

Eubios Journal of Asian and International Bioethics

EJAIB Vol. 24 (4) July 2014

www.eubios.info ISSN 1173-2571

Official Journal of the Asian Bioethics Association (ABA)

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Editorial: Bioethics and Ideas

There are seven papers in this issue from authors around the world. First is my report of the AUSN Conference on Bioethics, Public Health and Peace for Indigenous Peoples, which was held in Mexico City as a Satellite event of the 12th World Congress of Bioethics, which I also attended, spoke at and chaired several sessions at. The theme of bioethics for indigenous peoples is stimulating and there is a variety of views that affect both medical ethics and environmental ethics. Since the American University of Sovereign Nations (AUSN) launched our MPH and Masters in Bioethics and Global Public Health (MBGPH) degrees we have also started to see a number of students from around the world start the first MBGPH in the world. The curriculum is on the last pages of this issue. There are many students and a lot of discussion between people across the world.

The paper by the Boyd's is stimulated by the discussions at ABC14 in India in 2013, and explores lessons which shape the future of who we want to become. Dr. Simonstein explores the ethics of autism and how our ideas of what it means to be a human in the current society shape diagnoses of health and wholeness. The broad meaning of health includes physical, mental and spiritual elements. The papers of Rafique and Muktamiroh examine definitions of what is ethical and unethical, against a milieu of what current "Bioethics" judges to be ethical and what is not. Aggarwal discusses abuses of ethics across borders, when the perpetrators knew what they were doing.

The final paper by Lajaunie et al. reports on meetings in Asia to discuss the ethics of cataloging infectious diseases and the agents that cause it. We will expect to see greater attention on ethics of public health with the emergence of Ebola as a disease affecting thousands not just tens or hundreds as in the past known epidemics. We hope more readers will submit papers for publication.

- Darryl Macer

Barcoding, biobanking, ebanking for “One Health” projects in South-East Asia: considering ethics and international law

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Abstract

A first workshop held within the framework of the PathodivSEA project has been the occasion to identify the major research challenges regarding the emergence of zoonotic infectious diseases in South East Asia and the spread of pathogens responsible from those diseases. Based on supporting evidences indicating the zoonotic origins of those diseases, it appeared urgent to investigate the factors controlling the pathogens-human interface by addressing the “One Health” concept which integrates the study of human and animal health with conservation medicine. The necessity of pathogen, vector and reservoir identification (barcoding), pathogens and other tissues' preservation (biobanking) and open databases creation (ebanking) has been recognized, along with the importance of ethical and legal considerations.

Introduction

The project PathodivSEA (“Pathogen diversity in Southeast Asia”, AFD-CNRS) aims to develop a research network in South East-Asia to measure the diversity of zoonotic agents (virus, bacteria, parasites) and their vectors and reservoirs, allowing sharing tools and concepts in relation to their identification (barcoding), the preservation of tissues and living organisms (biobanking) and open databases (ebanking) in order to better understand their ecology (transmission) and evolutionary dynamics facing the ongoing environmental changes that affect South-East Asia¹⁻². Southeast Asia is a hotspot for emerging infectious diseases³, and the major explanatory factor of the increase of outbreaks of those diseases is thought to be biodiversity loss⁴.

The first workshop held within the framework of the PathodivSEA project has been the occasion to identify the major research challenges regarding the emergence of zoonotic infectious diseases in South-East Asia and the spread of pathogens responsible of those diseases. This paper aims to present a short synthesis of the main observations done during the workshop through the various presentations in different disciplines, results to be taken into account in order to tackle the pressing research issues identified.

The first findings can be summarized by a variation at different scales (global, regional, local) following a geographical axis from West to East (Europe to Asia) and a decreasing gradient of integration of results from human health to medicine conservation. We will discuss those differences through examples concerning barcoding and biobanking as well as microbiology and parasitology.

The questions raised in the areas of ethics or law and policy by those scientific studies are important to highlight as in one hand researchers might not be aware of the need to incorporate some ethical or legal rules into their studies and in the other hand their findings could benefit the whole community if they were taken into consideration by policy-makers to design an appropriate decision framework.

Material and Methods

During the workshop held in Singapore in August 2013, oral presentations from regional participants (Cambodia, Indonesia, Lao PDR, Malaysia, Singapore and Thailand) dealt with several topics related to epidemiology of infectious diseases and emerging diseases, wildlife conservation and diseases (conservation medicine), pathogens, vectors and reservoirs identification (screening and barcoding), tissues (wildlife) and pathogen preservation (biobanking), database (ebanking), ethics and regulations.

