## **Consultation Questions:**

Please see listed below the questions as they will appear in the Consultation Feedback Form:

Although there are only 6 main questions (in Sections 3 & 4), we are asking for text-based responses, therefore please ensure you allow sufficient time to complete the form in one sitting.

### Section 1

## **About You**

- 1) Please enter your Name
- 2) Please confirm your Job Title
- 3) Please enter your organisation name
- 4) Please confirm if you're responding as an individual or on behalf or your organisation?
- 5) Please confirm your type of organisation
  - a. Governing ¬Body
  - b. Funder
  - c. Private Biobank
  - d. Public Biobank
  - e. Patient Representative
  - f. Other
- 6) If OTHER, please give details

#### Section 2

## Consultation questions

- 7) In this document we set out a Vision for biobanking in the UK A data driven biobanking ecosystem that:
  - operates to open standards;
  - embraces and drives open science;
  - embeds public-led decision making;
  - re-uses infrastructure to drive sustainability; and
  - focuses on simplifying and streamlining access procedures

Do you think this Vision statement sets out the right priorities for biobanking over the next ten years? Please explain.

- 8) In the document we set out a proposal to create a new coordination centre that will, coordinate, create and manage the implementation of a single governance framework to enable sample and data access
  - a) Please comment on whether a single governance framework would/would not be beneficial to research.
  - b) Are there any other activities that would be necessary to make it achievable? Please also state if there are other activities should or should not be included in the remit of the coordination centre aside from those listed in the paper.
- 9) In the document, we propose that the public should be involved in decision-making, not only in terms of local sample access but throughout the biobanking ecosystem.
  - a) Please comment from you/your organisation's point of view how the public could and should be involved in decision-making.
  - b) Please also detail if you know of examples of other research infrastructures which have succeeded in involving the public in decision-making, and why the example is a success.
- 10) In you/your organisation's point of view, what commitment is needed from funders and government regulators for the proposed coordination centre's success?
- 11) Please list the organisations that you/your organisation feel should be involved or associated with the proposed coordination centre. Please also include the type of relationship should they have, and your rationale for their inclusion.

#### **Section 3**

# Please provide any comments in relation to the sections of the Vision document

This section is for any other comments regarding the related section or subsection of the Vision document: - State of Biobanking in the UK: Vision, Challenge and Task.

Please provide any comments for any of the relevant sections below.

- 11. Background
- 12. Researcher Attitudes
- 13. Review of Biobanking Coordination
- 14. Themes
- 15. World-leading Infrastructure
- 16. Lessons learned from TDCC
- 17. 2030 Vision
- 18. Establish a new governance framework
- 19. Funder and regulator alignment
- 20. Conclusion

**END OF MICROSOFT FORM** 

PLEASE PRESS "SUBMIT"