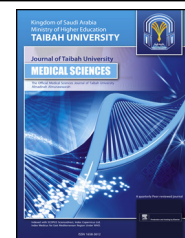




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Brief Communication

Population health data in KSA: Status, challenges, and opportunities



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Abstract

Population dynamics and health risk factors keep changing in the KSA, requiring continuous research and quality data. We aimed to review the current status of population health data, outline the available opportunities for data utilization, and provide recommendations for population data-related improvement initiatives. We provide practical solutions to support the collection, linkage, quality assurance, and governance of population health data.

Keywords: Data; Epidemiology; Health research; KSA; Population health

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Introduction

The Saudi healthcare system has improved significantly since 1960, leading to better access to universal healthcare, a lower infant mortality rate, and nearly a 30-year increase in life expectancy at birth.¹ The Saudi Vision 2030 emphasizes prevention initiatives at the population level, better treatments, and better quality of life.² Despite existing efforts, there are several improvement areas for population health data initiatives in KSA, including the limited availability of Unified Health Record (UMR) for the Saudi population and the lack of adequate policies and interventions related to population health data.

Health data at a population level is essential to monitor disease burden, formulate data-driven policies, and expand health research innovation.³ Population health data have witnessed improvements and initiatives on communicable diseases and non-communicable diseases (NCDs) and their risk factors in KSA.^{4–6} Yet, some challenges remain, and innovative approaches are currently needed to tackle the increasing burden of NCDs in the kingdom.^{7,8} These challenges include the need for reliable population data, the absence of relevant policies on the linkage of different population datasets, and the delay and complex process of making data available to researchers.

In this paper, we review the current landscape of population health data in KSA. Based on our experiences working on international population data, we then provide feasible and up-to-date recommendations to improve health

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data collection, linkage, quality assurance, and data governance.

Healthcare system and population health data in the Kingdom

The Ministry of Health (MoH) is the main provider of primary, secondary, and tertiary health services, and it is the supervisor for strategic planning and health policies.^{1,9} Healthcare services are also provided by the private healthcare sector, King Faisal Specialist Hospital & Research Centre (KFSHRC), military hospitals, and university teaching hospitals.¹⁰ In recent years, the Saudi MoH expanded its infrastructural capacity of national-based registries and started conducting national assessments of health risk factors such as smoking and nutritional status.^{6,11}

Efforts to improve population data in the Kingdom started with the establishment of a hospital-based cancer registry at the KFSHRC in 1992, which later became the population-based Saudi Cancer Registry in the Saudi Health Council (SHC).^{5,12} Since then, the communicable disease surveillance system has improved alongside the country's healthcare system with a major step of establishing the National Infectious Diseases Electronic Monitoring System in 2012.¹³ This program is designed to monitor infectious disease incidence across the country, with demographic and clinical information collected on every patient.¹³ The system also helps identify outbreaks through disease notification, tracks immunization services, and supports public health reports. Similarly, the NCDs surveillance system in KSA has also witnessed tremendous improvements in collecting population health data. Several governmental entities have conducted nationally representative surveys to assess the health, nutritional, and burden of diseases status of adults.^{6,14} The recently published World Health Survey - KSA 2019 was conducted by MoH as a collaborative project among the General Authority for Statistics (GASTAT), SHC, and World Health Organization (WHO).^{15,16} Moreover, data on risk factors such as Global Adult Tobacco Survey and the NCD Country Capacity Survey were also actively collected from KSA and reported to the WHO.¹⁵ Currently, multiple entities share the responsibility of health data registration, including but not limited to the MoH, GASTAT, KFSHRC, and SHC, who, by ministerial order, is responsible for all national registries.

More recently, digital health platforms have been expanded and developed in KSA by MoH and the Saudi Data & Artificial Intelligence Authority (SDAIA), especially after the expansion and adoption of virtual platforms as an alternative to regular health services in response to the COVID-19 global pandemic. Currently, more than 10 platforms provide services to the public and collect data from users that can be linked and integrated with other platforms. For example, *Sehhaty* - an application developed by the MoH in 2019 - is the most common mobile health application in Saudi.^{17,18} It is currently being used to book appointments in primary healthcare centers, obtain a quick virtual consultation, book COVID-19 test or vaccine, and even be integrated with step trackers' technology.^{17,18} In addition, registrations in most of these platforms are linked

with unique identification numbers for all citizens and residents of KSA, enabling opportunities for future data linkage with other platforms.