Based on these presentations, we proposed a schema of the advances of barcoding / biobanking / ebanking / ethics and law in relation to the different fields that are to some degree concerned with infectious diseases: public health (medicine), animal health (veterinary medicine) and wildlife health (conservatory medicine).

Results

Table 1 summarizes the advancements of each following subjects: barcoding, biobanking, ebanking, ethics and law in relation to public and animal (domestic and wildlife health).

Discussion

Barcoding in medicine, veterinary medicine and conservation biology

Efforts to control infectious diseases depend upon our ability to identify pathogens, parasites, vectors and reservoirs. In medicine, there is a perpetual quest for a gold standard test, which refers to a diagnostic test or benchmark that is the best available under reasonable conditions⁵. In the field of veterinary medicine, development and validation of diagnostic tools are under the head of the OIE (World Organization for Animal Health), which recognizes and gives label to national reference centers (usually specialized in one or several infectious diseases). As a matter of fact, this procedure is modeled on the process used by the WHO (World Health Organization) and its collaborative centers.

Table 1. Comparisons of the advancements of each following subjects barcoding, biobanking, ebanking, ethics and law and regulation in relation to public health, animal health and wildlife conservation.

	Public Health (Medicine)	Animal Health (Veterinary Medicine)	Wildlife Conservation (Conservation Medicine)
Screening/barcoding	Gold standard test, reference laboratory WHO	OIE, reference laboratory OIE	Barcoding (BoL, Barcoding of Life)
Biobanking	Reference centers (international, national)	Institution initiatives	Natural History Museum, Institution initiatives
Ebanking	Reference centers	OIE, FAO	GBIF, BOLD, ...
Ethics	WHO/CIOMS International Ethical Guidelines for Biomedical Research Involving Human Subjects	OIE Collaborating Centre for Animal Welfare Science and Bioethical Analysis National rules	National rules
International law and regulation	WHO International Health Regulations	OIE, WHO (zoonoses)	CDB, CITES*, CMS**

*CITES: Convention on International Trade in Endangered Species of Wild Fauna and Flora

**CMS: Convention on the Conservation of Migratory Species of Wild Animals

In the field of biodiversity, less than 10% of the all species have been described. As few taxonomists can identify species on a morphologically-basis, it has been proposed to develop an international consortium, the Barcoding of Life (BOL), which aims at promoting and developing molecular identification of living organisms⁶. DNA barcoding systems employ a short, standardized gene region to identify species (usually the mitochondrial COI gen). Hence, it appears that screening and identification although using similar genetic methodologies, may not use similar words (barcoding is rarely used in veterinary medicine, or in parasitology). Moreover, they rely on different protocols, and distinct data base systems (see below).

Biobanking

This discrepancy in screening and identification in pathogens, parasites, vectors, reservoirs can be also observed in the way practitioners from the different fields preserve tissues, parasites and pathogens.

Human medicine early recognized the necessity to cryopreserve human tissues and pathogens. Preservation of materials allows improvement of screening, genetic studies and treatments.

Storage of voucher specimens from wildlife are usually realized in internationally recognized institutions like national natural history museums⁶. This also concerns parasites but more rarely microbes, which might be conserved in medical institutions when they are of zoonotic concerns.

Finally, parasites and pathogens of domestic animals seem not to be preserved in official and recognized institutions, apart from OIE collaborative centers (although their primary missions are diagnostic and control).

Ebanking and open databases

Several international and national databases are available (WHO, OIE, FAO, Gideon data base, etc) with some geo-referencing. Most of them concern reports of disease outbreaks and few give access to information

on tissues/pathogens/parasites preserved in specific institutions. This is once more particularly true for veterinary medicine and conservation medicine.

In the field of biodiversity, an informatics workbench, The Barcode of Life Data System (BOLD) has been developed to aid in the acquisition, storage, analysis and publication of DNA barcode records⁷. The project CERoPath ("Community Ecology of Rodents and their Pathogens in Southeast Asia", (www.ceropath.org) for reservoirs of rodent-borne diseases in South-East Asia is one example. By assembling molecular, morphological and distributional data, it bridges a traditional bioinformatics chasm⁸.

