Capacity development, training ans research uptake

PO - (8522) - ESTABLISHING AN EQUITABLE GOVERNANCE FRAMEWORK FOR AN EBOLA DATA-SHARING PLATFORM

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Background

Despite the potential public health gains of enabling access to patient-level data on emerging infections, the launch of a centralized, international platform to deliver on this remit has not been achieved to date. Barriers include concerns over retention of national data ownership, patient privacy, appropriate consent, loss of academic recognition, criticism or exploitation of the data generators, perceived data misuse and the challenges of sharing benefits with communities where data is generated.

Methods and Results

To determine the best approach to these issues in the context of Ebola, we have assembled a collaboration of partners including governments of Ebola-affected countries, non-government organisations, academic institutions, funders and public health authorities to form the Steering Committee of the Ebola Data Platform. Following stakeholder consultation, research and debate, the committee has developed a governance framework to enable access to emerging infections data, beginning with the data from the West African Ebola outbreak.

Promoting fair and equitable sharing of benefits that arise from the use of data is a key element of the framework. Strategies to secure this principle include integration of platform data management activities with the national health institutions in Ebola-affected countries and collaboration with research communities in these countries to determine research priorities and plan analyses. Public health benefit in affected countries is further supported via training and strengthening of research capacity and infrastructure.

Conclusion

Developing a governance framework centered on the principle of equity has focused activities of the Ebola Data Platform on the affected health and research communities where they can have the most impact on patient outcomes, public health preparedness and future outbreak response.