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BIOBANKING BETWEEN ETHICAL ISSUE AND PROVIDING TREATMENTS FOR PEOPLE

***Ibtihal Alahmadi and Christian Bach**

Biomedical Engineering Department, University of Bridgeport

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ABSTRACT

Health is very important for humans, but sometimes treatment of disease becomes necessary. People have faced cancer before, in the last centuries, but these days cancer is more widespread. Because of this scientists are trying to find treatments to cure cancer. They need to study cancer cells and genes and do research so it will lead them to get lots of results. They therefore decided to build a biobank as store for human samples. In this review I will explain how a biobank is very important for finding treatments; how people can understand the benefits they can derive from a biobank and how to encourage them to donate to biobanks. It is important that they know their rights as to keeping their information safe, and researchers must be able to answer donors' questions. My goal is to encourage people to donate to biobanks to build a huge database which will lead scientists to discover more and better treatments for disease.

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INTRODUCTION

When I decided to write this paper, I had the following goals in mind: cure cancer and find treatments for disease. At the same time I wanted people to maintain their privacy due to many reasons, be they religious, societal, or ethical. Biobanks around the world can provide a lot of input information for research by identifying the causes of disease and by identifying the causes of disease and by doing meta-studies. Biobanks are an important part in clinical and biomedical researches. Scientists need many samples with good quality and the best way to provide these is in biobanks. When collecting samples they should follow standard procedures. Before 1990 it was very hard to for scientists to collect samples and work in cancer research and research for other diseases, so they built a biobank. A biobank is a large collection of human samples to enable researches in genomics and diseases in general in order to find treatments and develop more technological devices. Also, the way of collecting the samples is very important for understanding the relationship between disease and environment, for example, in some diseases such as asthma one needs to study both the gene which causes the disease, and the environment. Many biological samples are collected for researches purposes, as we known most of laboratories take samples from people, these

samples could be blood or urine. Biospecimens are saved in biobanks for future use in biological resource centers. Tissues can be frozen or preserved in formalin when they are collected in a clinical laboratory and then be used for diagnosing disease and geomantic research. Many organizations develop standard procedures for collecting samples which also specify the condition the samples should be in (Vaught and Lockhart, 2012).

One of the most important developments in biobanks is the use of newborns' blood samples, but for ethical issues few people are accepting having research done on their babies. Dried Blood Spots technique (DBS) is an examination of infants for their dried blood spots which could help infants with high risk diseases to find treatment (Rothwell *et al.*, 2012).

Important factors in the development of biobank research

F1: Provide number of Collections

By collecting many samples, scientists can answer many questions about diseases. The way of collecting the biospecimen and its good quality is very important. Donor health is a good tools to build basic biobanks (Hens *et al.*, 2011; O'Doherty *et al.*, 2012). Scientists can share information about their collections; most samples are blood, urine, skin cells, and tissue. Biobanks keeps all these samples in a good state until scientists can use them in their research. They need to study the specific genes which cause cancer, so by having

***Corresponding author: Ibtihal Alahmadi**
Biomedical Engineering Department, University of Bridgeport

samples of organisms available they will not lose time during collecting information because the biobank provides all samples (Thomas *et al.*, 2008; Bardales Posas *et al.*, 2009).

F2: The integrity of database and information

This refers to issues like what is a good method to keep samples, and how to choose donors. I think it is very important that the donor understands the disease, especially if the disease, e.g. heart disease, breast cancer and Downs syndrome (Bardales Posas *et al.*, 2009; McCabe and McCabe, 2011), is widespread in their family. Scientists in this step record all data in electronics health records or HER to save the data and integrate patient life style with their disease (Späth and Grimson, 2011). Sometimes researchers collect blood samples from children and infants, which some parents accept. They can use blood, urine and skin tissue samples, which they then have to keep in good condition (De Montgolfier *et al.*, 2006).

F3: Give license to many organizations to share data

The importance of building many organizations is to allow scientists access to the biobank database and share their result with one another (Liu, 2011; Veen, 2008). All organizations around the world can share their databases; this is a good tool to find treatments for diseases. Around the world there are many organizations. It is a good way that organizations collect different samples; if governments would do this no one would donate as people are afraid their information might be used against them (Kaufman *et al.*, 2009).

is protected by scientists, more people will participate in biobanks (Kaufman *et al.*, 2009; Claerhout and DeMoor, 2005). Most people will do the same thing; no one will normally give his or her information without warranty that it is safe and without the knowledge of what will be done with the data collected. Participants will do exams like physical exams, biological exams, and give their health and life style information to biobanks. For example, UK biobanks gives donors the right to ask questions because they know trust is the cornerstone to build a successful organization (Editorial, 2009)

Ethical issues

The biggest challenge for biobanks are ethical issues due to the fact that society and religious minded people want to keep their information private. We have to measure input and outcome information before we decide if the biobank is against our humanity or not (O'Doherty *et al.*, 2012). I am sure the advantages of biobanks are greater than their risks. If we want to balance the advantages such as available treatments with the risk, for example loss of privacy, treatment will win in the end. In ethics we have to distinguish between what is good what is good and what is bad for people's health (Knoppers and Zawati, Biobanks, 2012; Haga and Beskow, 2008). Policies around the world may impact the development in biobank research due to strict rules and regulations or as to how scientists are to take patient approval. Researchers collect the information for future research and donors will not get approval for specific research. Furthermore, building strong role models for ethical biobank research is important.

