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**Medical and Professional Ethics**

# **Biobank Ethics**

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# Outline

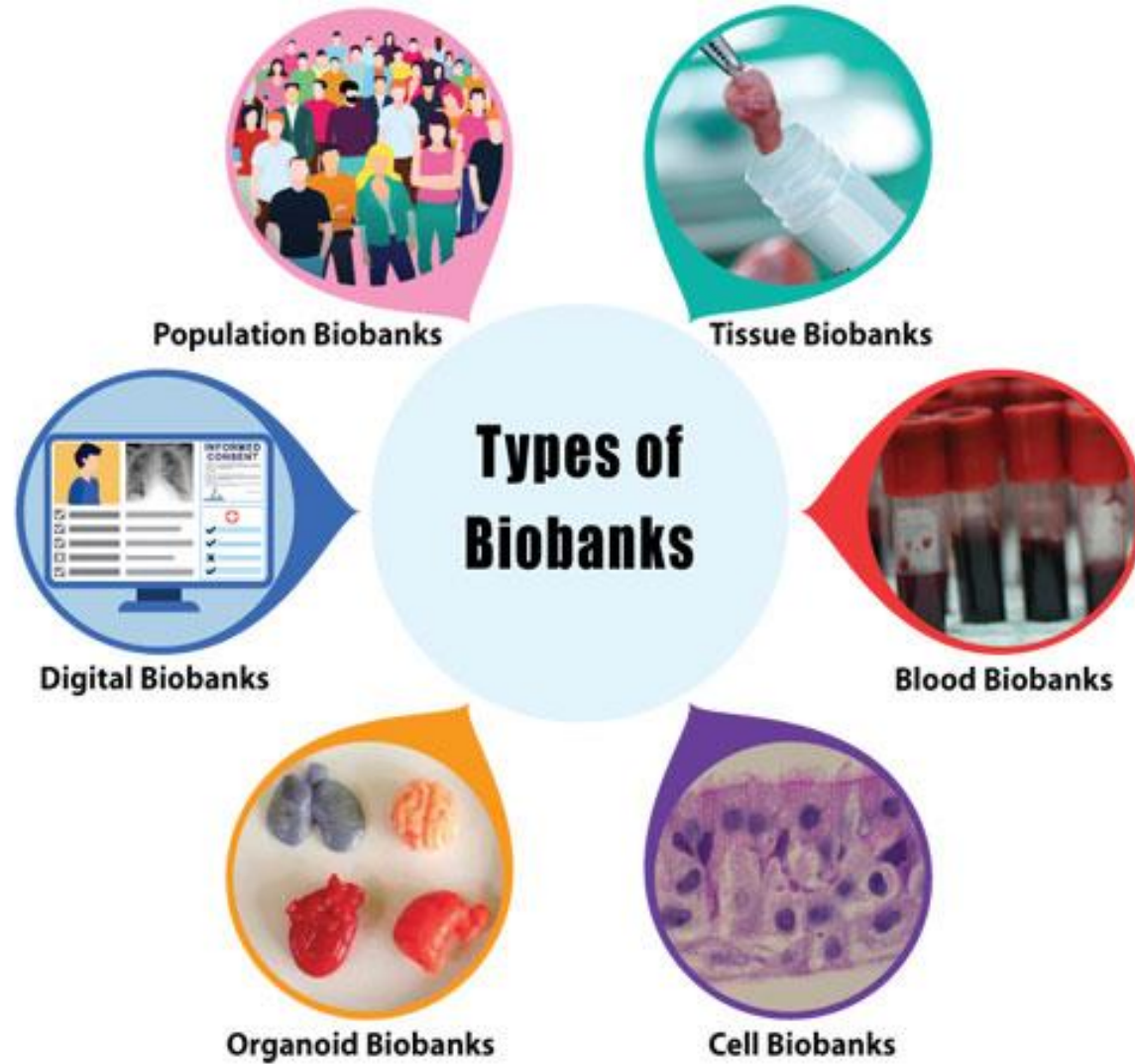
- **Definitions**
- **Importance of bioethics**
- **Types of bioethics**
- **Difference between bioethics and biorepository**
- **Ethical issue of bioethics**
- **Ethics of biobank**

## Definition

A **biobank** is generally defined as a collection of human biological samples (such as blood and tissue) and medical information about the people who gave their samples.



# Types of Biobank



# Importance of biobank

It has been widely used for cancer prevention, detection, diagnosis, and treatment on a worldwide scale and has evolved into an important element of personalized medicine.



