Dermatology research with the Observational Health Data Sciences and Informatics (OHDSI) network

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The Observational Health Data Sciences and Informatics (OHDSI) network enables access to billions of de-identified, standardized health records and built-in analytics software for observational health research. We review dermatology uses of OHDSI. The OHDSI collaborative incorporates a network of registries, cohorts, and a case-control network of registries that creates a range of observational data that can be made available to researchers and stakeholders for health research.

Geographic variations in cutaneous melanoma in the Russian Federation

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Cutaneous melanoma (CM) incidence has been increasing around the world. The goal of this study was to describe geographic incidence and mortality rates in Russia between 2001 and 2017. Oncological data from the Moscow Oncology Research Institute was gathered for the years 2001-2017, geographic information system (GIS) was used to map incident cases, and descriptive analyses were performed. International Classification of Diseases (ICD) C43 code (comprising C43.0-C43.9) was used to identify CM cases. Associations between ethnicity, geographic latitude/longitude, and CM incidence/mortality rates were studied. Routine methods of descriptive epidemiology were used to study incidence and mortality rates by age groups, years, and jurisdictions (i.e., Federal Districts and Federal Subjects of Russia). In total, 141,597 patients were diagnosed with melanoma in Russia over the period 2001–2017, of whom 62% were women. The overall age-standardized incidence and mortality rates were 4.27/100,000 and 1.62/100,000, respectively. A consistent annual increase in age-standardized incidence was observed in both men and women in Russia. Geographic mapping revealed north-to-south gradient corresponding with increasing UV exposure and east-to-west gradients due to darker skin phenotype in the east and generally colder climates.

Hidradenitis suppurativa

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Hidradenitis suppurativa (HS) is an inflammatory skin disease with recurrent painful, malodorous abscesses at intertriginous sites. Pain, which is the most burdensome symptom of HS, is more highly correlated with reduction in quality of life (QoL) than disease severity. Evidence guiding HS pain management is lacking, and individuals living with HS are at increased risk of chronic opioid use. This study employed a grounded theory approach to elucidate pain experiences as well as attitudes regarding opioid use among patients with HS. We gathered quantitative data from patient reported outcomes and disease characteristics and qualitative data from semi-structured interviews. Interviews were conducted with English-speaking participants who were at least 18 years of age with confirmed HS diagnosis and average Numeric Rating Scale (NRS) pain score of ≥7 over the preceding week. Data collection continued until thematic saturation was reached, requiring a total of 21 interviews. Mean age was 36 years (SD: 8) and 62.2% of participants were non-Hispanic white and 37.8% were non-Hispanic black. Among all 19 (94.7%) participants had Hurley Stage II or III disease. NRS score for pain over the preceding week was 5.24 (SD: 3.2), and 62% of patients had Dermatology Life Quality Index (DLQI) scores ≥14, indicating a very to extremely large impact of HS on QoL. Thematic qualitative data analysis yielded four preliminary domains: pain character, pain impact, pain management, and exacerbating/ameliorating factors. Participants described their pain using terms associated with both nociceptive and neuropathic pain character. Within the pain impact domain, patients reported the most severe impact on relationships, family, and work, and less severe impact on leisure activities and hobbies, and psychological well-being. Characterizing pain experiences in HS is a critical step into informing the development of interventions that will improve QoL, reduce opioid use, and strengthen the patient-physician relationship.