

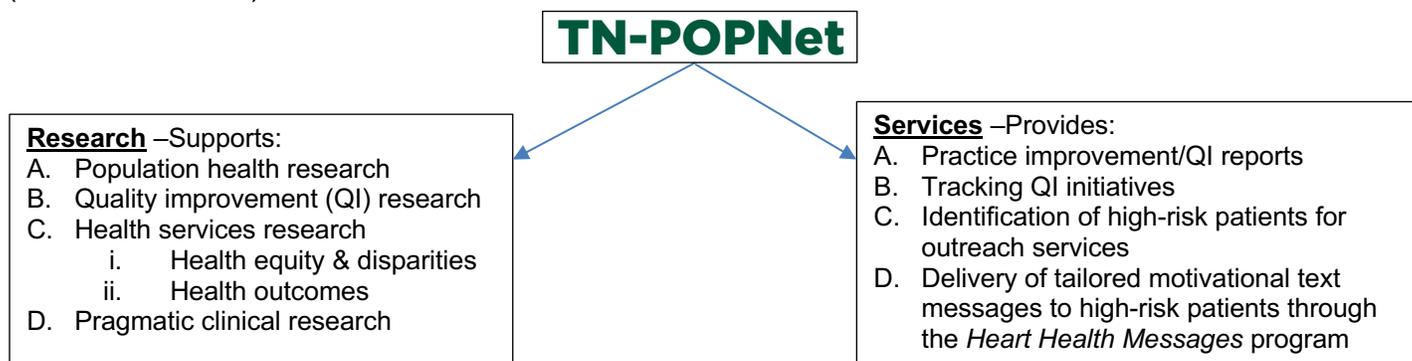


## Overview & Participation Process

### A. Introduction.

The University of Tennessee Health Science Center (UTHSC) Tennessee Population Health Data Network (TN-POPnet formerly known as the Diabetes Wellness and Prevention [DWPC] Registry and Practice-based Research Network) is supported by the UTHSC Tennessee Population Health Consortium, Center for Health System Improvement (CHSI), and Center for Biomedical Informatics (CBMI). The TN-POPnet serves as a specialized chronic disease registry and Agency for Healthcare Research and Quality (AHRQ)-approved practice-based research network (PBRN) designed to help improve care for people with or at risk for chronic diseases, including obesity, diabetes, cardiovascular disease, and cancer. TN-POPnet assist healthcare providers, clinical practices, and health systems and across Tennessee in measurably improving population health by: 1) tracking processes and outcomes of care for people with chronic disease to make sure they get recommended care, and 2) evaluating the impact of healthcare delivery/health systems improvement efforts.

TN-POPnet both supports population health research initiatives (requiring separate Institutional Review Board [IRB] approval) and provides core population health support services to its organizational partners (under its core IRB) as follows:



Providers, practices, and health systems participating in the Consortium and TN-POPnet pledge to work together to improve care and promote wellness for people with or at risk for chronic diseases in Tennessee and the Mid-South. Consortium partners can participate in learning collaboratives to learn and share best practices and develop patient-centered medical home (PCMH) capacity. TN-POPnet gives practices regular feedback through practice improvement reports from its component Diabetes, Heart Health, and Cancer Control and Prevention Registries. These component Registries provide partners increased ability to track key practice data on processes and outcomes of chronic disease care and to use it to improve care.

### B. HIPAA and UTHSC technology resources.

TN-POPnet is fully HIPAA compliant and meets stringent standards of the Office of the National Coordinator for Health Information Technology (ONC-HIT) and the Patient-Centered Outcomes Research Institute (PCORI) for data use in performance reporting and the conduct of registry studies for patient-centered outcomes research. UTHSC staff work diligently to maintain HIPAA compliance. In all Institutional Review Board (IRB)-approved research projects using Network data, each principal investigator (PI) controls data access to the level of individual variables. Thus, a PI can allow an off-site collaborator access to certain data by providing access to only a de-identified or limited dataset. UTHSC is a Covered Entity under HIPAA and conducts research governed by various federal and state laws and regulations. As such, UTHSC has active programs to ensure compliance with these statutes. Members of the Consortium, CHSI, CBMI, IRB,

Information Technology Services and the UT Office of Research Compliance help ensure that data are accessed under safe and compliant conditions.

The UTHSC network and computing facilities are owned and managed by UTHSC and all TN-POPnet systems are physically housed in the UTHSC ITS department computer center, which has electric power conditioning, UPS battery backup for short-term outages, and a backup diesel generator for long-term outages. The computer center also has fire suppression, temperature and humidity control, card key controlled access and video monitoring. The building has after-hours access controls and is monitored by the UTHSC police force. Networking equipment across the campus is housed in dedicated and locked wiring closets with battery backups and access limited to UTHSC network services personnel only.

A switched network with fully redundant network cores provides Internet connections to both the Internet and Internet 2. Network traffic crossing the UTHSC network boundary is examined by 4 different firewalls, a final Cisco firewall examines against its Access Control Lists. Access from outside the UTHSC network for public data is to known web server ports and services. VPN access is available to authorized users by NetID for off campus access.

### C. Schedule of data pulls.

Dedicated UTHSC personnel work with participating provider, practice, and health system IT personnel to establish and maintain data feeds and UTHSC personnel standardize all the data into a common data model for ease of use. Participating providers, practices, and health systems (clients) are expected to provide consistent data pulls; a monthly data pull is preferred.

