Informatics and Sickle Cell Disease - Challenges and opportunities for personal informatics, electronic health records, and registries

Abstract: Sickle cell disease is an inherited rare disease of the hemoglobin affecting 100,000 individuals in the United States, yet the cost of managing the disease is $3 billion annually. People with sickle cell disease are primarily members of overwhelmingly socially disadvantaged groups with disparities in care and treatment. This population faces stigmatization by institutions, healthcare providers, and the general public, and structural racism. Individuals with sickle cell disease face multiple costly episodes of intense pain (vaso-occlusive pain episodes) and long-term disease comorbidities such as chronic kidney disease, stroke, and cardio-pulmonary complications. While individuals with sickle cell disease face both healthcare and healthcare information technology disparities, there are several opportunities for informatics. In this talk, we will discuss the current landscape of informatics in sickle cell disease, barriers to informatics tools, and opportunities. By the end of the talk, the audience should be able to: 1) Understand what personal informatics tools can be used in sickle cell disease and what challenges and opportunities are present. 2) Describe the challenge of creating registries for individuals with a rare disease, such as sickle cell disease, and potential tools could help overcome these challenges 3) Describe the opportunities and limitations of different data sources, such as electronic health records that can be used to follow the clinical history of sickle cell disease.

About the Speaker: Dr. Robert Cronin is an Associate Professor of Internal Medicine at The Ohio State University. He earned his B.S. in Computer Science at Cornell University, attended medical school at The Ohio State University, completed a combined Internal Medicine and Pediatrics residency at Vanderbilt University Medical Center, and pursued his M.S. in Biomedical Informatics as a National Library of Medicine fellow at Vanderbilt. Dr. Cronin is a board-certified Internist and Pediatrician and cares for adult and pediatric individuals with and without sickle cell disease. He is also a board-certified Clinical Informatician with training and experience in clinical data systems and data science. He specializes in delivering primary care to individuals with sickle cell disease. Dr. Cronin’s expertise includes clinical informatics, sickle cell disease, data science, and personal health informatics. His knowledge in these areas includes patient portals, mobile health technology, electronic health records, health information needs, effective health communication, and patient engagement. He is interested in empowering individuals with healthcare and healthcare information technology disparities, evaluating and understanding the limitations of different data sources, including electronic health records, and designing and evaluating electronic surveys. Dr. Cronin has a career development K23 grant from the National Heart, Lung, and Blood Institute (NHLBI) and is the co-PI of the data consortium for NHLBI’s Cure Sickle Cell Initiative. He is a part of the Data and Research Center for the All of Us Research Program and contributed substantially to developing and evaluating health surveys for All of Us. He has published over 40 peer-reviewed manuscripts, presented at numerous local and national conferences, and written multiple book chapters. His research interests include sickle cell disease, data science, precision medicine, electronic health records, and personal health informatics.

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Associate Professor of Internal Medicine
Ohio State University Wexner Medical Center
Friday, September 3rd, 11:00am-12:00pm
Carmen Zoom