CODE OF PRACTICE FOR THE USE OF GCNIC DATA COLLECTIONS AND RESEARCH PARTICIPANTS - CHW

POLICY AND PROCEDURE ©

DOCUMENT SUMMARY/KEY POINTS

- This document will be used by health professional wishing to access data regarding neonatal patients held in the Grace Centre for Newborn Intensive Care (GCNIC) Database and the Neonatal Intensive Care Unit Study (NICUS) Database
- All requests are to be made to the Head of the Department of Neonatology on the attached form

CHANGE SUMMARY

- Included flow charts about access to Data.
- Updated form: Request for the Use of Data from Departmental Data Collections

READ ACKNOWLEDGEMENT

- To be read and acknowledged by health professional wishing to access data regarding neonatal patients held in the Grace Centre for Newborn Intensive Care (GCNIC) Database and the Neonatal Intensive Care Unit Study (NICUS) Database.

Approved by:	SCHN Policy, Procedure and Guideline Committee	
Date Effective:	1st July 2022	**Review Period:** 3 years
Team Leader:	Nurse Educator	**Area/Dept:** GCNC - CHW

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Grace Centre for Newborn Intensive Care – Code of Practice for the use of Departmental Data Collections and Research Participants

The Grace Centre for Newborn Intensive Care (GCNIC) currently maintains several data collections including NICUS, CCIS (historical database), and relevant electronic medical records that contain patient identified clinical records. Some of these collections are maintained in conjunction with the Agency for Clinical Innovation (ACI) and provide a mechanism where individual unit data can be collated on a State and National basis. The department maintains local data collections for the purposes of audit and research. These guidelines deal with the mechanisms for privacy, security and access for these data.

The patients and staff of GCNIC are also popular areas of research for clinicians and academics external to GCNIC and it is essential that such studies have a member of GCNIC staff as a co-researcher or designated contact.

Records of data collections and research proposals

The Grace Centre for Newborn Intensive Care will maintain records of data collections and research proposals including the following information:

- Name of data collection
- Purpose or objective
- A summary statement of data items collected
- Title of data sponsor
- Title and contact point for data custodian
- Statement of whether the collection includes personal information.
- These records will be stored in the password-protected network computer.

Data sponsor (Department Head)

For each data collection the data sponsor undertakes the duty of ownership including:

- Defining the purpose or objective of the data collection
- Establishing the scope and coverage of the collection
- Defining access and custody arrangements

Data custodian (Department Head/ Audit Officer)

Each data collection should have a data custodian with responsibility for:

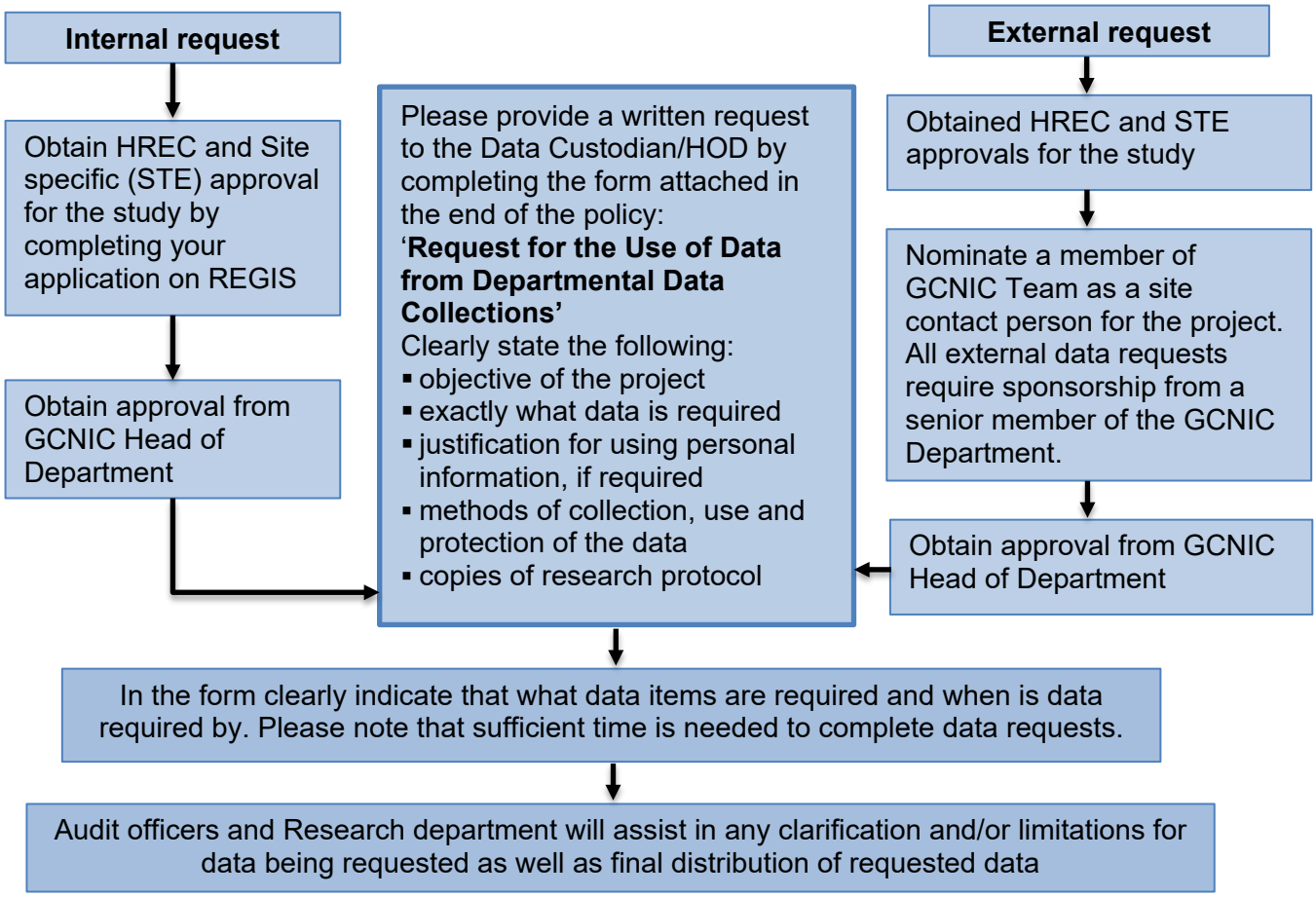
- Ensuring a secure environment for data including backups and other safeguards to prevent unauthorised access, destruction, use, modification or disclosure.
- Maintaining documentation of the existence, content and format of the data collection.
- Maintaining a list of authorised data users.

