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

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Reassuring Trends from Theory to Application

Theory

“The Pluripotent Rendering of Clinical Data for Precision Medicine”
Chute, C. and Huff, S.
Johns Hopkins, Intermountain

Application

”Scalable and Accurate Deep Learning with Electronic Health Records”
Rajkomar, A., Oren, E. et al.
Google, UCSF, Stanford, U Chicago

Studies in Health Technology and Informatics, August 2017
Nature Partner Journals: Digital Medicine, May 2018
Supports Any Combination Across Disease Areas

ASH Registry

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

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

Benefits of Approach

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