

## Northern Ireland Biobank

| Reference: NIB-F-020 |  |
|----------------------|--|
| Form for:            |  |

Collation and Use of Health Information for Research Purposes

| Version:              | 1                |
|-----------------------|------------------|
| Date Created:         | 12.06.2015       |
| Date of first review: |                  |
| Date of next review:  |                  |
| Name of Author:       | Priscilla Clark  |
|                       | Pusalla Clank    |
| Authorised by:        | Jacqueline James |
|                       | Jacqueti James   |

Signature:

## **Collation and Use of Health Information for Research Purposes**

The Northern Ireland Biobank (NIB) collects and stores clinical and pathological information related to the NIB prospective and retrospective tissue collections. NIB has ethical approval from OREC (NI) to be the custodian of this data and to release to researchers linked-anonymised data for approved NIB projects. There are SOPs and policies in place (see <a href="https://www.nibiobank.org">www.nibiobank.org</a>) and an agreement with NI Healthcare Trusts with regard to the governance of health & social care information.

This is an agreement between NIB and collaborators relating to the collation of clinical data for research purposes, undertaken under NIB ethical approval for enhancement of NIB resources.

| Name of Clinician/Pathologist (responsible for the collection of clinical/pathological data) |   |  |  |  |
|--|---|--|--|--|
| Ref  | Reference NIB Project (Title if appropriate):   |  |  |  |
| NIE  | B Reference Number:Type of Data:  |  |  |  |
| l ur   | nderstand and agree to the following terms and conditions:-   |  |  |  |
| 1.   | The use of clinical data for research purposes requires independent National Research Ethics Service ( <i>NRES</i> ) approval or approval from an NRES-approved Biobank to be the custodian of such data and I will not use the data I collate for any other purpose other than that agreed with NIB, without having appropriate separate ethics approval in place. |  |  |  |
| 2.   | The custodian of my de-identified clinical data collection is the NIB and this data will only be released to another researcher via the NIB Administrator and not directly by me.   |  |  |  |
| 3.   | NIB can release data to researchers on the understanding the researchers acknowledge the clinicians/pathologists responsible for the collection of this data.   |  |  |  |
| 4.   | NIB will communicate with me when data has been released to another researcher.   |  |  |  |
| 5.   | NIB cannot guarantee me that I am recognized as a co-investigator in all studies which receive the data and it is my responsibility to pursue this with the researcher concerned.   |  |  |  |
| 6.   | NIB may require the data to undergo revision and certain aspects of the data may be subject to further expansion. I am happy to be approached if this is required but am under no obligation to undertake further data collation.   |  |  |  |
| Sig  | ned & dated by Clinician/Pathologist:   |  |  |  |
| Sig  | ned and dated by NIB Scientific Director:   |  |  |  |