

## RHSCIR Data Steward Terms of Reference

### 1. Responsibilities

The RHSCIR Data Steward must be well versed in the purpose(s) of the data holding and able to communicate these to any Data Steward Delegates and other stakeholders. The RHSCIR Data Steward is responsible for managing access to the data holding and providing expert advice regarding its applications and limitations. These responsibilities include:

1. maintaining the privacy and security of the data by monitoring access to, and use of, personal information within the data holding, by:
  - a. reviewing and approving access for internal data users to the data holding; and providing a rationale for denial of such requests, where appropriate;
  - b. reviewing RHSCIR data applications for completeness and considering whether:
    - The request is consistent with Praxis's mission, applicable laws and agreements;
    - The request is consistent with the permitted purposes described in the approved research protocol(s);
    - It is feasible for Praxis to provide the data requested (e.g., availability of data elements requested, resource requirements);providing a rationale for denial of such requests to the requestors, where appropriate;
  - c. forwarding applications to the RHSCIR Data Executive Scientific Committee (DESC) and RHSCIR Data Access Committee (DAC) for review; providing a rationale for denial of such requests to the requestors, where appropriate;
  - d. facilitating and coordinating the DESC and DAC reviews;
  - e. deciding, if after a RHSCIR data use and disclosure request is approved at any stage of the process, if the requested changes constitute a material or non-material change. If a non-material change is requested the RHSCIR Data Steward/Delegate will determine if the information provided to either the DESC or DAC members has changed. If there are non-material changes that have changed the information the DESC or DAC members received about the request, the RHSCIR Data Steward/Delegate will contact the DESC or DAC members with updates to the request.
    - Upon receiving the email, each DESC or DAC member will be given five business days in which to revoke their approval or ask questions about the non-material changes. If a response is not received within five business days, approval of the non-material changes is presumed.If the RHSCIR Data Steward/Delegate determines that material changes have been made to the application, the application will need to undergo the full RHSCIR Data Use and Disclosure Policy process again;
  - f. serving as the data holding expert, and providing guidance to delegates, data requestors, analysts, and other stakeholders; and
  - g. participating in data access audits.



2. monitoring the accuracy and integrity of the data holding and, as appropriate, advising requestors of the limitations of the data; identifying procedures to ensure data quality and documenting data quality limitations.
3. maintaining an inventory of the data holding that includes information on the location of the data and the years for which data is available.
4. serving as a subject matter expert to DESC and DAC members as required.
5. ensuring that the data will be securely housed and destroyed upon termination of agreements, project completion or cessation.
6. providing support to the Privacy Officer in implementing privacy policies.

## **2. Meetings**

The RHSCIR Data Steward will meet with DESC and DAC members as required to resolve issues that have been escalated and will facilitate the reviews undertaken by both committees.

## **3. Records**

The RHSCIR Data Steward maintains accurate records including but not limited to email correspondence, reviews and minutes, on a secure designated location (that is only accessible to the RHSCIR Data Steward/Delegate(s) and applicable Praxis personnel) for a minimum of 5 years after the closure of an application/project.

## **4. Reporting Relationships**

The RHSCIR Data Steward has a direct reporting relationship to the Director, Research and Best Practice Implementation. The RHSCIR Data Steward has a responsibility to inform and consult with the DESC and DAC members on matters related to RHSCIR data use and disclosure.