WHO First Consultation on Ebola Biobanking
Starling Hotel, Geneva, Switzerland, 13 May 2015

Introduction

The current outbreak of Ebola in West Africa is unprecedented in scale, and has generated a great number and variety of biological samples. Such samples constitute a precious, non-renewable resource, which offers a unique opportunity to facilitate rapid expansion of our knowledge of the Ebola virus and its pathogenesis, in order to expedite the development of a variety of effective interventions with which to control and prevent EVD in the future. In order to ensure that the most knowledge is obtained from this resource, WHO convened a meeting on 13 May, to consider how these samples might be curated and managed.

Considering biobanks

Representatives of governments, including Ebola-affected countries, key laboratory partners, major non-governmental organizations involved in the Ebola response, disease and biobank experts, and relevant international organizations attended the consultation. The event provided a venue for an initial exchange of views, focusing on three topics: what samples exist and where; how samples are being, or planned to be, used; and what form efforts to curate and manage samples might take. Each were the subject of a dedicated working session.

Following introductory remarks, the first session opened with a presentation by the WHO Emerging and Dangerous Pathogens Laboratory Network (EDPLN) on the Laboratory Response and Laboratory Database used in the EVD outbreak. This was followed by updates from affected countries, those involved with taking and shipping samples, as well as recipient facilities to provide an overview of the current status.

The second session addressed the many ethical, legal, social implications of using these samples. Discussions also dealt with issues around the provision, sharing and handling of data. It also focused on the various practical and methodological facets of storing and using biological samples, including various models already in use. Three presentations helped frame discussions in the session. The first, by Professor Bernice Elger from the University of Geneva, Switzerland, reviewed the ethics of biobanking. The second, by Prof. Jean-Louis Romette from Aix-Marseille University, France, presented the European Virus Archive as a distributed model already handling some of the most dangerous pathogens on the planet. The third presentation, by Dr. Akin Abayomi from Stellenbosch University, South Africa, introduced lessons for biobanking in Africa from three ongoing projects: Human Hereditary and Health in Africa (H3Africa); the AIDS and Cancer Specimen Resource; and Bridging Europe-Africa Biobanking and Biomedical Research (B3Africa).

During the third session, participants worked in small groups to answer a series of prepared questions (annex). Three working groups considered issues the issues from a broad perspective and a fourth group focused specifically on ethical, legal and social
issues. The results of the group work were reported back in a plenary session and the
meeting concluded with a round table discussion as to next steps.

**Discussions**

Participants felt that as the outbreak winds down, rapid decisions must be made on the
fate of tens of thousands of biosamples – principally blood and plasma samples, along
with swabs of bodily fluids – taken from patients during the crisis. If these samples are
to be preserved, action is needed to identify suitable short-term storage options whilst
due consideration is given to longer-term needs.

Longer-term solutions considered during the consultation included creating one or
more “biobanks” that would store the biosamples under suitable laboratory conditions,
catalogue them systematically, and fairly and efficiently administer their use for
research. Participants examined a range of options for biobanking - ranging from
national, through regional to international models and including centralized physical
locations through disseminated virtual resources.

The discussions threw up numerous complications and obstacles to biobanking. For
example, ethical concerns around informed consent were a recurring theme. The
meeting heard that many of the existing samples were taken based on patients’
understanding that they would be used for diagnosis and treatment. Informed consent
was not explicitly obtained for the samples’ use as an information archive and for future
research. Obtaining informed consent retroactively would be difficult and costly – so
much so as to render the attempt largely unfeasible. In a significant number of cases
obtaining consent would be complication be the subsequent death of the donor.
Governments and the public-health community, on the other hand, do have obligations
to carry out research that might save lives during future Ebola outbreaks. This research
could be significantly aided by making use of these samples. The meeting explored
existing best practice in such cases.

Countries particularly affected by EVD, clearly and repeatedly expressed a wish to
retain control of the samples, to keep them within their territories or at a minimum
nearby in West Africa. There were calls for the creation of one or more biobanks and the
conduct of related research, to build scientific, administrative, and technological
capacities in the region. Such countries want to work in close partnership with
international experts in relevant fields and to expand national knowledge as part of the
process of developing improved treatments for the disease.

The consultation also identified a range of practical challenges that still need to be
addressed, including:

- Overcoming complications and the expense of establishing laboratories to enable
  the safe, long-term storage of the biosamples;
- Collecting and cataloguing the thousands of samples that currently are housed in
  mobile and temporary laboratories run by numerous international health partners
  who may soon be ending their operations;
• Deciding how to provide access to the samples so that the best and most useful research is carried out;
• Dealing with issues of intellectual property and commercialization of any treatments that result from the research; and
• Determining the scope for cooperation amongst EVD-affected countries.

**Next steps**

The consultation ended with a call for WHO to arrange a follow-up session to address these challenges, further consider how best to manage and curate samples, and bring together all the necessary stakeholders. As a result, the WHO has committed to hold a second consultation in West Africa within the next few months.
ANNEX

Questions considered during small group work

On biobanking

- What international treaties or other binding commitments might be relevant for the developing biobank(s)?
- What principles should govern samples and biobanks – for the current EVD epidemic and for future events?
- What structures, oversight or governance arrangements are needed, including to actively manage access?
- What elements would a governance structure for such biobank(s) need to address?
- What steps or activities should be included in setting up or running biobanks to enable the sharing of knowledge generated by the use of samples?
- How should biobank(s) review changes of understandings of EVD and associated priorities for research?
- How will the interests of the particularly affected countries be designed into such biobank(s)?
- Which of the models for biobank(s) discussed in the plenary might offer the best fit the needs for EVD samples?

On ethical, legal and social issues

- What international treaties or other binding commitments might be relevant for the developing biobank(s)?
- How should the issue of informed consent be dealt with for samples already taken?
- How can consideration of ethical issues be strengthened for samples yet to be taken?
- What principles should govern samples and biobanks – for (1) the current EVD epidemic; and (2) for future events?
- What structures, oversight or governance arrangements are needed, including to address ethical issues?
- What elements would a governance structure for such biobank(s) need to address?