OxU data sharing experience from the Ebola outbreak

Dr Gail Carson
30th November 2016

www.iddo.org
@IDDOnews
Infectious Diseases Data Observatory

IDDO’s vision is:
• Effective control and treatment of infectious diseases affecting the most vulnerable populations.

IDDO is:
• An independent, multi-disciplinary, global resource
• Building on the success of the WorldWide Antimalarial Resistance Network
• Bringing together clinical, laboratory and epidemiological data
• Coordinating work on malaria (WWARN), Ebola virus disease, visceral leishmaniasis, schistosomiasis, Zika, non-malarial febrile illnesses and medicine quality
• Providing reliable evidence on treatment efficacy and optimal clinical management
Data Collection Objectives

• Promote high-quality patient care to improve outcomes
• Triage patients to appropriate treatment regimens
• Determine prognostic indicators
• Refine case definitions & clinical guidance documents
• Evaluate research endpoints
• Inform public health policy
Data Standardisation Objectives

• Support high-quality, clinically-relevant science
• Harmonise outcomes and definitions
• Enable rapid pooling of datasets to strengthen power
• Allow interoperability of data platforms to promote flexibility and sharing
• Reduce launch time with prepared materials
• Avoid duplication of effort and development time
Challenges of the Ebola outbreak led to scattered and heterogeneous data collection.
The Challenges

• The data collected was often poor quality, hard to get out of high risk zones, used different definitions, was on different systems, and was not the same data that others were collecting.

• Now we are left with these partially harmonised, but mostly mismatched datasets and all of these partners want to make sure we maximise the outputs and knowledge from the data.
A new data-sharing facility

Our unique Ebola data-sharing platform provides a portal for collaboration across the Ebola clinical management and research community.

Ebola Virus Disease (EVD) is considered one of the world’s most deadly infectious diseases, killing approximately 50 per cent of people infected with the virus.

There have been more than two-dozen outbreaks over the past 40 years, and the size and consequences of the recent outbreaks were unprecedented. Despite this, there remains limited empiric or scientific evidence to inform advances in diagnosis, triage, management and follow-up of suspected and confirmed EVD patients.

However, there is a wealth of clinical, laboratory, and epidemiological data that could be used to address these questions. The overall goal of this platform is to bring together clinical, laboratory and epidemiological data to answer scientific and operational questions.

By sharing data and providing a platform for collaboration, we will enable the research community to maximize resources, prioritize research and leverage existing knowledge.

Together we can transform our response and reduce the impact of future EVD outbreaks.

Contact us or click on the links below to find out how you can participate in our data-sharing projects.

Data platform is built. Has data but not all.

Make data as accessible as possible to researchers, while protecting the interests of patients and their communities.

Ensure that the outputs and benefits of research are returned to the community.

No one has accessed the data yet because the ethics are not complete.

Ongoing challenges
Ebola Platform Governance

Steering Committee

Oversight of strategy, policy and management.

WAHO, WHO, WATER, MSF
Oxford, IMC, Wellcome

Data Access Committee

Decide on applications for data release.

Ethics Committees

Stakeholder Advisory Group

Advise on design, implementation and policy.

Secretariat

Universities & research institutions.
Administration, security and platform hosting.
Contributor

Individual patient data (any format)

Curator

Repository

Clean

Standardise

Map

Standardised data format

Collaborators

Meta-analysis

Publication

Treatment guidelines

Policy

Publication

Infectious Diseases Data Observatory
A master repository stores all data in a harmonised format.
Data visualisation tools are available to support planning of meta analysis.
Thank you

Any queries: laura.merson@ndm.ox.ac.uk