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Importance of data availability and timely information for epidemiological surveillance

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Today, in Brazil, a wide range of health problems is monitored through information systems from the national epidemiological surveillance. In May 2022, more than 50 health problems or diseases were listed as notifiable diseases, including events associated with the COVID-19 epidemic, such as cases of severe acute respiratory infection (SARI) and multisystem inflammatory syndrome in adults and children [1]. These systems aggregate data to monitor the situation in the national territory, identify new outbreaks, and formulate public health policies [2], acting as mechanisms of the Brazilian Unified National Health System (SUS) to support the network in several important aspects. Any occurrence of data unavailability in these systems can seriously compromise many relevant monitoring mechanisms to public health emergencies.

One of the objectives of information systems in health surveillance is to provide fast response to epidemics or unexpected events involving infectious agents. For example, the H1N1 virus epidemic showed the clear need to expand the Epidemiological Surveillance System for SARI (SIVEP-Gripe), to monitor the progress of cases [3]. In addition, several analytical studies for academic research are conducted using data from these systems, generating important conclusions and recommendations for public health [4,5,6]. In the beginning of the COVID-19 pandemic, the fast growth in the number of cases required recommendations of non-pharmacological measures to mitigate the transmission of the SARS-CoV-2. Recently, indicators built from COVID-19 morbidity assessments have supported decisions that recommended priority groups in early COVID-19 vaccination campaign. Later, analyses of COVID-19 vaccine efficacy showed important results indicating the need for booster doses of COVID-19 vaccines [6,7]. Therefore, any data unavailability in these systems implies delayed response, no identification of events of interest, and no provision of analytically-based recommendations.

Some delay is expected between the disease notification, which is usually made through notification forms, and the subsequent entry of information into the databases. In this sense, nowcasting procedures (to estimate the number of cases in a given moment) have been developed using statistical models that handle notification time patterns [8]. With data quality and availability, it is possible to assess temporal patterns in the reporting process. Clear examples that use such techniques are InfoDengue (https://info.dengue.mat.br/) and

InfoGripe (https://info.gripe.fiocruz.br), systems that perform weekly analyses of arboviral disease and SARI cases, respectively, providing an estimated number of cases and increasing, stable, decreasing trends. Weekly reports with these indicators are sent to administrators, surveillance technicians, researchers, and various professionals who analyze the epidemiological scenario. These nowcasting models have been analyzed in academic studies in several countries, since data reporting time is inherent to this process. Then, some data delay may occur, which must be addressed in the monitoring process. However, data unavailability, means absence of information and changes in patterns, causing very serious effects.

Concrete evidence of the impact from data unavailability is seen everywhere. A recent example refers to data outage caused by a cyberattack that shut down systems of the Brazilian Ministry of Health at a critical moment of the COVID-19 pandemic [9], on December 10, 2021. Systems and user access were restored and announced by the Brazilian Ministry of Health on January 12, 2022 [10], which meant data were unavailable for over 30 days. During this period, the world had already identified the new Omicron variant of the SARS-CoV-2, a highly transmissible variant [11]. Such data unavailability caused lack of analyses and indicators in systems such as InfoGripe and Fiocruz COVID-19 Observatory (https://portal.fiocruz.br/observatorio-covid-19). The circulation of the Omicron variant in the country was already known, but the number of cases in the period was obtained only after data were restored. According to a subsequent analysis of InfoGripe, 98,400 cases of SARI with onset of symptoms in the period were reported in SIVEP-Gripe. Surveillance services did not identify this scenario in a timely manner, i.e., during the critical period. Also, the Infogripe report immediately prior to the data outage for the Epidemiological Week 48 of 2021 [12] warned of the presence of the influenza virus among the reported cases in Rio de Janeiro, which preceded the influenza epidemic in December across the country. The cocirculation of influenza and SARS-CoV-2 viruses indicated a new factor that changed the risk groups for hospitalizations due to respiratory infections. Therefore, given that epidemiological services provide a "snapshot" of current scenario, in this period such "snapshots" were "blurred" or without definition.

