Abstract

Background: Historically, the lack of a detailed global patient registry has excited many questions about disease detection and control. While the World Health Organization’s reporting system is in place to routinely collect disease occurrence and mortality, questions remain about the natural history of the disease and its treatment. One way to address this is through the development of a global avian influenza patient registry. The Avian Flu Registry is a global, observational database of patients with epidemiological or laboratory confirmation of avian influenza A(H5N1). The registry, through high-quality, ethical presentations and publications designed to maintain the integrity and good standing of the registry, involves no therapeutic or behavioral interventions, and poses no risk to patients.

Methods: The registry was launched in May 2007, and is an observational database of patients with epidemiological or laboratory confirmation of avian influenza A(H51). The registry is structured around collection of demographic, clinical, and outcome data on retrospective and newly occurring cases of avian influenza through a web-based data entry interface. Patient data comes from clinical records and administrative data sources, and data are entered from the published literature or news reports on the internet. Collaboration was established between epidemiologists, medical doctors, and researchers. As of 30 June 2010, the registry has collected information from 205 laboratory-confirmed and 100 likely or confirmed cases from six countries, 404 are from clinical and administrative data sources, 81% are from published case series in six countries. In total, 105 new cases have been reported in six countries. Data collected on each case includes age, sex, country, symptoms, exposure, and outcome.

Results: The Avian Flu Registry is a prime example of a successful public-private collaborative effort that (1) adoption of bilateral confidence-building measures, including a long-term commitment and follow-up; (2) maintenance of data quality and consistency; (3) confidentiality of patient information that can be shared with competent regulatory authorities and international public health organizations, such as the WHO; (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.

Conclusions: The registry provides valuable, multidisciplinary, research that provides information critical to the understanding of influenza A(H5N1), in humans in preparation for any possible future pandemic. The portal also allows for the capture of important outcomes that are important for guiding future public health policies and strategies.

To find out more about the Avian Flu registry project, please visit http://www.avianfluregistry.org or contact Nancy Dreyer (lead investigator; ndreyer@outcome.com).

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