

**Data Models of
Participating Programs'
Proposed Shared Data**

**Child Health Advanced Records Management (CHARM)
Utah Department of Health**

Preparation of this publication was supported by a contract from
All Kids Count, a program of The Robert Wood Johnson Foundation.

**Data Models of
Participating Programs'
Proposed Shared Data**

**Stephen W. Clyde, Ph.D.
Monal Daxini**

**Child Health Advanced Records Management (CHARM)
Utah Department of Health**

December, 2002

This publication was supported by a contract from All Kids Count, a program of The Robert Wood Johnson Foundation, to the Utah Department of Health. The views, content and citations reflect those of the Utah Department of Health.

Ordering Information

This publication is available online at the All Kids Count web site, www.allkidscount.org.

Copyright © 2002 by All Kids Count, Center for Innovation in Health Information Systems. All rights reserved.

Table of Contents

1. Introduction	1
2. Vital Statistics (VS) Data	3
3. Early Hearing Detection and Intervention (EHDI) Data.....	11
4. Newborn Screening Data.....	16
5. Utah Statewide Immunization Information System (USIIS) Data	19
6. Early Intervention (EI) Data.....	23
7. Summary	26

1. Introduction

Over the past six years, the Utah Department of Health (UDOH) has developed and deployed a number of health-care information systems. Each of these systems belongs to a corresponding health-care program, which is responsible for managing that data.

Child Health Advanced Records Management (CHARM) is a concerted effort to share data among health-care information systems in real-time. The shared data for a child constitutes a virtual health-care record that we call the *Child-Health Profile (CHP)*. No single health-care system stores or manages the complete CHP. Instead, each system continues to manage its own data and specifies what parts are to be shared and with whom they can be shared.

A health-care information system that is willing to participate in and share data in CHARM is called a Participating Program (PP). The following PPs are considered in this document: Vital Statistics (**VS**), Early Hearing Detection and Intervention (**EHDI**), Heel-stick (metabolic) screening now known as Newborn Screening (**NBS**), Utah Statewide Immunization Information System (**USIIS**), and Early Intervention (**EI**) information systems.

The purpose of this document is to show the potential data that will be shared by each PP. The data for each PP is presented in separate sections with specific Unified Modeling Language (UML) diagrams. Notes are provided where necessary to assist the reader.

Data sharing agreements for each PP are in the process of being completed: agreements that reflect which data will be shared, with whom, and for what purpose. These data sharing agreements will also include services and functions that the PPs are willing to share and the business rules for sharing data or functions. The final agreements will be developed in coordination with the designated data stewards for each PP.

A brief description of each PP and the benefit derived by data sharing follows.

Vital Statistics

Vital Statistics has a successful history of data sharing. Vital Statistics has a special status in HIPAA--they are exempt in HIPAA with a few constraints on birth and death information. The data can be used for official purposes. Data can also be used by private individuals. Vital records serve two purposes: 1) civil registration, and 2) public health surveillance and monitoring. Several programs could avoid redundant data entry by pre-loading birth records information. Most of the PPs are very interested in receiving immediate infant death information so that they can avoid making telephone calls to families who have lost a child.

Early Hearing Detection and Intervention

This program focuses on screening infants at birth for hearing loss and tracking those with suspected loss through the identification of services provided. EHDI is interested in sharing data with USIIS and also EI. Currently, EI sites frequently call state EHDI personnel to get results from hospital screenings for children they serve. EHDI needs more data in terms of follow-up

information. That is, follow-up information on recommended actions for children with suspected hearing loss needs to be increased.

Newborn Screening

Newborn Screening is specifically designed to reduce the morbidity and mortality of certain metabolic, endocrine, and hematological disorders by identifying the disorder prior to the onset of symptoms. It is the one program that is the most independent of the PP. They are interested in sharing demographic information and are considering other data and functions that might be shared.

Utah Statewide Immunization Information System

USIIS is a central repository for all children's (0-18 years of age) immunization records that can only be accessed by authorized users. It is intended to aid health care providers with immunization information for patient care that includes tracking, recall, and reporting. Vital Statistics is the first source of data for USIIS. They also have reliable information on foster children, which is a great need for other programs. USIIS data is very important to EHDI in terms of following up on children who need further assessment or services.

