Chapter 1
Ethics and Privacy Considerations for Systems Biology Applications in Predictive and Personalized Medicine

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ABSTRACT

Integrative analysis and modeling of the omics data using systems biology have led to growing interests in the development of predictive and personalized medicine. Personalized medicine enables future physicians to prescribe the right drug to the right patient at the right dosage, by helping them link each patient's genotype to their specific disease conditions. This chapter shares technological, ethical, and social perspectives on emerging personalized medicine applications. First, it examines the history and

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research trends of pharmacogenomics, systems biology, and personalized medicine. Next, it presents bioethical concerns that arise from dealing with the increasing accumulation of biological samples in many biobanking projects today. Lastly, the chapter describes growing concerns over patient privacy when large amount of individuals' genetic data and clinical data are managed electronically and accessible online.

INTRODUCTION

Predictive and personalized medicine based on the use of detailed genetic information is being regarded as a major development in modern medicine (Hood, Heath, Phelps, & Lin, 2004). Despite tremendous success in the past 50 years, conventional medicine which is based on observing and treating of patients' critical signs and symptoms at the physiological, organ, or pathobiological levels, has its limitations when treating complex, polygenic, and chronic disorders such as type-II diabetes, cancer, neurodegenerative diseases, and mental disorders. A primary reason is that, while treatment plans have been standardized, an individual's genetic background varies, the result of which is that some treatment work, some do not help at all and some actually harm. To cancer patients, for example, only by trial and error will the right regimen and drug dosage be eventually prescribed correctly, sometimes after long periods of receiving toxicological side effects or non-response. Genomics, pharmacogenomics, functional genomics, proteomics, and metabolomics—the so called "omics" technologies present biology and medicine with a new set of analytic tools to mine more deeply the genetic data contained in many types of biological molecules in biological samples (B. Palsson, 2002). Taken together, the potential for more integrative analysis and mining of the omics data with computer modeling techniques of multi-scale biological structure, or Systems Biology, have led to the creation of modern molecular medicine that is predictive and personalized (Aebersold et al., 2009). Many promising breakthrough drugs and biomarker molecules are being developed to improve targeted therapeutics of drugs, minimize drugs' side effect, and monitor clinical outcome of treatments. Given these development, it can be expected that more personalized "omic-based" medicine will be adopted as a standard clinical practice to improve health care quality and reduce health care cost (Naylor & Chen, 2010).

As we note below, systems biology aims to unify publicly accumulated knowledge of genes, proteins, molecular functional annotations, molecular interactions, and molecular measurements into integrated in silico models. Driven by advances in systems biology, personalized medicine is expected to gain wide-spread support for clinical adoption (Hood et al., 2004). It is expected that there will be concerns associated with the electronic storage, computerized processing, and online sharing of genomics and functional genomic information among biomedical researchers, health care providers, and patients. Ethical concerns about how this information may be misused or abused arise, as privacy concerns emerge about how to enforce patients' rights to protect their genetic information. In this paper, we provide a historical perspective on the emergence of predictive and personalized medicine, its relationship with systems biology, bioethics concerns when developing biobanks, and privacy considerations when dealing with large amount of electronic molecular medicine data.