Current challenges to population health data in the Kingdom

Although there have been gradual improvements in population health data in KSA over the years, challenges remain (Figure 1).⁴⁻⁶ First, most of the currently available datasets do not allow for deep assessments of the wide determinants of health. Related challenges include the lack of any granular level analyses variables. These include gender and other information on socioeconomic status (SES), such as income, education, occupation, and living area, which can assess healthcare delivery and outcomes using case-mix analyses. For instance, SES is a significant determinant of health and has been linked to access to care, health status, low birth weight, cardiovascular diseases, diabetes, hypertension, and cancer.¹⁹ Indicators of SES at a national level in KSA have not been integrated along with other data sources at a population level.²⁰

Second, UMR is crucial in involving patients in their care process, giving health professionals access to all clinical data, making the quality of care transparent, and supporting innovation and growth through research. The UMR is another Saudi Vision 2030 goal that aims to have a unified health record for each citizen or resident in KSA.²¹ Many hospitals and medical cities across the Kingdom use different UMR platforms⁴ without any current plan of an agreed minimal dataset, making it harder to combine and link the data at the national level. Hospital Episode Statistics (HES) are the backbone of national diseases registrations and care utilization statistics. Nevertheless, there is a limitation of unified dataset gathers quality assured HES data across the Kingdom. As a result, healthcare cost data are absent, and the inability to conduct rigorous economic and cost analyses that have the power to inform decisions and improve the system's overall performance. Besides the lack of UMR infrastructure, the lack of population data collection, management, and exchange plans are barriers to collecting reliable data on patients across their journeys in the Saudi healthcare system. These challenges in collecting reliable data in the current fragmented system have created multiple issues for data linkages leading to potential systematic biases and inaccurate results.

Moreover, death registration is another essential aspect that can help policymakers assess and monitor the overall disease burden, and the specific and leading causes of mortality.²² While death data is recorded for all citizens and residents in the Kingdom through the National Information Center (NIC),²³ it is not routinely linked to the other databases or registries as in other developed countries. More work is needed to make this data available to researchers and confidentially linked with national disease registries. Achieving such a step is expected to improve the national data-driven policies on population health and enable more local population-based health outcome research.

Access to data is another challenge that the population health researchers face. Although several health datasets









Challenges	Recommendations
 <p>The Lack of determinants of health variables on a population level such as income, education, socioeconomic status, and living area.</p>	 <p>Data linkage between several population datasets available across the government's entities.</p>
 <p>The absence of a Unified Medical Record platforms across the Saudi Universal healthcare system.</p>	 <p>Establishing a minimal dataset between hospitals to share hospital episode statistics.</p>
 <p>The lack of routinely linked death data is not to other health dataset.</p>	 <p>Annual linkage and update of death data with all population-based registries and datasets to improve outcome research.</p>
 <p>The complexity of accessing population health data by researchers.</p>	 <p>A significant investment in establishing population health data infrastructure to quality assure data and make them available to researchers beside.</p>

Figure 1: Summary of population health data challenges in KSA and our proposed recommendations to eliminate these challenges.

have been continuously made available on the Open Government Data portal, clear policies and procedures for navigating the rest of the healthcare data in the Kingdom are not yet well-developed. Data availability is critical in two ways. First, data need to be cleaned and made available to policymakers through a data visualization portal; hence, findings on population health can easily be drawn from this data to support decision-making. For example, there is a need for a website in the Kingdom that shows the incidence and mortality of NCDs or the status of disease risk factors by demographic factors. Such information is only partially accessible through global databases such as those available at WHO and Global Burden of Diseases.²⁴ Second, researchers struggle to access population health data and publish using them, indicating the great need for significant investment in establishing population health data infrastructure to implement data-driven policies for Saudi Vision 2030.

Future directions and recommendations

The healthcare system is undergoing massive transformation as part of Saudi Vision 2030. The recent change includes several initiatives that aim to improve population health and advance the health research ecosystem. From our experiences in the field, here we present some recommendations to address the challenges we explained in the previous section.