The following is an example of how a client might submit files on a monthly basis.

Start date	End date	Date sent to UTHSC	Notes
01/01/2014	12/31/2024	06/15/2021	First data pull, data from 2014-May 2021
06/01/2021	06/30/2021	07/15/2021	All new May 2021 data
07/01/2021	07/31/2021	08/15/2021	All new June 2021 data

### D. Data elements and files.

The data requested is for all patients seen one or more times by the participating provider, practice, or health system. Inclusion of all patient data enables accurate quality reporting at the practice- and population-level based on complete denominator information.

The required data elements can be viewed as a group of six different sets detailed below (please send as .csv files if at all possible). Clients are encouraged to provide complete data but can begin participation by providing a more limited data set including the most essential data elements indicated in *italics* below:

**Demographics:** Contains demographic and identifiable and geographic information for all patients (*Zip Code* and *race* most essential).

**Summary of Visits:** A summary of the visits, primarily including dates of admission and discharge if applicable, length of stay if applicable, facility or location and the main reason for visit (*date* and *type of service* most essential).

**Plan of future Visits:** A summary of the scheduled future visits if available, primarily including, facility or location and the main reason for visit.

**Health Plan:** Includes the payer or insurance information and primary care provider associated with the plan. No amounts, only descriptions and names. Ie. Medicaid, TennCare, Blue Cross Blue Shield, etc..

**Diagnosis:** List of all diagnoses at each visit with their allocation, primary diagnosis, secondary, etc.

**Procedures:** List of all procedures (if available) at a specific visit with their allocation, primary diagnosis, secondary, etc. (*CPT codes for smoking cessation counseling* [99406 and 99407] most essential).

**Labs:** All lab information by patient and date, preferably linked to a specific visit, but not necessary. Labs we are interested in are: HbA1c, Glucose Serum; Glucose Accucheck, I-Stat Glucose, LDL, HDL, Total Cholesterol (*HbA1c* most essential).

**Physical:** Anthropometrics by patient and date preferably linked to a specific visit, but not necessary, this includes: weight, height, and systolic and diastolic blood pressure (*weight, height, and systolic and diastolic blood pressure* are essential). We also ask that if available, please provide heart rate and any other anthropometric available.

**Pharmacy:** All prescribed and/or filled medications data by patient and date. Information on generic name, brand name, NDC, days supply, quantity, duration, frequency etc.

Data elements should generally be provided in multiple .csv files as stated above, but this is not essential. Filenames should follow the same specific criteria all the time, this criteria is up to the sender to set. An example will be a demographics file named "demographics\_XX\_XXXX" in which the "X" state the month and year or the data pull, this format should never change, file name can not be changed to "demo\_XX\_XXXX" or other file name.

#### **Important notes:**

An identifier for each patient is necessary, can be patient account number, Medical Record number, etc.

An identifier for each visit is necessary.

Data elements and file names need to be sent **always** in the same format, headers of files or fields should always remain the same.

#### **E. Data dictionary.**

See attached excel file for information regarding the current data dictionary. We ask that you provide as much as you can in this format.

#### **F. File transfer system.**

We use an in-house built system called "Charon", please see attached PDF for details, Charon acts as a safe layer between the entity sending files (clinics and hospitals aka 'clients') and UTHSC.

This requires some setup from UTHSC Information Technology Services, and that can create some delays, so please plan accordingly.

##### **a. Requisites.**

- Client needs to generate a public and private key-pair and share the public part with UTHSC contact.

For instructions you can contact you local IT team or if using a Windows machine:

<https://www.codeenigma.com/host/faq/how-do-i-create-ssh-public-key-windows-pc>

If using a mac: <https://www.siteground.com/kb/how-to-generate-an-ssh-key-pair-in-mac-os/>

- Client needs to provide its IP address, can get it from this site:

<http://whatismyipaddress.com>

- Client needs to be able to use a file transfer software, we recommend filezilla.

<https://filezilla-project.org>

- Client will always use the same machine (with private key installed) and same network (IP address) to send files to UTHSC.

##### **b. Overview of protocol.**

1. UTHSC contact will create an account in Charon system.

2. Client will generate keys and send by email public key along with IP address.

3. UTHSC ITS provides space allocation in the server, opens ports and match keys.

4. A notice will be sent to client to start testing, testing should be done with text files containing readable words and multiple lines. See attached file Test.txt.

5. Once file transfer is successful client can start sending files as scheduled.

6. Files are transformed into a common data model used by the registry and uploaded into UTHSC Oracle server.

### **G. Final data repository.**

Once data is transformed and uploaded into UTHSC Oracle server, we are able to provide a set of platforms for quality reporting and potential participants to be consented and recruited into the clinical trial.

If another institution or researcher wants to have access to this repository, it will need to be cleared by IRB and follow procedures that are out of the explanation scope of this document.

### **H. Deliverables.**

UTHSC is to deliver a quarterly "Practice Improvement Report" based on the demographics for each participant clinic compared against the whole registry. See attached document "DWPC Practice Report Template.docx".

Most measures are based on HEDIS standards and changes/updates to the report will be at UTHSC discretion.

Other deliverables or services, like possible patient cohort, more specific reports or any other not mentioned in this document are out of scope and will be assessed in a case by case basis, based on documentation already in place (Data Use Agreements) and procedures set by Institutional Review Boards.