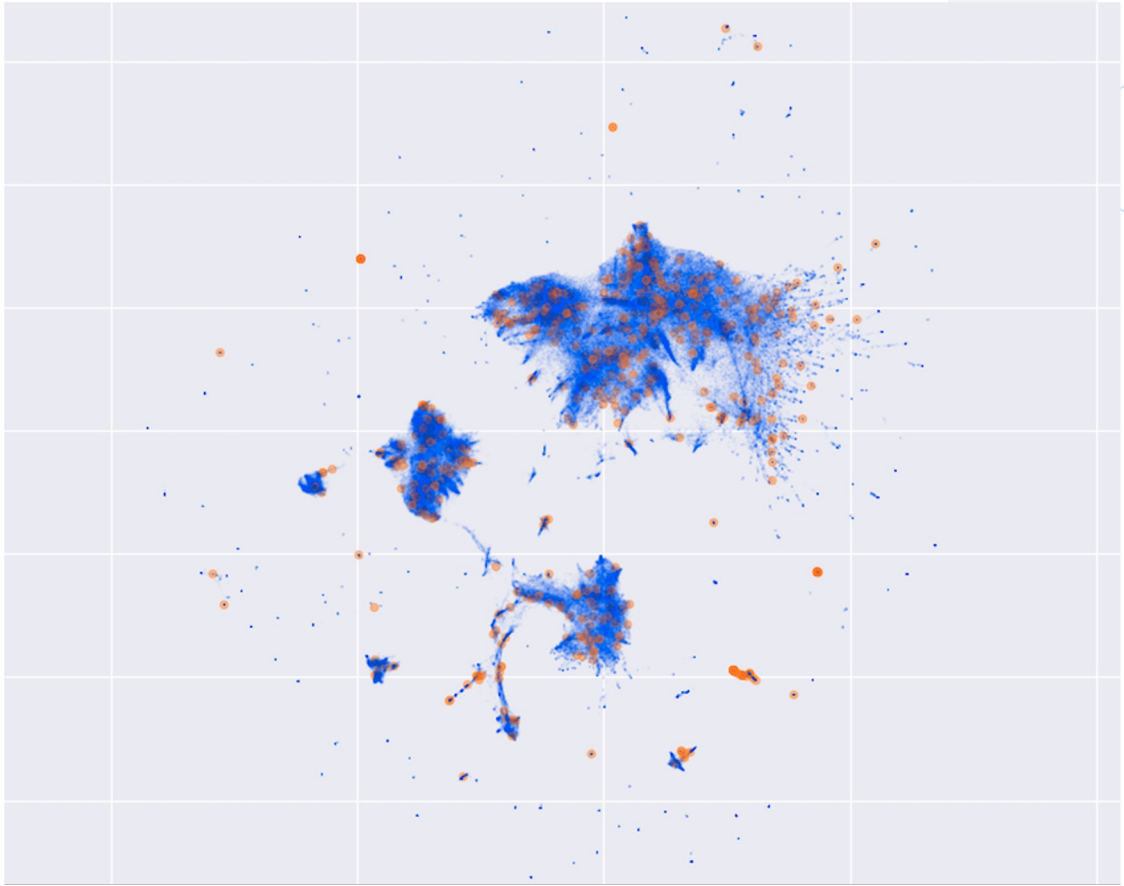
PCD Feature-Space Map of Patients

~500K randomly sampled pediatric patients clustered by local similarities in feature space (X/Y axes not meaningful)

- Blue Dots - All patients with Claims
- Red Circles - All patients in PCDF Registry
- Orange Circles - Patients predicted to have PCD using ML model [1]

[1] [Precision ~0.57, Recall ~0.83]

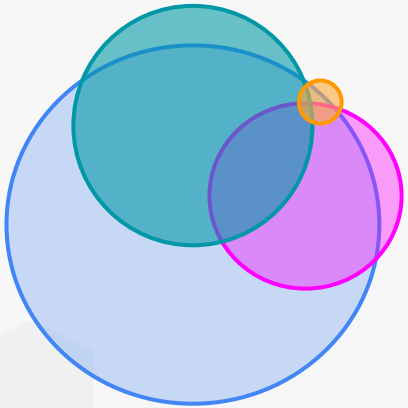
ML trained on 83 pediatric PCDF registry patients as well as 342 pediatric patients with Q34.8 diagnosis + Electron Microscope procedure codes



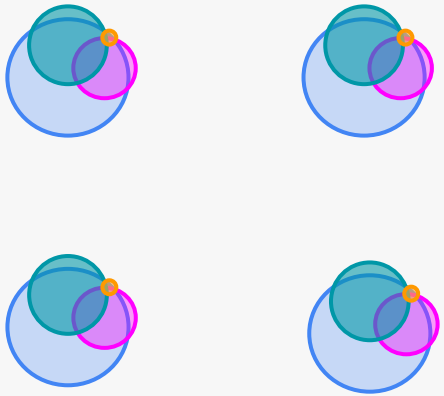
FUTURE

Next Steps and Opportunities for Real-world Data Linkage

Augmenting with more real-world data



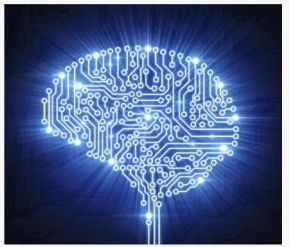
Repeated for other rare diseases with registries



Future data science inquiries

Deep Learning

Patient Embeddings



Natural Language Processing

The potential is here

Insurance claims has promise to provide a screening tool for rare disease, as well as other real-world data

Partnership and collaboration across stakeholders will replace outdated ways of thinking that have created data silos

A real-world data infrastructure can transform our understanding of rare disease at a global level

Questions? Contact Us.

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