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Global patient registry for A/H5N1: a modest success story

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Abstract

Background: A key ingredient to the success of these long-term partnerships has been: (1) adoption of bilateral confidence-building measures, including a long-term commitment and follow-up; (2) maintenance of contact with all contributing parties after the project’s conclusion; (3) support from funders; (4) the ability to communicate and accept data in many languages; (5) responsiveness to collaborators’ analytic needs; and (6) delivery of country-specific and aggregate information.

Introduction

Pandemic influenza outbreaks take place when a novel strain, which humans are immunologically naïve, emerges and develops efficient human-to-human transmission.2 To find out more about the Avian Flu registry project, please visit http://www.avianpandemicflu.org/pandemicflu.html.4

Conclusions

The protocol for the registry has been reviewed and approved by critical review committees in many countries as required. Governance and reporting

Governance and reporting

The protocol for the registry has been reviewed and approved by ethical review committees in study countries as required. The Data Access and Publication Committee (DAPC) is responsible for facilitating efficient dissemination of results from the registry to key audiences. The DAPC consists of a steering committee known as the Data Access and Publication Committee (DAPC). The charter clarifies the interactions of the DAPC with the CIG.

Methods

The registry was launched in May 2007, and is an international platform of investigators, involving information on clonally confirmed and likely cases from countries involved. The Contributing Investigators’ Group (CIG) comprises investigators who actively contribute clinical or epidemiologic data, or who contribute substantially to the acquisition of data. The CIG (Figure 1) may include laboratory confirmation of influenza A/H5N1 (A/H5N1) cases is critical to the understanding of influenza A/H5N1 in humans in preparation for any possible future pandemic. The protocol also allows for the future capture of information relevant to other influenza strains.

Data collection and collaborator involvement

The process of establishing effective collaborations included: (1) adoption of bilateral confidence-building measures, including a long-term commitment and follow-up; (2) maintenance of contact with all contributing parties after the project’s conclusion; (3) support from funders; (4) the ability to communicate and accept data in many languages; (5) responsiveness to collaborators’ analytic needs; and (6) delivery of country-specific and aggregate information.

References

1. The Avian Flu registry is a prime example of a successful public-private collaborative research effort that has proven to be an effective means of aggregating, analysing and disseminating information on the clinical course and effective treatments for influenza A/H5N1. To find out more about the Avian Flu registry project, please visit http://www.avianpandemicflu.org/pandemicflu.html.4

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