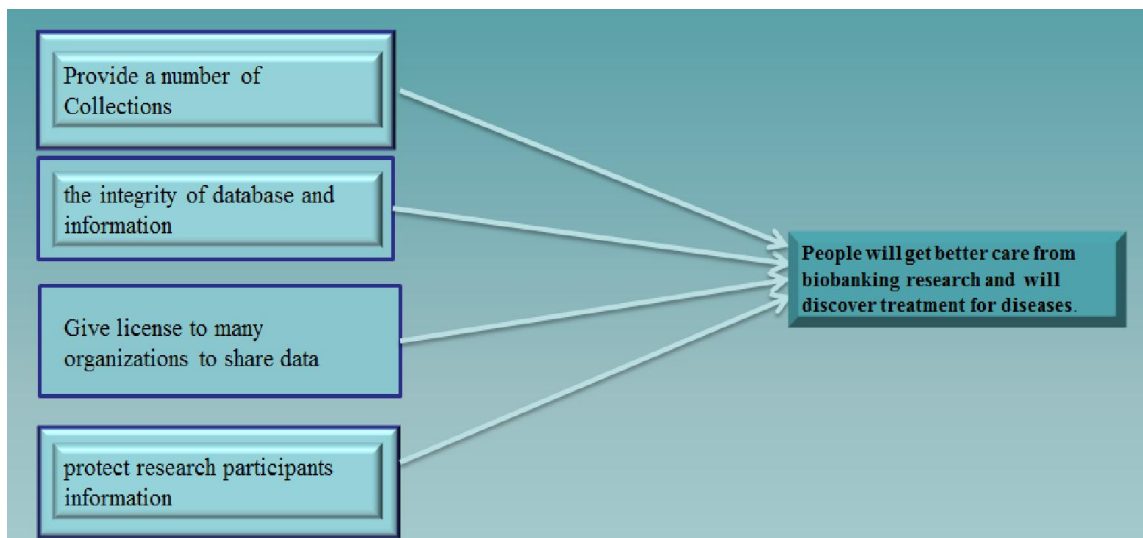


Figure 1. Biobanking between ethical issue and treatment

F4: Protect research participants information

Privacy concerns issues like data protection after people have given their information, unwanted contact with other, and how this information can be used (Bansal *et al.*, 2010). The desire for privacy makes people unwilling to share their information with others, such as biobanks. Scientists should understand these scares and find appropriate ways to collect the information from people. People should be asked first if they want to participate in biobank research, and informed about their right to privacy and about sharing their information. As long as participants in biobanks are sure that their information

When donors are participating in research, they have a right to privacy under the concept of human ethics. Patients should know what the exact reason for the research is and, then what kind of future research could happen on their donated samples. As concerns future research, taking the approval is good ethically and it should happen by making personal information safe, giving donors the right to withdraw their approval, and any change or new research studies should be accepted by an ethics review board. Donors should know that by giving their approvals for using their samples or blood, they allow biobanks to legally do multiple future research (Hansson *et al.*, 2006). For example, when researchers want to study cancer,

they found it difficult because they could not identify the genetic risk factors due to the lack of information. Vilhjalmur Arnason said that “the more general the consent is the less informed it becomes. It is misleading to use the notion of informed consent for participation in research that is unforeseen and has not been specified in a research protocol” (Árnason, 2004). So what kind of information the biobank can use depends on the procedures of scientists and the approval from patients and the risks involved in the research of the research (Hansson *et al.*, 2006). Research ethics include the application of primary ethical principles to many better: to many areas, for instance to the clinical field. There are many arguments in biobank research, for example that biobank researchers do not need to get donors' approval for using their samples, and that information for every research should be for specific, approved by donors, and that there should be evidence of bio bank researchers respecting donors' wishes. The research can be done as long as arguments like these do not endanger the quantity and quality of research. The problem here is should biobank researchers have to ask donors in each study if their approval is still valid? That will lead to a decrease in the number of donors. Most donors know it could take biobank researchers a long time to find treatments, and the possibility that their related diseases tissues are studied is low. The good thing in biobank researches for donors is that they will get the benefit of medical progress. Scientists should be encouraged to introduce biobank research to our community and allow researchers to get donors samples and get their approval for all kind of research (Hansson *et al.*, 2006). Some studies found that donors want to know what the specific research which happens with their samples is, and others want to know what the future research which could happen on their samples will be, in order to give their approval for biobank research.

withdraw their approval, which does not mean withdrawing old results, but that new research with donors samples cannot be done (Hansson *et al.*, 2006)

How Could Donors Trust Researches?