- Authorising new data users and providing advice and assistance on any constraints which apply to use of the data.
- Determining and implementing appropriate levels of protection for the data
- Dealing with requests for access to data other than from authorised data users, and ensuring that they are dealt with in accordance with relevant policies and procedures.

Data Access

HREC Approved research

Requests from applicants engaged in bona fide research or other projects requiring data should include following steps:



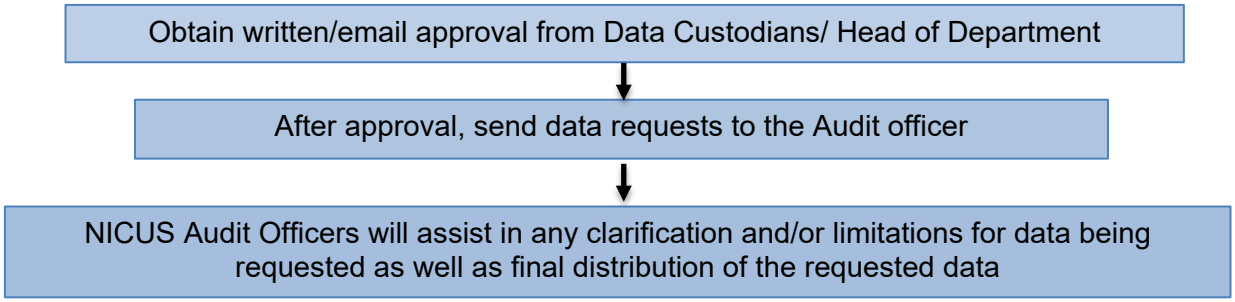
QI Project or unit service delivery data

Data requests from applicants engaged in local unit based service delivery or quality improvement projects requiring data should provide a written request to the data custodian including the following:

- Objective of the project
- Exactly what data is required
- Justification for using personal information if required
- Methods of collection, use and protection of the data

- Copies of research protocol or project proposal

Requests can be made in following steps:



It is important to have clear request about the required data. Once data request is received by the audit team, sufficient time is required to complete the data requests.

Data custodians may approve use of personal health information for purposes consistent with those for which it was collected provided they are satisfied that:

- There is compliance with any constraints placed on the data
- The data will only be used for the project for which the data has been requested
- Adequate security exists to protect the data during transfer
- The number of people having access to the data is the minimum necessary to achieve the objectives of the project
- Excel or word data files including patient information are password-protected.
- These data files are stored in the password-protected network drive.

Applications will be assessed, by the department's head or Research leads, using the following criteria:

- Are there any legal or other binding constraints on use of the data?
- Is it essential that identifying data be used for the project?
- Is the requested level of access to data the minimum required for the success of the project?
- Is the research design or project valid?
- What disposal procedures will apply?
- What security measures will apply?
- Will informed consent be obtained from the subjects?

If access is granted, the principal applicant should sign an agreement to apply, as a minimum, the standards of privacy protection contained in the NSW health privacy Code of Practice.

A copy of the application for data will be maintained by the data custodian. It is expected that the research department will receive a copy of any published work that arises from the use of the department's data collections.

All research proposals involving patients in GCNIC or staff are to be signed by the HOD of Grace Centre for Newborn Intensive Care indicating their approval for the research to be carried out in GCNIC.

Grace Centre for Newborn Intensive Care - Form

Request for the Use of Data from Departmental Data Collections

Name: _____

Institution: _____

Address: _____

Contact Telephone: _____

Department Sponsor: _____

Project Title:_____

_____

Objective of Project: _____

_____

Data Items required: _____

_____

When is data required by: _____

Is the use of personal information required? **YES/NO**

If personal information is required please outline the justification. _____

_____

Nominated GCNIC staff member for the project: _____

Who will have access to the data: _____

How will the data be secured: _____

_____

How will the data be disposed of at the completion of the project? _____

_____

Where do you intend to present this data: _____

A copy of the research protocol along with HREC approval and STE approval or project proposal should be attached.

Declaration

I, (name).....understand that, I may be granted access to confidential data, which includes the identity of, and personal and health information about individual persons. I undertake strictly to preserve the confidentiality of this information and I will not divulge any identifying, personal or health information regarding individual persons. In order to fulfil this undertaking I will ensure that, so far as is within my control, such information, whether in the form of paper documents, computerised data or in any other form, cannot be viewed by unauthorised persons, and that the information is stored in a secure and orderly manner which prevents unauthorised access.

Signed …….. …… **Date** ……

GCNIC HOD signature: …… **Date** ……..……..
(or alternatively attach HOD approval email)