

	Privacy	Rio Grande Valley HIE	Policy: P12
	Effective Date 11/06/2015	Last date Revised/Updated 11/06/2015	Date Board Approved: 11/06/2015
Subject: Analytics and Research, Disease Registry			

FEDERAL and STATE LAWS AND REGULATION:

45 CFR §§164.508, 164.512, 164.508 (b)(5), 164.506(a)(b)(c)
45 CFR 160.103, as amended by NPRM, July 14, 2010
Texas Health & Safety Code § 181.154(b), (c)
PIN ONC-HIE-PIN-003, Privacy and Security Framework Requirements and Guidance

POLICY:

RGV HIE’s has established a chronic disease registry to support providers in reducing the prevalence of diabetes initially, and other diseases in the future, in the Rio Grande Valley.

Participating providers enter data into a unique chronic disease registry database through electronic transfer of data from their EMRs to the Registry. Providers will use the registry data to proactively contact, educate, and track patients by disease status, risk status, self-management status, community and family need. Reports will be generated from the Registry which will assist providers to develop and implement targeted plans for disease management.

RGV HIE will apply the RGV HIE authorization policies to inclusion of data in the chronic disease registry, and providers will establish their own procedures for patients to choose to participate in any disease management program. Patient data will automatically be included in the Disease Registry unless they opt-out. *See RGV HIE Policy and Procedure P1 Authorization.* The provisions in P1 related to the patient’s ability to opt-out of participation in RGV HIE also apply to opting-out of participation in the Disease Registry. This policy should be read in conjunction with P1.

It is the responsibility of providers participating in RGV HIE to obtain the signature of patients on any authorization forms when required. RGV HIE participating providers will establish procedures for collecting patient signatures which comply with ONC’s PIN 003 Guidance to afford patients meaningful choice as required by RGV HIE Policy and Procedure P1. Authorization.

PROCEDURE:

I. AUTOMATIC INCLUSION IN DISEASE REGISTRY DATABASE

- A. Selected Data about a Patient that is contained in a connected Electronic Medical Record

maintained by a RGV HIE Participating Provider, or its Authorized Users, shall be automatically contributed to the RGV HIE Clinical Data Repository and exchanged through the HIE.

- B. Including Patient Data in the RGV HIE database or exchanging Patient Data through the HIE does **not** automatically permit access to such Data by Participating Providers and Authorized Users.
- C. Patient Data maintained or exchanged through RGV HIE shall not be available for Access by any Participating Provider or Authorized User unless such Access is authorized, is a permissible use, and procedures are followed for granting access to authorized users, as set forth in these RGV HIE Policies and the Business Associate Agreement, Master Services Agreement and Core Service Agreements, as applicable, between the Participating Provider and RGV HIE.

II. HIE EDUCATIONAL MATERIALS

- A. Participating Providers are responsible for providing Patients with educational information regarding RGV HIE chronic disease registry, as well as any disease management program, and the Provider's participation in the Registry and/or the Program.
- B. Participating Providers shall be responsible for their own internal tracking of which of their Patients have or have not received information regarding the Disease Registry
- C. To facilitate Patients' understanding regarding where their Data is being generated, stored and being made accessible for exchange, a list of Health Care Providers participating in RGV HIE and the Chronic Disease Registry shall be made available through RGV HIE's website, a link to which may also be placed on each Participating Provider's website. Each Participating Provider shall also be responsible for providing a hard copy of such list if requested by a Patient.
- D. In addition to providing educational materials, Participating Providers must inform patients about Provider's data exchange with RGV HIE and participation in the Disease Registry and be responsible for obtaining any signed patient authorization form required under state and federal privacy and security laws and regulations.

III. "OPT-OUT" CHOICE

All Patients who are treated by a Health Care Provider that is a Participant of RGV HIE shall have the option and opportunity to choose to not have information about them accessed or made available through RGV HIE. This option shall also apply to data shared through the Disease Registry and the opt out procedures contained in P1 Authorization will be applied.

IV. AUTHORIZATION FOR SHARING SENSITIVE DATA

Each Participating Provider shall remain responsible for knowing and determining whether, and if, additional Patient authorization must be obtained prior to allowing access to Patient's Data through The RGV HIE Disease Registry. The procedures in P1 Authorization will be applied.