Pathogens research confronted with Ethics and Law

The ethical issues linked to research in infectious diseases are diverse and depend notably on: the source of material studied (animal, human), the storage of sample for future uses such as in the case of predictive medicine, or the activity of research itself.

The constitution of biobanks implies the notion of consent of the persons concerned. As stated in the Universal Declaration on Bioethics and Human Rights (2005) "*scientific research should only be carried out with the prior, free, express and informed consent of the person concerned*". The need of prior informed consent for a future storage and use of any removed part of a human body challenged the idea of the absence of proprietary rights over our body or body parts⁹. The notion of consent is assumed in Material Transfer Agreements (MTAs) signed in the case of transfer of research material in order to precise the use of the material and to define the rights over material and any derivatives. The example of the UK biobank, a long-term research resource, shows that the consent encompasses many aspects including the use of sensitive information, a possible link to the medical record, the confidentiality with anonymisation but giving a possibility to re-contact the participant in the future. It illustrates the necessity to clearly inform the

participants about the actual or potential uses of samples and to give him the right to withdraw.

Regarding animal health, ethics concerns should comprehend animal welfare and take into consideration animal suffering by enacting good laboratory practices and ultimately addressing the legal issues of animal rights.

In addition, the activity of research should respond to the ethical concerns of solidarity and mutual assistance¹⁰ and include the necessity for researchers to return benefits to providers.

Some ethical issues such as the prior informed consent or mutual agreement are integrated into the Convention on Biodiversity (CBD, 1992) in the article providing the access to genetic resources. The Convention also regulates the issue of benefit sharing and solidarity with a particular concern for the respect of traditional knowledge. In order to implement those provisions of the Convention, the Nagoya Protocol (2010) detailed the access obligations to be implemented at the national level insisting on the need to promote and encourage research contributing to biodiversity conservation and sustainable use. Concerning the benefit sharing obligations, the non-monetary part relates to the sharing of research results, transfer of technology or training and education. ASEAN urges the States to adopt national measures regarding the access to genetic resources and benefit sharing and to ensure its enforcement through institutionalized arrangements.

The monetary benefits should be shared with the provider and there should be a necessary trade-off between the legal protection of Intellectual Property Rights and the respect of benefit sharing, traditional knowledge and cultural biodiversity.

The "One Health" approach could help to turn those ethical and legal considerations into practical policies integrating the notions of equity and justice.

Conclusion

Based on supporting evidences indicating the zoonotic origins of those diseases, it appeared urgent to investigate the factors controlling the pathogens-human interface by addressing the "One Health" concept which integrates the study of human and animal health with conservation medicine as well as other disciplines that might influence those factors such as policy, law or ethics.

Moreover, important achievements should be accomplished in terms of barcoding (sharing protocols and concepts), biobanking (particularly for parasites/pathogens of animals and wildlife) and ebanking (access and sharing of geo-referenced data, collections and tissues).

Acknowledgments

The authors declare no conflicting financial interests. This study was funded by the French ANR CP&ES, grant ANR 11 CPEL 002 BiodivHealthSEA (Local impacts and perceptions of global changes: Biodiversity, health and zoonoses in Southeast Asia), and by the Bio-Asie program of the Agence Française de Développement (AFD) and CNRS for the PathoDivSEA project (Pathogen Diversity in Southeast Asia).

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Some Moral Questions on Genetic Science

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According to many the most promising frontier in modern medicine is genetic research. Genetic science finds its modern origin in Gregor Mendel, who in 1866 discovered the laws of heredity. The heart of this hard science comes from the secret of the nucleus. The nucleus of an organism possesses the chromosomes, which has the DNA (deoxyribonucleic acid) that serves as the very building blocks of life. The study of the DNA has propelled the advances made in genetic research. These advances have opened doors to many possibilities in medicine and patient care. But there are moral issues to consider.

Ethics and Genetics

According to John Harris, "ethical issues are raised by the use of embryonic cells, tissues, or other products and indeed the use of neonates and aborted fetuses as sources of therapeutic or experimental material".¹³ Scientists say that genetic research is vital. Today, it is modern medicine's most promising weapon in the battle against certain types of cancer, Parkinson's disease, Alzheimer's disease, diabetes and other degenerative genetic malignancies.

¹³ John Harris, *Clones, Genes and Immortality* (Oxford: Oxford University Press), 43.