P1476 REVEALING THE POWER OF DISEASE REGISTRIES IN REAL-WORLD PATIENT CARE AND RESEARCH – THE SAUDI NATIONAL SICKLE CELL DISEASE REGISTRY SUCCESS STORY

Topic: 26. Sickle cell disease

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Background:

The transformation in healthcare driven by the expansion of digital health is reforming clinical practice and medical research. Real-world health data is playing an important role in this transformation. National registries are recognized as one of the main sources for real-world data that is utilized to enhance practice and conduct of medical research. The value of national registries is profound when collecting health data for rare diseases as Sickle Cell Disease (SCD). In Saudi Arabia, the prevalence of sickle cell trait ranges from 4.5% to 27% and up to 1.4% for SCD.¹-³ Lacking data about SCD hinder informed decision making on healthcare, research and health policies in Saudi Arabia. As a result, the Saudi Ministry of Health has acknowledged the need for a national SCD registry to serve as valuable resource for real-world data. In 2019, the Saudi MOH launched national SCD registry to collect data for all SCD patients treated within MOH hospitals. This abstract aims to describe the registry, its current status and future plans.

Aims:

The registry aims to collect data on SCD patients from all hematology treating units within MOH hospitals. Within that scope and serving relevant stakeholders (patients, providers, and payers), the registry intends to achieve multiple aims as describing baseline clinical and demographic characteristics of patients with SCD, disease patterns, prevalence, clinical outcomes, effectiveness of therapy, Quality of Life (QoL), patient reported outcomes and healthcare resource utilization, with the goal of enhancing patient care and value-based outcomes.

Methods:

Following established guidelines for registries, Saudi MOH implemented multiple steps in building the registry which include establishing registry team, defining the scope, objectives, and data sets, establishing a governance and oversight plan, and developing a project plan and timelines.⁴-⁶ The registry is composed of a developed digital platform that collects, manages, and analyzes the data. For sites with paper based medical records, data entered into the platform manually by site coordinators while for sites with Electronic Medical Records (EMRs), data captured using integration solutions within the platform. The registry captures data on patient demographics, medical history, procedures and interventions, laboratories results, medications, blood transfusion, SCD complications and pain crisis.

Results:

Between 2019 and 2021, the registry collected data on 22,956 patients from 15 MOH sites. The registry generated important insights such as patient average age (28 years), average number of missing days from school and work in one year (16.04 and 90.35 days, respectively) and pain assessment (96% of patients who experienced pain, of which 29% was mild, 51% moderate, 19% severe and 1% very severe).
Summary/Conclusion:

The Saudi MOH established a national SCD registry, with the long-term aim of developing value-based healthcare and enhancing medical research at the community and country level. After successfully completing the initial phase of the project, the Saudi MOH is planning for a second phase to expand the number of hospitals and patients. The registry platform will be modified and upgraded to include other features such as remote monitoring, patient reported outcomes and outcome-based agreement execution with the vision to leverage the registry data for AIML implementations. Lastly, the registry data will be leveraged to support multiple MOH systems such as Seha virtual hospital, NHCC, national call center (937) and appointments.