What is trust? It is a state of mind of what a person expects during an interaction with another or others, such expectation being getting a benefit and not suffering harm. , Trust can increase or decrease as a result of human interaction with one another (Thiede, 2005). This leads to failure and distrust when we want protect our cultural values. Trust is a social experience for all people, it is in our humanity, our roots, and we cannot ignore this is fact, we might depend on it in harmful, emotional, or physicals experiences (Thiede, 2005). Scientists should encourage people to donate, by media, education, through the respective departments of health and other organizations. We cannot succeed with biobank research without finding a lot of samples, as long as we can provide many samples we can find treatments and develop many ways to understand cancer cells. Refraining from giving health information could impact the development of biobanks. Scientists need to enhance biobank databases, but the problem is how do they make people trust them? For most people, the issue of trust revolves around the kind of information, the sensitivity of the information, and the privacy (Bansal *et al.*, 2010). Donors want to know what their rights are in their information privacy; we can describe information privacy as determining their information and the limit of giving this information to others (Bansal *et al.*, 2010). If people trust, scientists' biobank research will succeed, because they will donate to biobanks and give their samples. When scientists and researchers make agreements with other organizations to develop ways for keeping donor information safe, many people will trust biobank research.

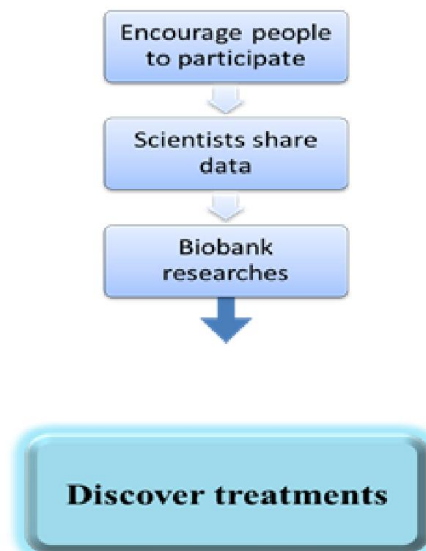


Figure 2. shows the importance of biobanks

Actually, a broad conception of the issues will limit biobank research (Hansson *et al.*, 2006). In my opinion, the problem in biobank research is covering the purpose of the research, and that donors should know where biobanks could use their samples, because a broad approval could lead to consumption of donor samples, or to use of samples in commercial or in political applications. Donors should have the right to

For example, some countries such as the United States established large organizations to manage health information for patients such as Health Insurance Portability and Accountability (HIPAA) (Damschroder *et al.*, 2007). If we look inside normal health information in any hospitals, no one is allowed to access patient information without permission. Due to the large number of medical records and the permission

issue, it is difficult for researchers to access to patient information. Also for each study patient permission must be obtained. Furthermore, even if researchers reach patients, they still need to get waivers from standards requests, all this leads to less health services research (Damschroder *et al.*, 2007).

Research methodology

In this paper I used the UB database; it was a good tool for me because it gives access to important science journals such as Science Direct. It was a good way for researching my factors. In my factors I explained how important these data are and how scientist can collect their information for clinical proposes. All factors that I found have a positive effect on the development of biobank research. Privacy is a strong factor, and as long as the donors' trust in the organizations and the scientists can be maintained, the research will succeed. My goal is finding many treatments for diseases and I start looking for that in, for example, the question of what is the gene which causes breast cancer and how could the researchers make sure to find it. They need very many samples to do experiments on, and time is necessary to build huge collections with these biological specimens. Some diseases are growing in certain environments, or could it be that the environments affect the gene in these diseases.

Then I propose ways of how we can build huge data bases, which we need together with many samples, which is hard work. We have to encourage people to donate. The problem is people will not give their information without being sure why scientists collect their data: will the researchers use their details against them in future, can a person withdraw his or her information after giving it. They need to know their rights and as long as they believe they will donate (Deng *et al.*, 2011; Posas Fabio *et al.*, 2009). There after that I am considering what the impediments for people are to give their samples, and the result was privacy and ethical issues. So I believe if the donors know their rights from the beginning, they will give their data.

Conclusion

Biobanks are a good way to discover treatments for many diseases; they should lead to people living long healthy lives. Many countries regard biobanks as a serious way for providing treatment, for instance South Korea, Taiwan, USA, China (Heysa *et al.*, 2011). Even though the environment is very important, when scientist start to collect information about donors, they have to know about their environment, for example, some disease such as asthma starts from the genetics of a person, and sometimes from their environment (Hens *et al.*, 2011). We cannot talk about biobank research without mentioning some benefits of this research, for example: in cancer research due to the development in the technology and the number of donors; this will lead to discover many treatments for cancer. Through biobank research, the world discovers many things such as the genetic heterogeneity of acute leukaemias by biobank samples (molecular cytogenetic). Biobank research, by taking samples from large families, discovered the relation between breast cancer and genes. They confirmed the relation between the human papillomavirus and cervical cancer (Hansson *et al.*, 2006).

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