Welcome to My Survey

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
- ◯ MPhil
- ◯ MSoc Sci
- ◯ MSc
- ◯ MBChB
- ◯ Honours
- ◯ Bachelors

Other (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
- ◯ Clinical
- ◯ Academics/Lecturing
- ◯ Administration
- ◯ Not applicable

Other (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:

- ◯ Yes
- ◯ 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

Other (please specify)

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

Please choose only one of the following:

- ◯ Never been involved
- ◯ Less than 1 year
- ◯ 1-2 years
- ◯ 3-5 years
- ◯ 6-9 years
- ◯ More than 10 years

9. Have 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:

	Strongly Agree			Somewhat Agree		
			Neutral		Somewhat disagree	Strongly Disagree
The use of abroad consent for research that anticipates	○	○	○	○	○	

p
a
t
e
s
f
u
t
u
r
e
(
u
n
k
n
o
w
n
)
r
e
s
e
a
r
c
h
s
t
u
d
i
e
s
i
s
a
c
c
e
p
t
a
b
l
e
.
A
ge

neral consent should only be accepted when samples are anonymous.	○	○	○	○	○
A research participant has the right to establish limits regardi	○	○	○	○	○

ng the research that can be done using his or her tissue.

The limitss hould apply even after the tissss

	Strongly Agree	Somewhat Agree	Neutral	Somewhat Disagree	Strongly Disagree
The research was conducted anonymously	○	○	○	○	○

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

Please choose the appropriate response for each item:

	Strongly Agree	Somewhat Agree	Neutral	Somewhat Disagree	Strongly Disagree
The researcher was	○	○	○	○	○

nts to investigate a different, but related, condition or clinical manifestation.

The researcher wants to investigate an unrelated condition or

clinical manifestation.	○	○	○	○	○
The researcher wants to add genetic measures to a study that did not originally include them.	○	○	○	○	○

The researcher wants

to share the participant's de-identified sample or data (without a linkage file) with an investigator at another institution.

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	Somewhat Agree	Neutral	Somewhat Disagree	Strongly Disagree
Parental consent is sufficient for storage of biological samples for genetic res	◯	◯	◯	◯	◯

ear ch of an y chil d wh o ca nn ot as se nt (gi ve per mi ssi on) be ca us e he/ sh e ca nn ot un der sta nd the nat ure of res ear ch.

Once a child can understand the implications of biological sample storage and genetic research, he/she must be allowed to assent (give permission).	○	○	○	○	○
	○	○	○	○	○

A child should have the right to withdraw their biospecimen/data from a repository when he/she is 18 years old.

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:

- ◯ 0-3 years
- ◯ 4-6 years
- ◯ 7-9 years
- ◯ 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:

- ◯ 0-3 years
- ◯ 4-6 years
- ◯ 7-9 years
- ◯ 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 de-identified/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 would not be available to other investigators.

Please choose the appropriate response for each item:

	Strongly Agree	Somewhat Agree	Neutral	Somewhat Disagree	Strongly Disagree
The storage of human biological specimens and data	○	○	○	○	○

a
t
a
f
o
r
f
u
t
u
r
e
g
e
n
e
t
i
c
r
e
s
e
a
r
c
h
i
s
a
c
c
e
p
t
a
b
l
e
a
s
l
o
n
g
a
s
t
h
e
y

areanonymized.

Apartic ipant whodonatesbloodforscientific

research ethics committee oversight is/herblood.	○	○	○	○	○
Use of coded human tissue spe	○	○	○	○	○

cim
ens
con
stit
ute
s
hu
ma
n
sub
ject
res
ear
ch
(As
su
me
res
ear
che
rs
do
not
hav
e
acc
ess
to
the
link
bet
we
en
the
ori
gin
al
an
d
cod
ed
dat
a).

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			Somewhat Likely	Neutral	Somewhat Unlikely		Strongly Unlikely
How likely is it that a research participant	○	○	○	○	○	○	○	○

w
o
u
l
d
b
e
p
e
r
s
o
n
a
l
l
y
i
d
e
n
t
i
f
i
e
d
i
n
a
s
t
u
d
y
i
n
v
o
l
v
i
n
g
c
o
d
e
d
d
a

t
a
?

H
o
w
li
k
e
l
y
i
s
it
t
h
a
t
a
r
e
s
e
a
r
c
h
p
a
r
ti
c
i
p
a
n
t
w
o
u
l
d
b
e
h
a
r
m
e
d

as a result of identification from coded data?					
How likely is it that a govern m					

enforcement agency or other law enforcement agency might compel investigators to disclose information about genetic research

ch
pa
rti
ci
pa
nt
s?

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:

- ◯ Strongly Agree
- ◯ Somewhat Agree
- ◯ Neutral
- ◯ Somewhat Disagree
- ◯ Strongly Disagree
- ◯ 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:

- [ ] 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

CHALLENGES IN ETHICS REVIEW

We would appreciate it if you answered the following two questions

1
1

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:

- ◯ 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

1
2