**The sample questionnaire used in the study is attached here:**

**Title of the study:**

**The awareness and perception about the Ethical concerns related to the Biobanks among medical and dental practitioners- a questionnaire based survey**

The aim of this study is to assess the knowledge and perception of the existence, objectives and specially the ethical concerns related to the Biobanks.

I am a research scholar from Center Of Ethics, would request you to kindly take a few minutes to read about the Biobanks and answer a few questions related to it. Here is a brief description provided about the Biobank, in the sense about the origin, existence, aims and objectives of it along with the challenges that they are facing in the current scenario.

A Biobank is a type of [biorepository](https://en.wikipedia.org/wiki/Biorepository%22%20%5Co%20%22Biorepository) that stores biological samples (usually human) for use in research. Since the late 1990s Biobanks have become an important resource in medical research, supporting many types of contemporary research like [genomics](https://en.wikipedia.org/wiki/Genomics) and [personalized medicine](https://en.wikipedia.org/wiki/Personalized_medicine). Biobanks give researchers access to data representing a large number of people. Samples in Biobanks and the data derived from those samples can often be used by multiple researchers for cross purpose research studies. Thus, in the recent few years Biobanks have undergone rapid proliferation and have become increasingly complex. An increasing trend in Biobank research is to pool collections of biological samples in international scientific studies, thereby amplifying their potential scientific value. The pooling of samples, however, poses several challenges to national/international legislation and ethical guidelines relevant to Biobank samples and also introduces new issues for patient/donor interests.

With this brief introduction about Biobank, you are kindly requested to answer this questionnaire.

The choice you have for few questions is to decide whether you agree or disagree to the statement and to what extent by rounding off the appropriate number. The remaining questions can be directly answered by putting a tick across your choice.

**Strongly agree** (1), **Agree** (2), **Don’t know** (3), **Disagree** (4), **Strongly disagree** (5)

**Part 1: Awareness about the Biobanks**

1**.**Biobanks store the biological materials and therefore are also called **'DNA Banks' or 'Bio Banks'.**

YES NO DON’T KNOW

2. Biobanks are infact commercial centers for storage of blood **ONLY.**

YES NO DON’T KNOW

3. A Biobank is just a Non profit organisation for storage of plants and animals **ONLY**.

YES NO DON’T KNOW

4. Biobanks need large number of samples in order to ensure the **accuracy** of research results.

YES NO DON’T KNOW

5. **Biobanks are supposed to run for a shorter period ONLY**

YES NO DON’T KNOW

**Part 2: Perception based questions**

6. Do you think that a Biobank could be a nationally or internationally recognized center for the advancement of **medical research.**

YES NO DON’T KNOW

7. The objective of biobank, do you think is to help in exchange of biological materials among the different centers for commercial interest **ALONE**.

YES NO DON’T KNOW

8. Do you agree that the Biobanks are set up so that researchers can examine DNA and try to establish how **faults in DNA** cause diseases.

YES NO DON’T KNOW

9. Do you agree with the fact that their whole objective is to carry out only single gene mutation studies **ALONE.**

YES NO DON’T KNOW

10.According to you storing the bone marrow sample from the individuals could be one of the **objectives** of these Biobanks..

YES NO DON’T KNOW

**Please rate the following questions according to the severity of your agreement.**

**Strongly agree** (1), **Agree** (2), **Don’t know** (3), **Disagree** (4), **Strongly disagree** (5)

11. The most common aims of Biobanks include *t*reatments for the most common genetic disorders, development of personalised medicine as well as stem cell research including regular health surveys.

 1 2 3 4 5

 12. Do you think that Biobanks are **safe to join** as there is only a tiny physical risk of sample taking which is a very simple procedure.

