

Addressing challenges of data scarcity in the Middle East North Africa (MENA) region: How World RePORT can identify research disparities and pave the path for the future

Although researchers often focus on existing data to identify and study global health disparities, it is just as important to consider the lack of data when identifying program priorities. World RePORT, a project of the National Institutes of Health, finds that the Middle East North Africa (MENA) Region—comprised of 22 different countries—faces a unique challenge because of scarcity of research projects, grants and collaborations dedicated to improving health in this region. Furthermore, the ongoing political turmoil has eroded existing systems and prevented the development of novel programs to build an infrastructure that can enable greater research collaborations focused on health equity in the MENA region. The ACCESS Arab Health Summit is a one-of-a-kind scientific forum that serves as a fertile ground to build, strengthen and grow relationships between academic and organizational stakeholders in the U.S. and in the MENA region, as well as their counterparts in other countries with Arab immigrants.

The Socio-Political Environment in the MENA Region. Arab communities around the world face a wide range of health disparities that are greatly impacted by political climate and lack of infrastructure. The countries in the MENA region are diverse not only geographically, but also in their economic and political stability as well as access to resources. As an example, the difference in life expectancy between countries like Yemen and Lebanon can range up to 20 years. The demographic diversity of the MENA region countries is also prevalent when studying immigrant Arab populations, especially in the United States.

Demographics of Arab Americans. Arab Americans in the United States come from the 22 countries across the Middle East and North Africa (MENA region). The total population of Arab Americans is at least 2 million¹, and includes large numbers of people that trace their ancestry to Lebanon, Egypt, Syria, Iraq, Palestine, Yemen, Somalia, Morocco, Jordan, Sudan and other Arab countries. The community has been undergoing significant demographic changes since the U.S. invasion of Iraq in 2003, which pushed the numbers of Iraqi immigrants and refugees to the highest numbers in history. Arab Americans represent various cultures, religions and an array of health behaviors and needs, ranging from those who are new immigrants and/or refugees to those who have been in the U.S. for several generations. The health risk factors in the Arab American community are often directly correlated to various social determinants of health including access to care, acculturation and socioeconomic status.

Data Scarcity and Health Disparities Among Arab Americans. It is difficult to provide an accurate assessment of the health status of Arab communities in the MENA region and the United States for many reasons. First, Arab communities globally face data scarcity. To our knowledge, there is no active process to collect health data on these communities in a systematic manner.

¹ Due to the myriad of ways that Arab Americans self-identify and the problems with obtaining accurate national samples from smaller ethnic groups, it is difficult to find an exact number. According to the weighted population figures from the American Community Survey (ACS), there are around 1.9 million people with Arab ancestry in the U.S. The Arab American Institute (AAI) estimates that, due to historic undercounting of the Arab populations in the U.S., that the total number of Arab Americans is closer to 3.6 million.

Second, it is extremely challenging in the U.S. to study the population-level health trends in Arab communities because the U.S. Census federal datasets do not classify Arabs as a separate racial/ethnic group and lists them under the white/Caucasian category. Some health systems in geographic localities with high concentrations of Arab Americans have attempted to generate internal classification systems to capture some of this data. Thus, knowledge about Arab American health is limited to data collection efforts done by independent researchers, largely in ethnic enclaves rather than national, standardized research. A [literature review of Arab American physical and mental health](#) conducted in 2018 by Nadia N. Abuelezam, Abdulrahman M. El-Sayed and Sandro Galea found “conflicting evidence in the prevalence of diabetes and cardiovascular disease based on study sample”, along with many methodological shortcomings due to existing limitations of identifying and recruiting diverse samples of Arab Americans across the country. These findings further underscore the need for population-level research that can paint a fuller picture of the health needs of Arab Americans.

The ACCESS Health Summit and the resulting ACCESS Health Journal are two other venues where relevant data has been presented and discussed. However, these attempts are also fraught with methodological limitations including selection bias and inclusion of individuals from other regions of the world where Arabic names are commonly used. These systems exclude Arabs whose names had been modified over the years. As a result, it is not currently possible to reliably study national trends on health issues among U.S. communities from the MENA region. Global data scarcity in Arab communities also has a profound impact on health outcome. The absence of research makes it difficult to determine the status of the community’s health and determine the most effective ways to allocate resources that can create a positive impact.

