ASH Registry: An Agile Data Repository for Enabling Concurrent Clinical Research Initiatives

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Design Principles that push boundaries

1. **Fully portable** data and software *(owned by ASH)*

2. **Scale rapidly** and accommodate concurrent initiatives

3. **Support all disease areas** in the ASH portfolio

4. **Facilitate curation** of data from disparate sources

5. **Maximize reusability** of all data *(pluripotent modeling)*

6. **Deliver tailored data** to members, industry, and academia

Launch Projects that span the health continuum

Multiple Myeloma

- Malignant blood disease with well-characterized patient cohorts

- Rich clinical research findings exist; but are siloed in disparate institutions

- **Integrate these findings into one, unified MM community data asset**

- **Iteratively enhance with longitudinal & social determinants data sources**

Sickle Cell Disease

- Nonmalignant blood disease with poorly-characterized patient cohorts

- Limited research focus; inconsistent diagnosing and standards of care

- **Facilitate creation of a clinical trials network & data asset**

- **Iteratively enhance with patient-reports & industry collaborations**

Reassuring Trends from Theory to Application

Theory

"The Pluripotent Rendering of Clinical Data for Precision Medicine"

Chute, C. and Huff, S.

Johns Hopkins, Intermountain

Studies in Health Technology and Informatics, August 2017

Application

"Scalable and Accurate Deep Learning with Electronic Health Records"
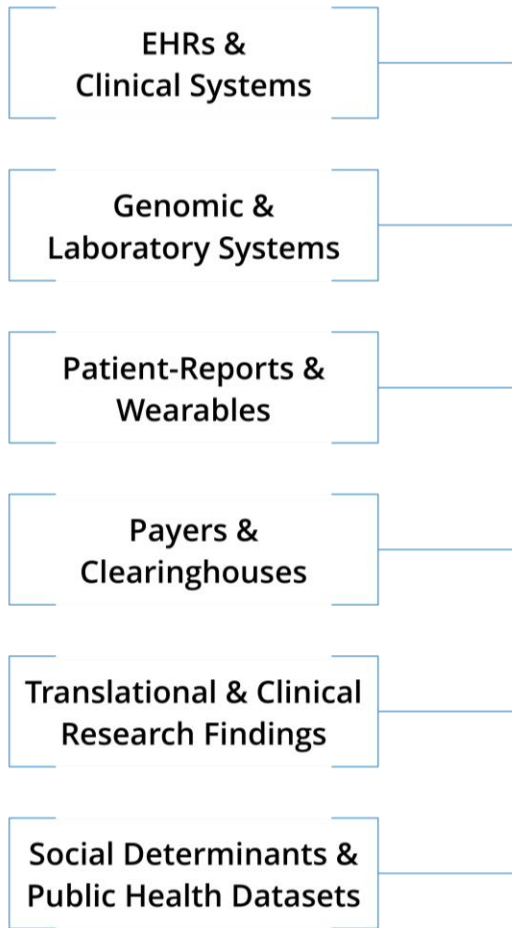
Rajkomar, A., Oren, E. et al.

Google, UCSF, Stanford, U Chicago

Nature Partner Journals: Digital Medicine, May 2018

DATA SOURCES

- EHRs & Clinical Systems
- Genomic & Laboratory Systems
- Patient-Reports & Wearables
- Payers & Clearinghouses
- Translational & Clinical Research Findings
- Social Determinants & Public Health Datasets

Supports Any Combination

ASH Registry

Across Disease Areas

DATA USES

- Quality Improvement Research & Guidelines
- Investigator-Initiated Biomedical Research
- Clinical Trial Networks & Research Consortia
- Precision Medicine & Predictive Analytics
- Government & Industry Data Partnerships
- Cross-Speciality Collaborations

American Society *of* Hematology

Benefits of Approach