9 Ensure flow of health data across all levels of governance

In a public health emergency, the rapid sharing of data is critical to the ability of governments, to respond to, coordinate, adapt and manage effective response strategies, both domestically and globally. Sharing data with relevant stakeholders makes effective use of limited resources and helps reduce the time between identification of a public health emergency and the mounting of an effective, coordinated response strategy.

KEY ELEMENTS

Collects timely and accurate data: Public health data collection systems—such as IDSR—must be developed prior to a public health emergency. The legal framework should establish robust mechanisms for the regular and timely collection of public health surveillance data throughout any emergency, including standardized forms and processes that ensure quality control and accuracy of data.

Protects data privacy: Generally, anonymized aggregated data is sufficient for emergency planning and response, and individually identifying information is rarely necessary. The legal framework should require anonymization of shared data and protect people’s identifying information. If individually identifying data is necessary, access should be limited to only those who require the data, and only for the specific public health purpose for which it is required. Individually identifiable information should not be automatically shared with third parties, including agencies responsible for national security, law enforcement, or the allocation of social benefits.

Shares data with all relevant stakeholders: Data pertaining to a public health emergency should be shared widely among all relevant stakeholders—across government agencies, between national and sub-national levels of government, with international partners, and the public—as appropriate and in accordance with privacy and data protection rules. The legal framework should mandate that data be shared with or made accessible to all relevant stakeholders with as few restrictions, either technical or legal, as possible.

Standardizes data to be collected: To ensure accuracy, the law should regulate what data sources can be included in official statistics. For example, cases may need to be confirmed through blood test at a government-certified laboratory. Overly strict standards may block crucial information needed by decision-makers and the public.

ASSESSMENT QUESTIONS

Does your legal framework:

- Mandate the collection of public health data on a timely and regular basis?
- Ensure the quality and accuracy of data through the use of standardized forms and processes?
- Ensure that public health data is accessible by stakeholders across all relevant sectors and tiers of government, as well as international partners and the public?
- Protect all individually identifying information of patients?
- Clearly limit any exceptions to the protection of individually identifying information to that which is strictly necessary?

ADDITIONAL RESOURCES