Early Intervention

This federal program, funded by the Individuals with Disabilities Education Act, provides early identification and developmental services for families of infants and toddlers (birth to three years of age) through the Utah Department of Health. EI is willing to share follow up data for infants with disabilities with EHDI and is interested in obtaining prevalence rates to help in predicting the number of children EI should be serving. Also EI would like access child immunization and foster care information.

2. Vital Statistics (VS) Data

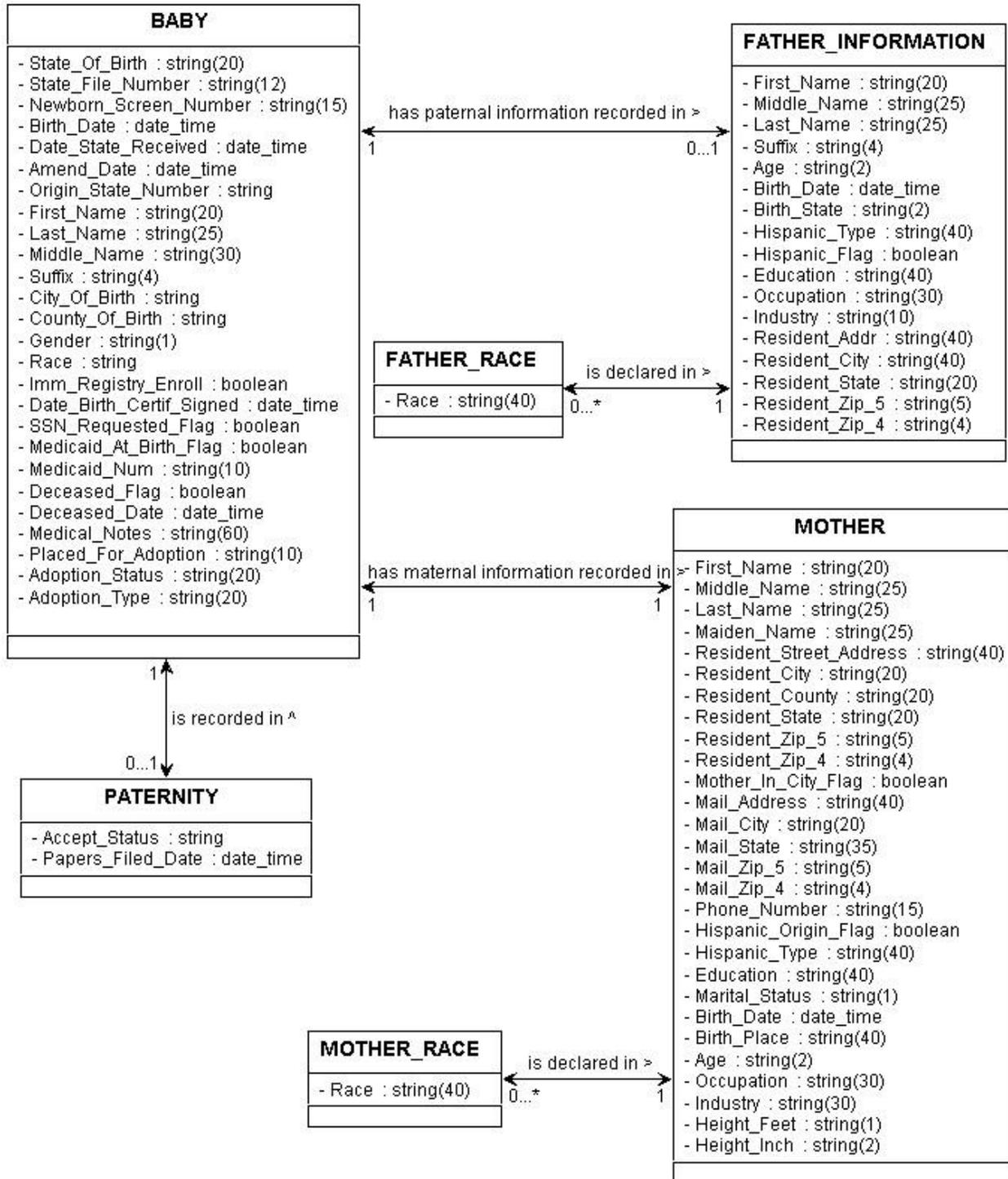


Figure 2.1. VS Baby demographics.

