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Cancer registry operations in the Caribbean during the COVID-19 pandemic: a report of lessons learned and opportunities identified to support strong and sustainable health systems

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Abstract

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Background Population-based cancer registries (PBCRs) are crucial for cancer prevention and control planning. Building and maintaining resilient information systems within cancer registries that enable consistent and uninterrupted operations during public health emergencies is important. We report on the impact of the COVID-19 pandemic on the operations of Caribbean PBCRs, together with opportunities, lessons learned, and strategies to strengthen and sustain PBCR operation and data quality.

Methods The International Agency for Research on Cancer Caribbean Cancer Registry Hub (known as the Hub) was created within the framework of the Global Initiative for Cancer Registry Development, led by the International Agency for Research on Cancer and implemented by the Caribbean Public Health Agency and key partners. The Hub works closely with Caribbean PBCRs to provide training and technical support, conduct research, and promote regional cooperation. Communication between the Hub and individual PBCRs continued throughout the COVID-19 pandemic to establish its impact and to assist with developing resilient strategies to mitigate identified challenges. In 2020, the Hub supported an International Agency for Research on Cancer survey to assess the impact of the COVID-19 pandemic on PBCRs.

Findings Ten (77%) of 13 Caribbean registries contacted responded to the survey. The impact of the COVID-19 pandemic on Caribbean PBCRs varied across countries. During the early phases of the pandemic, five (50%) of ten PBCRs reported that the COVID-19 pandemic negatively affected operations, mainly in terms of data collection. Reasons included inability to fully access physical data sources and reduced capacity or inability to receive cancer notifications and files. Less severe effects reported by the other five PBCRs were linked to strong existing registry infrastructure and practices, consistency of financing, and no staffing reduction. These PBCRs took independent initiatives to adapt to changes in registry operations by establishing remote access to data sources and switching from physical to virtual data abstraction when possible. A follow-up survey is underway to assess and characterise the long-term effects of the pandemic on PBCR operations, including data reporting. A crucial need identified is integrated electronic data capture systems, which can complement in-person data abstraction through increased electronic reporting from sources to PBCRs and help to strengthen registry data management systems. In response, the Hub accelerated efforts to pilot the District Health Information Software version 2 Oncology Module, developed by the Rwanda National Cancer Registry, in the Caribbean.

Interpretation Lessons could be learned from registries, particularly those for which operations remained largely unaffected during the pandemic. Through a better understanding of the impact of the pandemic and by improving the availability of digital solutions, the Hub is supporting efforts to strengthen the resilience of Caribbean PBCRs and health information systems in the face of emergencies.

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Declaration of interests
We declare no competing interests.