# Importance of biobank

Bio banks will undoubtedly revolutionize research, advancing genetic studies and identifying future drug targets



# The purpose of biobanking

Bio banking is the process by which samples of bodily fluid or tissue are collected, annotated, stored and redistributed for research to improve understanding of health and diseases.

# Biobank VS Biorepository

**Traditionally, collections of human biological material are referred to as 'biobanks', while biorepositories refer to collections of specimens from all living organisms. This distinction, however, has been overlooked in the past, with animal tissue repositories also being termed as biobanks by some groups**

Several ethical concerns exist, **Materials collected, stored, shared, transported, or studied in biobanking are often de-identified to protect donors**, implying that biobanking is low risk and that de-identifying materials provides adequate protection to donors

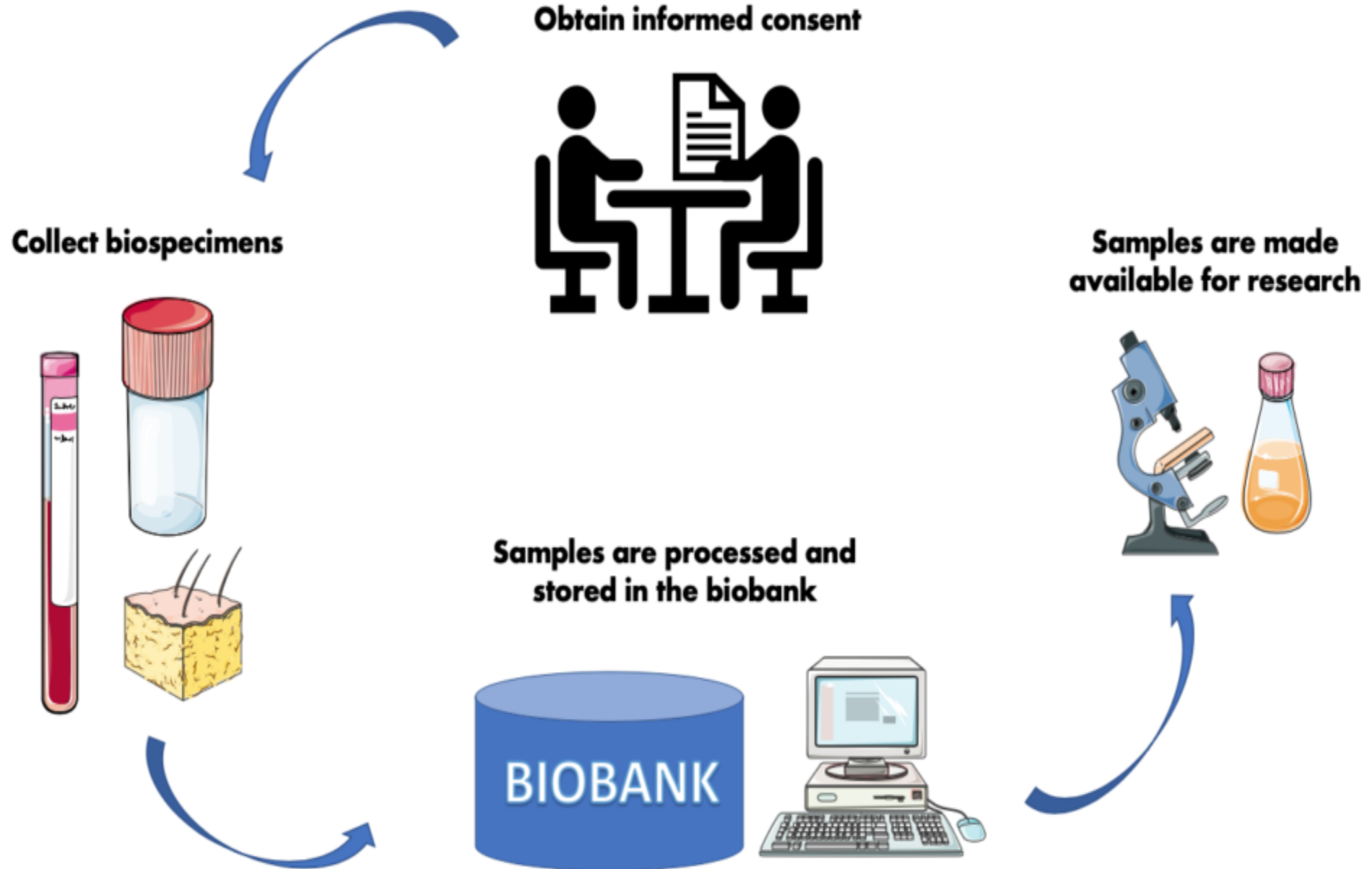
# How many biobanks are there in the world?