Health Research in the MENA Region. In the MENA region, scarcity of research is most pronounced when looking at the data generated using the World RePORT. World RePORT is an online, open-access interactive database of health research projects hosted by the U.S. National Institutes of Health (NIH) and with sponsorship from a number of other big international health donors, including NIH itself, the UK’s Medical Research Council (MRC), the Bill & Melinda Gates Foundation, the European Commission (EC), the Canadian Institutes of Health Research, and the Wellcome Trust. Data from World RePORT shows that although the number of MENA Region institutions receiving awards has more than doubled from 37 in 2015 to 89 in 2017 (Figure 1), the number remains extremely low for a region with 22 countries. By comparison, the country of Kenya alone is home to 155 awarded research institutions.

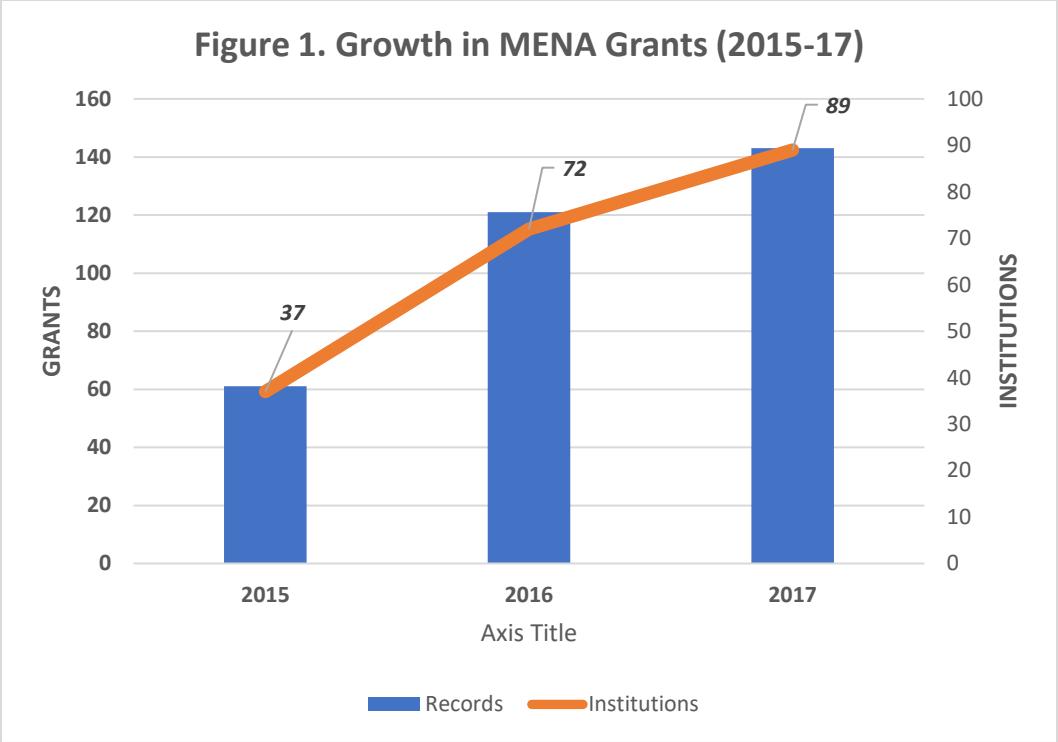
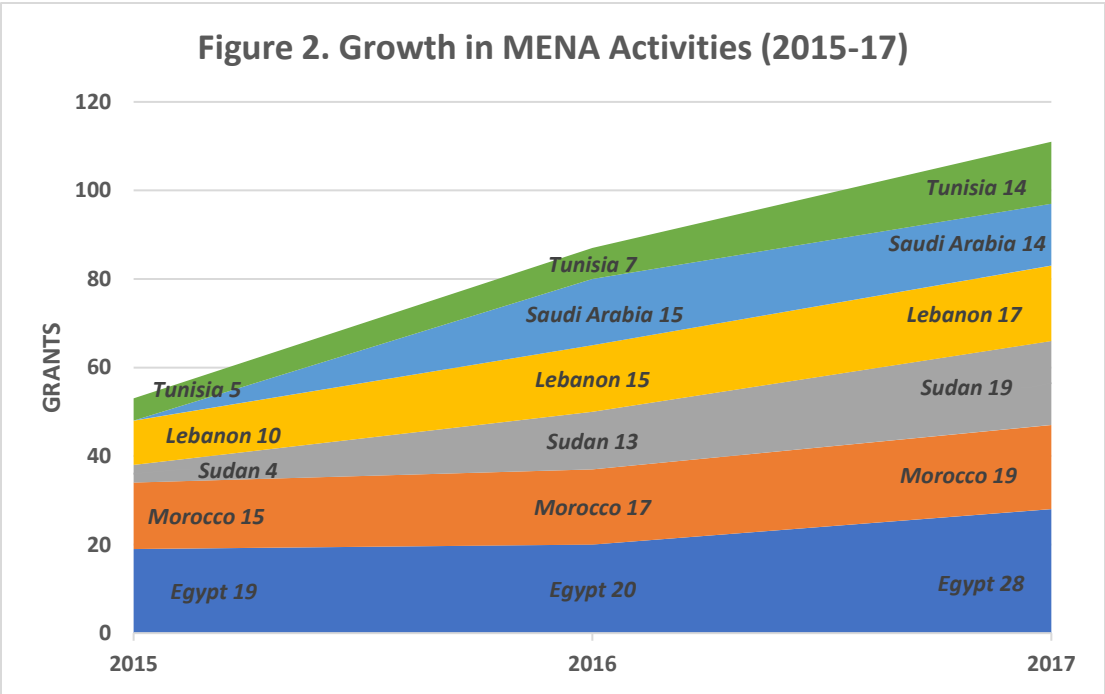
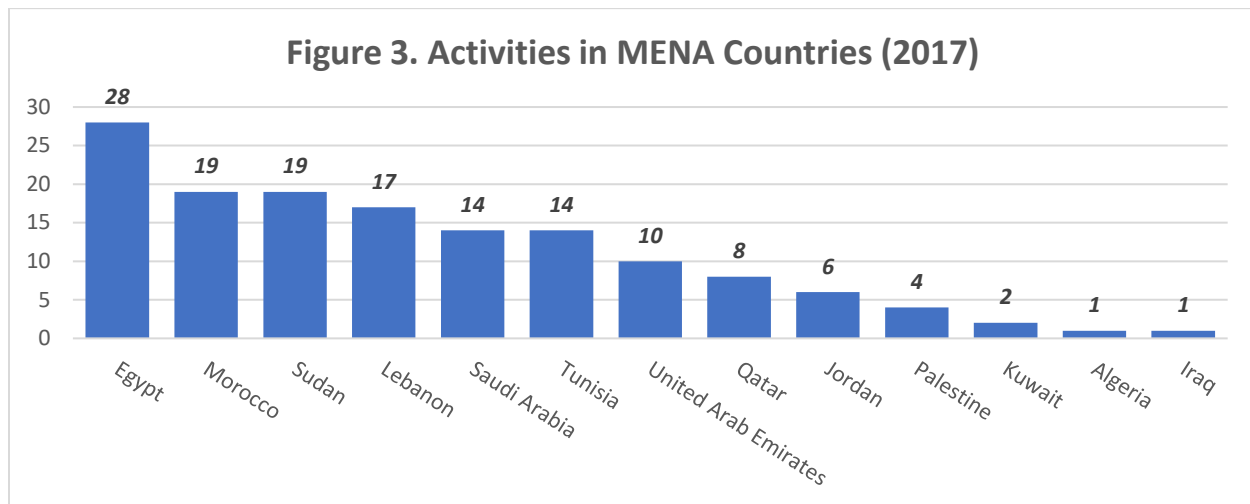


Figure 2 below shows that while the numbers of awards are modest beginning in 2015, the top 6 MENA countries receiving awards demonstrate a positive upward trend.



WorldRePORT shows that in 2014, fourteen (14) of 22 MENA countries had no research activity while in 2017, nine countries still had no NIH research activity and 2 countries had only 1 award each (Figure 3). The top 6 countries had 75% of the total awards. Egypt had the greatest research

activity with 20% of 2017 awards and almost 25% of organizations receiving awards in the region, followed by Morocco, with 51 awards (16%) in 31 institutions (18%).