 1 2 3 4 5

## **13.** Supposing if the Biobank closes down, Do you think all the samples stored there should be just transferred to another Biobank

1 2 3 4 5

14. In the above question, Do you think all of them should be **just destroyed**?

1 2 3 4 5

**15. Do you think, a Biobank for its efficient progress and better scientific research results should look to recruit the following types of volunteers. Please rate them according to your perception.**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Type of recruitements** |  **1** |  **2** |  **3** |  **4** |  **5** |
| **Individual volunteers** |  |  |  |  |  |
| **Group of same family members** |  |  |  |  |  |
| **Twins** |  |  |  |  |  |
| **Different nationality individuals** |  |  |  |  |  |

**Part 2: Ethical concerns about the Biobanks**

16. In case if you decide to join a Biobank, Do you think your consent should be a taken as a **general consent** for all different types of research they want to do with your tissue sample ?

1 2 3 4 5

17. Or Do you think the consent should be taken as individual separate consent for every different type of research they would like to do using your donated sample?

1 2 3 4 5

18. Do you think, the Biobanks should give you a **free choice** to consent or refusal for each type of research they would do using your sample tissue **every time ?**

1 2 3 4 5

19.Do you think**,** you can **TRUST** these Biobanks for your sample you donated not to be used by them for the research you have not consented for?

1 2 3 4 5

20. If the research by the Biobank where you have donated your sample, has found you to be having a **very rare genetic disorder** which is **not curable** by the latest therapies available. In that case would like to be told you about that?

 1 2 3 4 5

21.In the above question, Do you think you should be informed if the disorder is **curable enough?**

 1 2 3 4 5

22. Do you think the information about your donated tissue samples research results by the Biobank should be **shared** ? If **yes**, with whom? Kindly show your degree of consent for the following choices given.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Shared with whom?** |  **1** |  **2** |  **3** |  **4** |  **5** |
| With you only |  |  |  |  |  |
| With your family only |  |  |  |  |  |
| With your relatives only |  |  |  |  |  |
| With researcher only  |  |  |  |  |  |
| Every one registered in the same Biobank |  |  |  |  |  |
| Among other Biobanks |  |  |  |  |  |
| With police for public safety concerns |  |  |  |  |  |
| With insurance companies |  |  |  |  |  |
| Should be published  |  |  |  |  |  |
| Agree for **ALL the choices** given above  |  |  |  |  |  |

23. Do you think, you should be allowed to **leave** a Biobank after you have joined one ?

1 2 3 4 5

24.The Biobanks should give direct benefit such as better medicinal care or financial rewards in almost **every participant** case?

1 2 3 4 5

**Part 3: Ownership issues**

25. Please rate the following, for the **Ownership claim**  (Intellectual property) about the research results of the specimen that you have donated to a Biobank.

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Ownership claim by** |  **1** |  **2** |  **3** |  **4** |  **5** |
| Donor only |  |  |  |  |  |
| Researcher only |  |  |  |  |  |
| Biobank only |  |  |  |  |  |
| Donor and Biobank |  |  |  |  |  |
| Researcher and Biobank |  |  |  |  |  |
| Donor and researcher |  |  |  |  |  |

26. Do you agree if your donated samples to be stored in the Biobanks even **after your death** for the altruistic nature towards the betterment of the society?

1 2 3 4 5

27. Or Do you agree if your samples to be destroyed **after your death**?

1 2 3 4 5

28. Would you like to **donate your specimen** to Biobank for the scientific research?

YES NO DONT KNOW

29. If **YES**, please show your degree of agreement or disagreement for the following specimens

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Type of specimen |   1 |   2 |  3 |  4 |  5 |
|  Blood only |  |  |  |  |  |
| Skin only |  |  |  |  |  |
| Eyes only |  |  |  |  |  |
| Teeth only |  |  |  |  |  |
| Ova/sperm only |  |  |  |  |  |
| Heart only |  |  |  |  |  |
| Brain only |  |  |  |  |  |
| Don’t mind donating every part of your body  |  |  |  |  |  |

30. Would you like to recommend your **family members** for any tissue sample donation?

YES NO DONT KNOW

31. Would you like to encourage your **patients** about the same?

YES NO DONT KNOW

 Thank you for your valid participation in the study