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Team science: The need for integrating natural histories into EHRs for more accurate diagnosis

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Approximately 7000 rare diseases exist in the world today, affecting 1 in 10 people and an estimated 350 million people worldwide. These are striking numbers, especially considering that 90% of those affected with a rare disease are treated with off-label prescriptions, and less than 1% of rare diseases have an FDA approved drug. Individually these diseases are rare, but it is not rare to have a rare disease as shown by the number of people affected worldwide. Information on each disease can be as rare as the disease, leaving families with little to no information and support after a diagnosis. Families, physicians, and researchers all over the world need information on rare diseases, but all in different forms. Physicians and researchers lack a common source of patient data needed to further their research and clinical trials in turn, prohibiting the development of new therapeutics for treatment of rare diseases. In 2010, Sanford Research started the Coordination of Rare Diseases at Sanford (CoRDS) to curb the lack of centralized, collated and available patient information. CoRDS is an international registry dedicated to accelerating research on rare diseases by being the most robust, cost free rare disease registry in the world. The registry enrolls anyone with any rare disease, partners with patient advocacy groups, and serves as an open data source to investigators. There are over 4,500 participants in the registry from all 50 states and 58 countries representing over 700 different rare diseases.

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