Building Research and Data Sharing Capacity. There is an evident need for building the research capacity of academic institutions and organizations that are interested in studying health issues in Arab communities globally. In order to bridge the gap in research in Arab communities, and with the understanding that in order to accurately measure the health outcomes and impact on Arab Americans, over two decades ago, ACCESS launched its Community Health and Research Center. One of the primary goals of the Research program is to be the breeding ground for community-based research on Arab populations and create a platform that can lead to greater academic collaborations on Arab health research locally and globally. The most prominent outcome of the ACCESS Research program is the ACCESS Arab Health Summit, a scientific forum that brings together academics, public health leaders, health professionals and other stakeholders to present and preserve research on Arab health.

Role of the ACCESS Conferences and Next Steps. The ACCESS Arab Health Summit is the only international conference to focus on Arab Health needs from a global perspective. Innovation is reflected in the purposeful cross-fertilization of participants from diverse backgrounds, complementary expertise and relevant life experiences around an overarching theme that cuts across multiple health issues of broad relevance for cancer diagnosis, epidemiology and management on a global scale. Such innovation and diversity of backgrounds is reflected in the leadership team assembled for this proposal and for the development of the Summit itself. The depth and breadth of the scientific program enhances the applicability of research results that are shared to more than one health related topic.

Innovation is a theme that is embedded in the programming and includes presentations on an array of practices including utilization of portable data and electronic devices to increase access to health care for refugees and improve coordination of care for chronic disease patients. To maximize resources, researchers report on the impact of engaging informal services of trained health care staff, who were themselves displaced, in the provision of essential aid to patients.

We have seen firsthand the impact that research presented in the Summit has had at local, national and international levels. A noticeable trend, for example, was the culmination of presentations at conferences over the years focused on hookah in Arab American communities, which highlighted the importance of more research and intervention focused in this area. This identified need resulted in ACCESS creating and piloting a “Be Hookah Free” app, the first of its kind, aimed at helping hookah smokers quit. Themes related to health literacy in previous conferences also prompted our involvement in the University of Michigan Insure Detroit project. Through this project, we came to understand that while Arab Americans have high levels of health literacy, they are least likely to utilize services due to mistrust. These results were shared at the 8th Summit and will be used in support of evidence-based programming to address gaps in trust and utilization.

ACCESS Conferences have also paved the way for many transnational partnerships. The American University of Beirut, the MENA region’s premier academic and research institution, has built and sustained an official partnership with the University of Michigan School of Public Health through conversations started at previous Summits, and similarly, a partnership has subsequently grown between the University of Nebraska and Sultanate of Oman Ministry of Health.

ACCESS, in partnership with various academic institutions, has also worked on generating national data on Arab Americans. Through the ACCESS Arab American Research Initiative, ACCESS partnered with Dr. Jen’nan Read at Duke University and Dr. Kristine Ajrouch from Eastern Michigan University, with assistance from Jessica West (Duke) [to publish data from the American Community Survey \(ACS\)](#). ACS data for this particular report is from the 2010-2014 five-year estimates and is one of the few national surveys that includes an Arab American category. We hope for this report to be one step in the right direction to address population health needs, and ultimately pave the way for an empowered and healthy Arab American community.

The ACCESS Arab Health Summit has also paved the way for the creation of the Future Health Leaders Program (FHLP), focused on creating learning pathways and professional development opportunities for students and young professionals in the healthcare field, with a focus on the health needs of Arab communities. Through FHLP, over 20 students received partial or full scholarships to attend the conference.

We are excited to announce an important conference occurring later this year in which ACCESS will be participating, [**“The Global Syrian Refugee Crisis: Health and Socioeconomic Perspectives, Challenges and Opportunities”**](#) taking place from October 14-18th, 2019 in **Gaziantep, Turkey**. Much of the conversations that have led to this event began at the 8th Arab Health Summit given the demonstrated pressing need of more conversations surrounding the needs of Syrian refugees. This humanitarian crisis has had a large impact on the lives of those we serve, and we understand intimately that what occurs abroad impacts our local communities at home.

Through these efforts, our aim is to increase the workforce, network and collaborative efforts of those whose work focuses on Arab health, with the goal of increasing the breadth and depth of research on Arab communities locally and globally. To learn more about the ACCESS Arab Health Summit, and view our latest proceedings journal along with previous issues, [visit our website here](#).