## DEMOGRAPHIC INFORMATION

1. What is your gender?

Female

Male

2. What is your race?

Please choose only one of the following:						
Black						
White						
Coloured						
Indian						
Other (please specify)						
3. Highest degree attained						
PhD						
MMed						

$\bigcirc$	PhD
$\bigcirc$	MMed
$\bigcirc$	MPhil
	MSoc Sci
	MSc
	MBChB
	Honours
	Bachelors
Oth	er (please specify)

# 4. What is your institution of affiliation?

Please choose all that apply:

University
Research institution
Hospital/Health facility
Public Health
Repository/Biobank
Other academic institution

Other (please specify)

5. What is your most frequent work activity?

Please choose only one of the following:

	Research
$\bigcirc$	Clinical
$\bigcirc$	Academics/Lecturing
	Administration
	Not applicable
Othe	er (please specify)

6. Have you ever participated in research involving the collection, storage and future use of human biological materials? *Please choose only one of the following:* 

$\bigcirc$	Yes	
$\bigcirc$	No	

7. What is/was your role in repository/biobank research?

Please choose all that apply:

	Principal investigator
	Co-Principal Investigator
	Researcher
	Clinician
	Pathologist
	Laboratory/Repository personnel
	Bioethicist/REC member
Othe	er (please specify)

8. How long have you been involved in repository/biobank research?

#### Please choose only one of the following:

	Never been involved
$\bigcirc$	Less than 1 year
$\bigcirc$	1-2 years
$\bigcirc$	3-5 years
$\bigcirc$	6-9 years
	More than 10 years
9. H	lave you ever served on a Research Ethics Committee?

Please choose all that apply and provide a comment:

Yes

No

10. If yes for how long?

## **INFORMED CONSENT**

This section explores your perspectives on informed consent in human research that involves the collection, storage and future use of human biological specimens.

Please indicate your level of agreement with each statement on a scale from strongly agree to strongly disagree.

11. Studies that involve the storage of human biological materials for future research require separate informed consent forms for the current study and another one for each new study using the stored sample.

Please choose only one of the following:

Strongly Agree
Somewhat Agree
Neutral
Somewhat Disagree
Strongly Disagree
Don't know

The next set of questions is about broad consent and general consent.

In <u>general consent</u>, at the time of sample collection participants consent for the use of their samples in any and all future studies with no restrictions on the purpose of the research.

In <u>broad consent</u>, at the time of sample collection participants consent for the use of their samples in the current study and a wide range of future research studies based on a broad category and whose specifics are unknown.

12. What is your opinion on the type of consent that is applicable to biobank-related research?

Please choose the appropriate response for each item:

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## 13. I believe it is ethically necessary to obtain re-consent from research participants if:

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	Disagree			Strongly Disagree	
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14. In case re-consent is not possible would REC approval for all new studies suffice?

Please choose only one of the following:

Yes

No

#### **INFORMED CONSENT**

#### The following questions address consent and assent from minors (< 18 years)

15. Please indicate your level of agreement with each statement on a scale of "Strongly agree to Strongly disagree".

Please choose the appropriate response for each item:

	Strongly Agree Disagree		Neutral	Somewhat Agree Somewhat Strongly Disagree	
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implications of biological sample storage and genetic research, he/she must be allowed to assent (give permission).			

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16. From which age do you think children can understand the implications of storage of biological samples for future genetic research?

Please choose only one of the following:

$\bigcirc$	0-3 years
$\bigcirc$	4-6 years
$\bigcirc$	7-9 years
$\bigcirc$	10-12 years
	13-15 years
	16-18 years

17. From which age do you think children can understand the implications of genetic research?

Please choose only one of the following:

$\bigcirc$	0-3 years
$\bigcirc$	4-6 years
$\bigcirc$	7-9 years
$\bigcirc$	10-12 years
	13-15 years
	16-18 years

## HUMAN PARTICIPANT PROTECTION

This part is about the protection of human participants in research involving the use of their biospecimens.

18. For the following questions where the term "coded" is used, it refers to deidentified/anonymized specimens, samples, or data in which the original investigator maintains a linkage file (with study numbers and personal identifiers) separate from the specimens/samples/data. This linkage <u>would not</u> be available to other investigators.

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	Disagree		Neutral	Strongly Disagree	
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#### Please choose the appropriate response for each item:

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19. We would appreciate your opinion concerning the following statements.

Please indicate your level of agreement with each statement on a scale of very likely to very unlikely.

Identifiability and possible harms:

Please choose the appropriate response for each item:

	Very Likely		Neutral	Somewhat Likely Somewhat	
	Unlikely		Neullai	Strongly Unlikely	
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20. Improper handling of research results can cause harm to the community from which a sample donor belongs

Please choose only one of the following:

$\bigcirc$	Strongly Agree
$\bigcirc$	Somewhat Agree
$\bigcirc$	Neutral
$\bigcirc$	Somewhat Disagree
$\bigcirc$	Strongly Disagree
$\bigcirc$	Don't know

## **REC REVIEW PROCESS**

This section addresses the ethics review process.

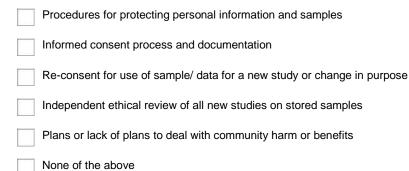
21. Which of the following issues (if any) have required considerable discussion between researchers and REC in the review of research involving the future use of biospecimens e.g genetic research? By 'considerable discussion' we mean more than 2 or 3 back-and-forth rounds and/or more than a 1-hour conversation

#### Please choose all that apply:

Procedures for protecting personal information and samples	
Informed consent process and documentation	
Re-consent for use of sample/ data for a new study or change in purpose	
Independent ethical review of all new studies on stored samples	
Plans or lack of plans to deal with community harm or benefits	
None of the above	
Other (please specify)	

22. Which of the following issues (if any) have required considerable discussion between researchers and REC in the review of research involving the future use of biospecimens e.g genetic research? By 'considerable discussion' we mean more than 2 or 3 back-and-forth rounds and/or more than a 1-hour conversation

Please choose all that apply:



### **CHALLENGES IN ETHICS REVIEW**

We would appreciate it if you answered the following two questions

23. Have you ever had any challenges in the ethical review of research involving the use of HBM?

Please choose only one of the following:

$\bigcirc$	Yes

No

24. If yes what challenges did you face? Suggests ways in which such challenges can be overcome?

Please write your answer here:

25. What is your opinion on the export and sharing of biological specimens and associated data e.g in genetic research?

Please write your answer here:

26. Thank you for participating in this study, if you choose, please feel free to offer any comments you would like to share with us