

Chapter 13

Biobanking: Justice, Social Consensus, and the Marginalized

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ABSTRACT

It is important to recognize that the four “p”s - power, position, prestige and profit - too frequently drive science, business, academia, and the professions. This chapter is concerned with the importance of appropriate consent, the just distribution of the material benefits of scientific research, and the possible exploitation of research subjects. Informed consent and social consensus may not adequately address the related ethical issues involved in biobanking and other related research. Past experiences internationally, especially among the marginalized, are reviewed. The chapter explores whether benefits that accrue to those involved in research, and even the larger community, can rely on the concept of social consensus. Is there sufficient attention to transparency and adequate consideration of present and future harms and benefits to research subjects, their descendants and the broader community? Are conflicts of interest, real and potential, adequately acknowledged and addressed?

INTRODUCTION

There may be unsolvable dilemmas when “modern science” and its associated technologies have unanticipated or undesired social and economic impacts. It is possible that, although there may be benefits to individuals because of scientific and technological advancement, unanticipated, and even unrecognized, harm may result to those who

are initially benefited and their off spring. There may also be adverse effects on others, including contemporary more distant peoples, as well as future generations. Especially when genetic studies are undertaken, what should be considered are not just the potential benefits and harms, but also the belief systems, values, basic needs, and priorities of all affected parties. There are times when, because of the values and priorities of those involved, what may seem to be “scientifically appropriate” may not be ethically correct when all the individuals involved

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are considered. This concern extends not just to the measurable benefits, but also to outcomes that may be in conflict with, and disruptive to, alternative and traditional values and belief systems. Because something can be done does not mean it should be done.

It may be that the most *efficient* policy is to obtain a broad consent that anticipates and authorizes future scientific research and development. It is not at all clear that a policy of broad consent without adequate justification is the most *ethical* policy. At what point can the rights of the research subject trump potential benefits of research, especially when there is no feasible way to review the consent process? It can be argued, for example, that participants should maintain their right to request destruction of the material and to opt out, in advance, of any secondary research. Although it may be time consuming, a clear provision at the time of initial consent for possible future use of the material and results of the study is essential. Although it may not be possible to anticipate all potential uses and benefits, does the consent process consider the issue of possible future material benefit and financial gain?

Biobanking refers to the practice of creating a repository for biological material or data. The associated activities include the collection, storage, analysis, and distribution of the biological material or data. Although material or data may be included from animals, bacteria, or the environment, the material is typically from human sources and includes tissue and blood samples as well as relevant clinical data or records. A common goal of biotechnology firms is to obtain data that may result in marketable developments that will improve the health and well being of both the studied population and society in general. From the perspective of the biotech industry, indigenous peoples, for example, may offer valuable information about the treatment of certain diseases because of their genetic homogeneity, disease prevalence, diet, etc. Technology companies have at least two financial incentives to be involved in, and supportive

of, biobanking. By obtaining patents that secure the commercial rights over genetic material, any profits from pharmaceutical and other products developed typically go to the holder of the patent. In addition, future researchers who make use of the data must typically pay a fee.

Although the indigenous peoples represent only a relatively small portion of the population --or *because* they represent a small percentage of the population-- they should be of special concern. There are, in fact, several hundred million indigenous peoples throughout the world. The issues raised are relevant whether the studies are designed for ethnic studies, disease research, or both.

There are several reasons for geneticists to give special attention to indigenous populations. DNA from the indigenous populations is of particular interest to researchers because it may demonstrate genetic markers that have remained unaltered for many centuries. It is presumed that these groups have a more homogenous biographical ancestry than more diverse societies and that there is a higher probability of obtaining archetypal blood samples. This is of special interest to those interested in understanding the origin, migration, and history of humankind.

Another justification is the possibility that, through adaptation, indigenous groups may have developed specific genetic patterns that influence either their susceptibility or resistance to certain diseases. In addition their experiences with traditional medications may give clues to possible therapeutic interventions and associated pharmacological inquiries. The indigenous people may, and often do, actively resist involvement because of their history of past experiences, their fear of future exploitation, their sense of a low probability of benefits for them, and their different world views.

On the subject of the future use of specimens the World Health Organization (WHO) in its 1998 proposed international guidelines on ethical issues in medical genetics and genetic services stated that "specimens that could be useful to concerned

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