The COVID-19 pandemic in the country has had several periods with fluctuations in the number of cases and deaths, or even several weeks with a clear trend of increasing incidence, commonly called "pandemic waves". The analysis of such waves, trends, and new waves requires quality data and timely information. Any interruptions in data access could mean failure to detect changes. Since some periods presented high lethality, fast detection significantly supports surveillance recommendations, which can prevent thousands of deaths and serious cases.

It is important to highlight that intense debate was held in December 2021 and January 2022 in Brazil regarding the approval of vaccination for children. Experts representing entities with extensive experience in immunization and respiratory viruses presented safety and efficacy data of vaccines approved for this audience, as well as indicators of COVID-19 risks for this age group, while individuals without the same level of knowledge and scientific evidence questioned this decision [13]. In this scenario, monitoring and reporting of SARI vaccine effectiveness in the Brazilian population could be an incentive for vaccination adherence.

Even with the Omicron variant and the progress of vaccination, now in a phase with lower fatality rates when compared to previous stages of the pandemic, important questions still remain with an answer. In addition to monitoring the immunization campaign effectiveness, severe cases and deaths are periodically monitored to determine if COVID-19 incidences present downward trends or new patterns from a relatively lower level of cases.

The recognition of a potential endemic scenario of SARS-CoV-2 virus infections requires temporal analyses, and all these issues require data availability with timely information.

Possible system fragmentations in states and/or municipalities also cause significant effects. This problem of creating parallel systems must be eliminated when there is already a system in place. Instabilities in the national system end up encouraging the development of independent reporting systems by states and municipalities. Such systems, although important for autonomy and adaptation to local needs, generate rework for health professionals as they have to fill in more than one notification form to be inserted in the respective databases. This situation reduces the quality of the national system, leading to underreported cases. During the course of the COVID-19 pandemic, especially in 2020, significant differences were observed between the numbers of SARI cases reported in SIVEP-Gripe and in the panel provided by the Mato Grosso State Health Department [14], probably because the Mato Grosso maintained a state-wide panel. This mechanism does not allow a deeper analysis of trends in this state over several years.

In addition, restoring data flow after a data outage is extremely stressful, particularly during a pandemic or a public health emergency. Efforts to restore the system demand data curation to ensure data integrity. The procedures involve restoring backups and re-aggregating data from every state of the country. In the worst case, it may be necessary to retrieve notification forms and enter the information again to computer systems. This cost, in terms of human resources at a time of a pandemic or public health emergency, is prohibitive. For example, the temporary interruption of vaccination data service from the Information System of the National Immunization Program (SI-PNI), to automatically fill in the vaccine status of SARI cases in SIVEP-Gripe increased the percentage of cases without information in December. This issue affects the quality of follow-up analyses of vaccine effectiveness. As these fields are retroactively updated in SIVEP-Gripe at the federal level, these manual corrections are made on a case-by-case basis by the teams of the state health departments, making it a costly process and, in practice, neglected due to the other activities of these teams.

Then, systems must have protection against failures and vulnerabilities, and contingency plans must be developed to quickly restore access and minimize the risks of data unavailability. Of note, the fact that these systems offer public access does not make them vulnerable, if best practices based on these schemes are respected to protect information. System modernization is required in terms of adaptation to new database and security technologies and upgrade to meet new demands. These efforts are welcome, but they must always consider compatibility with legacy systems.

Surveillance systems, such as SIVEP-Gripe, SINAN (Brazilian Information System for Notificable Diseases), SIVEP-Malaria and the other national systems, are consolidated and have improved over the years. They are an important tool to achieve better efficiency in health surveillance. Open data availability with weekly update about the COVID-19 pandemic is an important milestone in the history of health surveillance in Brazil. This practice must be maintained after the pandemic and extended to other health systems and diseases monitored in the country. Data unavailability cannot be accepted, particularly during a public health emergency, because the lack of timely response and detection of important events, as well as gaps in recommendations and decision making due to absent indicators have consequences, leading to overloaded SUS and, more importantly, with potential impact on severe cases of monitored diseases and number of deaths.

Contributors

D. A. M. Villela wrote and revised the first, revised, and final versions. M. F. C. Gomes wrote and revised the revised and final versions. Both authors approved the final version.

Additional informations

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