

**National Network for Nurse Managed Centers (NNNMHC):  
Data Ownership, Handling, Access, and Disclosure Protocols  
September 29, 2005**

This document specifies ownership of, and access to Data supplied by Nurse Managed Health Centers to the NNNMHC for inclusion in the Data Warehouse.

In this document, the term “Center” refers to the Nurse Managed Health Centers that supply data to the NNNMHC Data Warehouse.

“NNNMHC staff” include those individuals directly paid to work on NNNMHC activities, including, the Primary Investigator, the Executive Director, and staff of the Michigan Public Health Institute (MPHI) where the Data Warehouse is housed.

MPHI has an Institutional Review Board (IRB) with Federal Wide Assurance that reviews all research projects. The IRB also performs the role of Privacy Review Board, and MPHI has a designated Privacy Officer. The NNNMHC Data Warehouse currently does not collect sensitive individual data, or protected health information, and therefore has been determined to be “Exempt” from Human Subject approval and non-privacy sensitive in relation to the HIPAA Privacy rule.

These protocols also assume that data contained in the Data Warehouse are annual summary data for Centers, and not individual patient-level data. Should the Data Warehouse begin to collect individual patient-level data, the project will become privacy sensitive and these protocols will have to be revised substantially, with much additional detail, to ensure HIPAA compliance. In any case, these protocols and related policies and procedures will be reviewed annually and updated as needed.

### **Data Ownership**

1. Data are owned by the NNNMHC and therefore access to data is governed by the NNNMHC Board of Directors.
  - 1.1. The NNNMHC Board of Directors must approve of these protocols.
  - 1.2. It is assumed that individual sites will maintain copies of the data they submit on their Centers, and may use it however they choose.

### **Data Handling**

Once data are submitted to the Center, NNNMHC staff will do the following.

2. Create two files: a working database, and a database with identifying information on the Center, the ownership organization, and individual Center Contacts.
  - 2.1. Working data files will be stripped of directly identifying information. Directly identifying information includes: Center name, address, website, ownership organization name and address, contact name and address.
  - 2.2. Centers will be assigned a unique identification number that will link tables.
  - 2.3. Only NNNMHC project staff will have the key that links identification numbers to Center names and contact information.

- 2.4. Data will be housed at MPHI on secure servers with limited access. MPHI's data security protocols are available upon request. They include both electronic and physical security systems, shredding and other appropriate ways to discard data, training of all employees regarding data confidentiality, and signing of data confidentiality statements by employees.
3. If data are submitted using paper forms, NNNMHC staff will shred the paper forms once data have been entered in the electronic database and verified for accuracy.

#### **Data Access**

4. The following levels of access to data are specified:
  - 4.1. Network Staff (defined above)
    - 4.1.1. Have access to all data and can run any analysis within the parameters of the data disclosure protocols and MPHI policy regarding confidentiality, human subjects, and other data related protocols.
  - 4.2. Centers that Provide Data
    - 4.2.1. **May have one electronic download of data submitted, free of charge, if requested.**
    - 4.2.2. Will receive summary reports created by Network staff (at no charge), including the following:
      - 4.2.2.1. Feedback on data quality and completeness
      - 4.2.2.2. Calculation of certain financial ratios for their own Center
      - 4.2.2.3. Boiler plate reports: including graphs and tables summarizing volume, patient demographics, services offered, and financials. Tables and graphs will be broken down by clinic type to the extent there are enough cases per category to do so.
    - 4.2.3. May request one additional analysis not to exceed 1 hour of work on the part of NNNMHC staff (at no charge).
    - 4.2.4. May request additional analyses or access to the data, for a fee, and governed by protocol 4.3 below.
  - 4.3. Researchers affiliated with Centers that Provide Data and individuals actively participating on the NNNMHC Board of Directors and Task Forces
    - 4.3.1. May request aggregate summary data for a set discount (in accordance with NNNMHC data pricing structure to be determined in the future)
    - 4.3.2. May request access to data files also at a set discount and subject to the following data use protocols.
      - 4.3.2.1. May only be granted access to "Working data files" that do not include directly identifying data as described in 2.1 above.
      - 4.3.2.2. Are required to submit a concept paper/description of why they want the data and how it will be used. Acceptable uses include:
        - 4.3.2.2.1. Informing policy makers, funders, university administration, health coverage organizations
        - 4.3.2.2.2. Scholarly research
        - 4.3.2.2.3. Grant writing
        - 4.3.2.2.4. Market research

- 4.3.2.3. Are allowed to use data only for what they are proposing and for no other purpose.
  - 4.3.2.4. Must specify when they will complete the data analysis, and are expected to destroy/delete all copies of the dataset at that time.
  - 4.3.2.5. Must assure that they will make no effort whatsoever to identify individual Centers.
  - 4.3.2.6. Must be approved by NNNMHC Board of Directors – either directly or through a Board-established process for approval
- 4.4. Outside Researchers
- 4.4.1. May request aggregate data summary for a specified purpose
  - 4.4.2. Are not eligible for a discount, but will be charged according to a defined fee structure to be determined in the future.
  - 4.4.3. May request access to data files subject to the same data use protocols listed in 4.3.2.1-4.3.2.6, above.
- 4.5. Denial of Access to data
- 4.5.1. NNNMHC staff will develop and the Board will approve a policy and procedure regarding access to aggregated and disaggregated data to be applied for every request regardless of status or affiliation with the network.
  - 4.5.2. Reasons for denying access to data for specific purposes may include: data quality, intended purpose, lack of reputation on the part of the applicant for high quality nursing research, etc.

### **Data Disclosure/Publishing**

- 5. Working data files (stripped of identifiers) may be disclosed to researchers both affiliated with the NNNMHC and not as described under 4.3-4.4 above, subject to approval of the NNNMHC Board of Directors.
- 6. Center names, addresses, websites, and contact information will not be disclosed in association with more detailed client, service, or financial data to anyone other than NNNMHC staff, without written permission from the Center Director.
  - 6.1. One such disclosure will be to include the Center in the NNNMHC Directory, which includes name, address, contact information, and summary information on client volume, demographics, and health insurance status
  - 6.2. In the future, Centers may decide to form research networks and authorize disclosure of contact information for that purpose.
- 7. When data are presented by NNNMHC staff or outside researchers, they will be presented as aggregate summary information (means, medians, percentiles, frequencies, standard deviations, ranges, etc.).
  - 7.1. The only exception to this is the presentation of ‘Best Practices’ or model Centers. If data are presented for individual Centers identified as a model in some way, the Center will be assigned an anonymous letter or number (i.e., Clinics A, B, and C etc.). Moreover no other information which could identify a Center can be published at the

individual level (even with the anonymous label) without written permission from the Center Director.

8. In case the Network data are reported in publications or presentations, all researchers must provide the Network with a copy of the publication/presentation and a full citation of where it will appear by the time of presentation/publication.
9. Anyone who uses or publishes data from the Network Data Warehouse, must acknowledge the Network as the source of data.