

“Minimal Data Set” - A Tool for Integrating the Existing Disease Reporting Systems Across Pakistan

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Disease surveillance, a key epidemiological approach, involves the collection, analysis, and interpretation of an enormous volume of data to identify disease trends and patterns, any change in pattern possibly the outbreaks, their etiologies along with their monitoring and control.¹ Like other LMICs Pakistan has a wide spectrum of disease reporting systems like vertical programs, dashboards, disease registries HMIS and DHIS with Integrated Disease Surveillance and Response System IDSRS being the most recent approach.²

The major limitation of IDSRS currently is its focus on communicable diseases as only 33 “notifiable diseases” which are all communicable ones; are being tracked in this system at public sector primary and secondary health care facilities.² It explains the limited scope in terms of its geographical span, generalizability and representativeness. Thus forth, indicating a long way to go for a reporting system of a country with 230 million inhabitants primarily using private healthcare services.^{3,4} Other challenges of DHIS or IDSRS include lack of coordination between different disease reporting systems particularly the vertical programs and disease registries using different reporting forms and different interfaces at all levels.⁵ Challenges with utility of health information system are multifold and disintegration and isolated data systems is only one of these.⁶

It is simplistic to assume that there exists a straight relationship between information generating evidence and thus paving the way to policy for improving the health. However, in real situations such simple linear relationships are hardly

existent.^{7,8} It is particularly important for utilizing this information at the higher levels of health system where data and decision-making are linked in a more extremely complex manner and many externalities come into play while embarking upon strategic decision making. More so when competing interests are there between available resources and infrastructure and different stakeholders interact. In order to strengthen the country's health information systems, it is essential to undertake context specific system strengthening integrated approaches.⁸ Through various reporting systems, undoubtedly our country is in possession of tons of data none the less what needs to be emphasized is its mere availability alone does not guarantee that it will be used for improved decision-making.⁴ Once the health information system has started converting data into information, the information produced needs to be used regularly at all levels. This conversion of making sense out of the primary data to information and then to evidence requires an appropriate and simple toolkit of targeted methods aimed at providing relevant feedback.

One of such approach to enhance data sharing across multiple reporting systems is “Minimal Data Set” (MDS) in public health surveillance. This refers to a standardized data collection of essential and minimal elements necessary to monitor and analyze the trends within a population.⁶ It's a carefully drafted set of variables that are considered fundamental for effective surveillance without unnecessary redundancy. It not only delineates what data is to be collected but also about how that data is analyzed, and used for public health policies and interventions at national level. MDS can be one of the effective ways to start with, extemporize and expand with the expansion in country's capacity to cater the whole data at a central place.⁷ MDS is aimed at identifying and developing targeted sets of data for use through its guiding principles such as leveraging upon already existing reporting systems the first one.^{7,8}

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Reducing the amount of information is its second guiding principle hence termed as “minimum dataset”.^{6,7} This reduces the burden of data collection and thus improves data quality. Thirdly it should principally be establishing a consensual information architecture as a shared resource at national and subnational levels in view of devolution and respect for provincial autonomy for an enhanced participation and improving information practices and enabling the data sharing at all levels.⁸

Fourth guiding principle shall be building broad-based consensus and stakeholder involvement essentially underscoring the importance of building upon existing initiatives as strengthening should not take place in a vacuum.⁷ Furthermore, it requires a realistic target- oriented approach in a way that takes into consideration that data integration across various systems is designed in realistic manner with targets that can be achieved within available resources and capacities-the fifth guiding principal. Last but not the least the sixth principal entails that MDS shall be aimed at gradual and incremental expansion and not entail total overhaul of the existing system with a long-term vision.

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