First, UMR for the whole population in the Kingdom is a core initiative in the National Transformation Program, which is expected to play a major role in improving future

data. Several health institutions in the Kingdom have already adopted several types of medical records systems. While this step may increase the overall coverage of UMR data, it lowers the chances of health data standardization across the health system due to the variability of bioinformatics systems. A possible solution for this is establishing an independent office of HES at regional and national levels that collect datasets from hospitals, quality assures them, and makes them available to researchers and other agencies for research and linkage purposes. A successful example in this area is the United Kingdom National Health Services Digital Unit, where many years of HES data are collected and made available to researchers and policymakers to monitor trends in hospital activities, assess care delivery effectiveness, and monitor and evaluate care policies.²⁵ The new establishments of the Public Health Authority, the efforts from SDAIA, and the passing of the New Personal Data Protection Law are expected to improve population data quality and handling. These institutions have the chance to host such intuitive infrastructure and play a crucial part in building capacities in advancing the local population health data field. Additionally, in line with the digital epidemiology growth worldwide, digital platforms can be utilized to collect large data on the population health in the country, such as population-health surveys.²⁶ The COVID-19 surveillance efforts are proof of the power that big data can play in initiating a prompt response to a public health threat, identifying the population at risk, and implementing the appropriate intervention based on sound evidence.^{17,27} The advantage and usability of these platforms are maximized as the Saudi population is relatively young, with almost

70% of the population under the age of 35.²⁸ Policymakers and researchers need to be aware of the representativeness limitations of these platforms' users compared to the general population.

Second, there is a need to develop national socioeconomic indicators in KSA. There is established evidence of the strong relationship between SES and exposure to health risk factors, access to care, and subsequent healthcare outcomes.²⁹ Although many factors such as education, living area, employment, or income can indicate a person's SES, financial income has been used in several countries as the main indicator.^{30,31} For example, in the United Kingdom, the income domain is divided into five quartiles to indicate the SES of all citizens.³¹ The Saudi Vision 2030 has introduced several Social Protection Programs that gather data on people's education, employment status, and financial income at the individual level, such as the Citizen Account Program.³² The utilization of such data is expected to improve the landscape of population health research in the Kingdom and enable researchers and policymakers to address one of the most important determinants of health. Therefore, future research is needed to assess the validity of using this comprehensive data as an indicator of SES in KSA.

Furthermore, there is also a need to continuously link different population datasets together for better utilization of these data on diseases and risk factor metrics. Disease-specific registrations and death data are fragmented in the Saudi health care system. Vital statistics are well recorded for all citizens and residents in the Kingdom through the NIC, yet it is not routinely utilized and linked to the other databases or registries. For example, the Saudi Cancer Registry has been collecting data on all cancer incidents since 1992 but linking this data to well-established vital statistics requires a long process.⁷ In other countries, such data are linked annually to give policymakers an insightful tool to assess care outcomes. The Nordic countries possess a unique model for setting up long and complete follow-up population-based registries. Denmark, for example, has over 200 population-based registries.³³ The governments in those countries maintain registries that collect administrative, health, and clinical quality data in universal healthcare systems. The information recorded in digitized workflows feeds into national health registries daily. Such registries can be established in KSA, yet they require dedicated funding for continuous data collection processes.³⁴ Some of the similarities that Nordic countries share with KSA is the assignment of a personal identification number, equivalent to the national identity number in KSA, to each citizen that follows the person's lifespan until death. A similar number is assigned upon birth or residency identification for expatriates in the Kingdom. Identity numbers critical as they are the key identifier in all registries and databases, allowing accurate, individual-level data linkages.³⁵ Although not entirely complete, the large-sized registries of Nordic countries intend to cover the entire population with a given set of traits, exposures, or events, minimizing the possibility of selection bias.

Finally, population health data are essential for monitoring and evaluating disease burden and associated risk factors. However, establishing and sustaining reliable population health datasets requires strong governance and

dedicated funding from all stakeholders. The recent establishment of the Saudi National Institute of Health is expected to play a vital role in improving the national health research outputs across many fields, including population health. Therefore, promoting the collection, use, and linkage of population data and making them available to researchers would promote policy-relevant research and justify further investment.

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Conflict of interest

The authors have no conflicts of interest to declare.

Ethical approval

Not applicable.

Authors contributions

SAA conceptualized the article's structure and drafted the introduction and parts of the other section. MM and MA contributed to drafting the current challenges and future direction section. SA reviewed and provided critical comments for the improvement article continuously. AA designed figures and substantially reviewed the article drafts. All authors edited this manuscript and approved the final version. All authors have critically reviewed and approved the final draft and are responsible for the content and similarity index of the manuscript.

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