There are **more than 120** biobanks worldwide, having evolved over the past 30 years.

They range from small, predominantly university-based repositories, to large, government-supported resources.

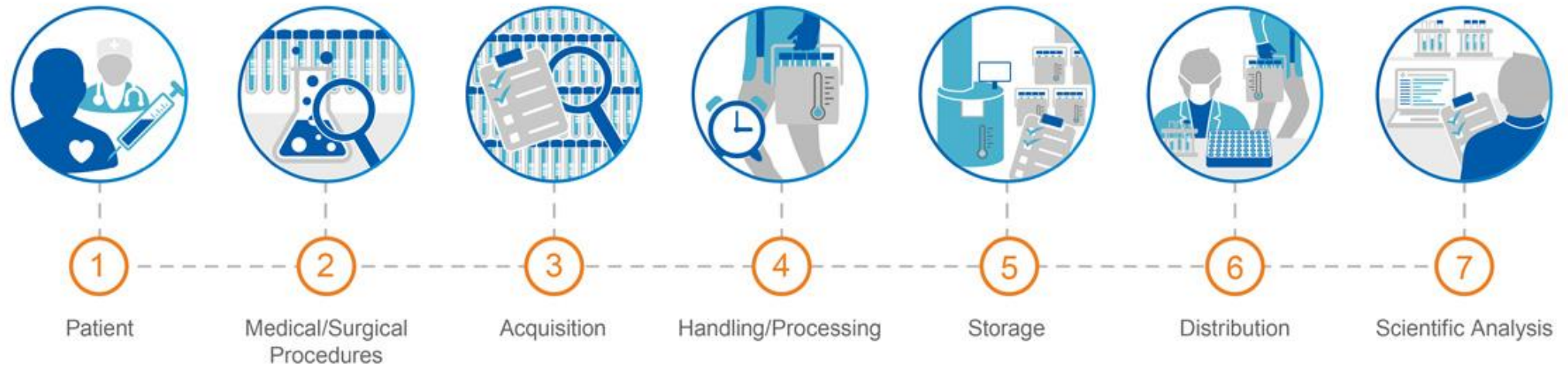
## Key ethical issues in biobanking include:

1. Respecting research participant autonomy
2. Informed consent
3. Ethical considerations for return of results
4. Data privacy and donor confidentiality
5. Data storage and consent
6. Diversity in biobanking to promote equity



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# Biobanking Process



# Biobanking Ethics



# Biobanking ethics

## 1. Informed Consent

Informed consent is crucial in ensuring that ethical standards are followed in both research and therapy.

It ensures that the participant understands “**the nature, duration, and purpose** of the experiment; the method and means it is to be conducted; all inconveniences and hazards reasonable is to be expected; and the effects upon the individual’s health may be due to the participation in the experiment.”

# Biobanking ethics

## 2. Broad Consent

There are some experts who believe that broad consent can be a potential solution to the issues of informed consent in biobanking. However, there are some who disagree as it offers minimal protection and minimal guarantees. Broad consent is the permission given by the donor for the biobank,

# Biobanking ethics

## 3. Confidentiality

One of the main features of genetic information is that it can be used to identify the donor and those related to them. While ethicists argue that identification can be discouraged through various methods of anonymization, there is always the possibility that identification is possible.

# Biobanking ethics

## 4. Property and Profit

There is also the issue that participants or donors do not own their tissue samples.

Ethicists have argued that there are valid reasons for following the “no property” rule for biospecimens. Allowing property would restrain studies and research to the point where it would become untenable.

# Biobanking ethics

## 5. Feedback To Participants

Another ethical issue is whether or not to tell participants regarding incidental findings from their donated tissue samples. Incidental findings can be defined as “observations of potential clinical significance that have been discovered unexpectedly in a healthy subject unrelated to the purpose and variables of the study.”

## Biobanking ethics

### **6. Participation, Representation, Maintenance of Trust**

Biobanks are also worried about the mass withdrawal of participants as it will ultimately result in the loss of set-up costs. The maintaining of trust between the public and biobanks are crucial to prevent participant withdrawal and biobank failure.

# Biobanking ethics

## 6. Re-contact

Re-contact is becoming an increasingly crucial issue as there is very little industry conformity on how re-contact should be managed.

# **NO MAN IS A MAN WITHOUT HIGH MORALS AND ETHICS**

MEHMET MURAT ILDAN