Note. Demographic information of a baby as stored by VS is shown in Figure 2.1.

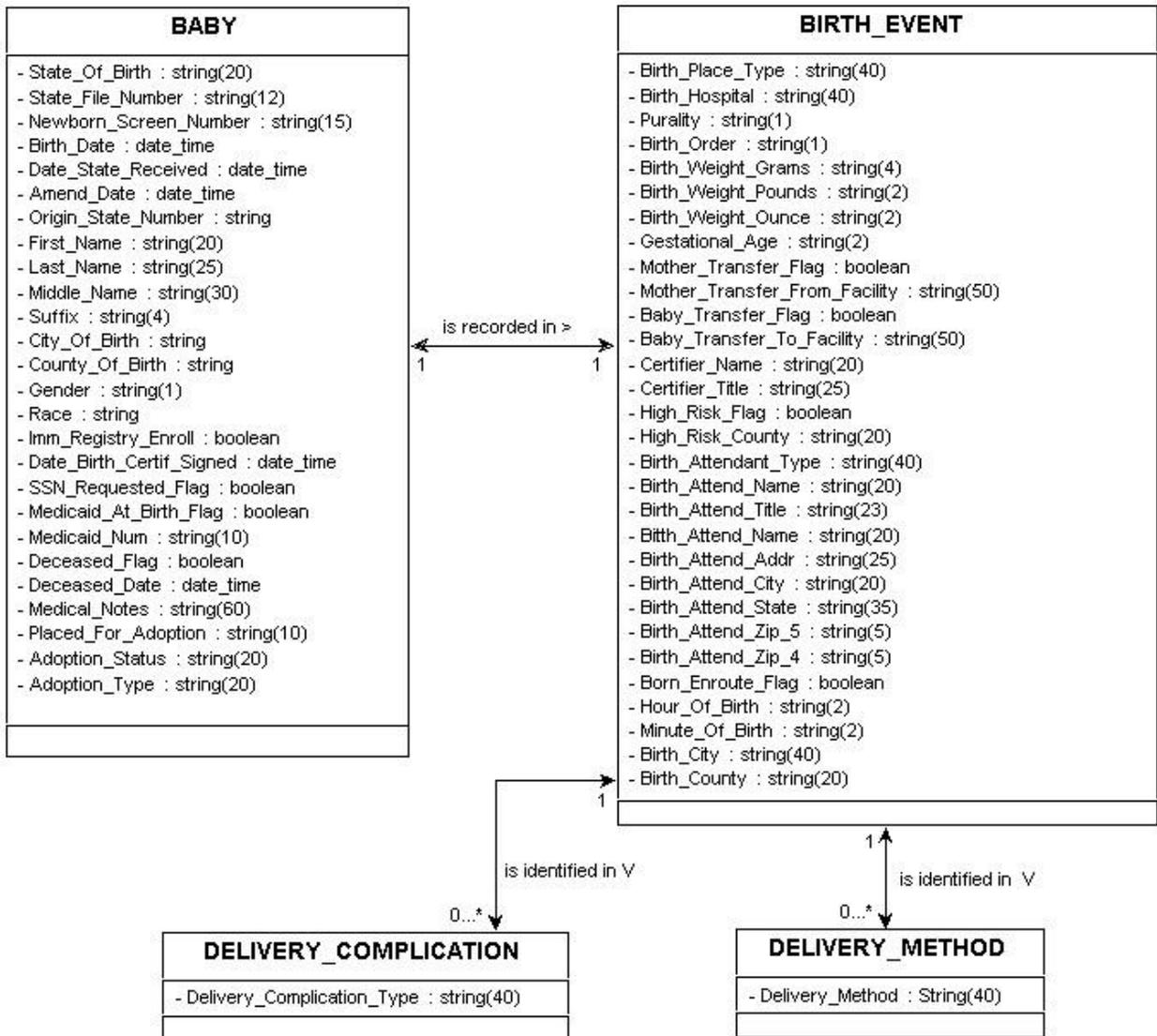


Figure 2.2. VS Birth event of a baby.

Note. Details of the birth of a baby are shown in Figure 2.2.

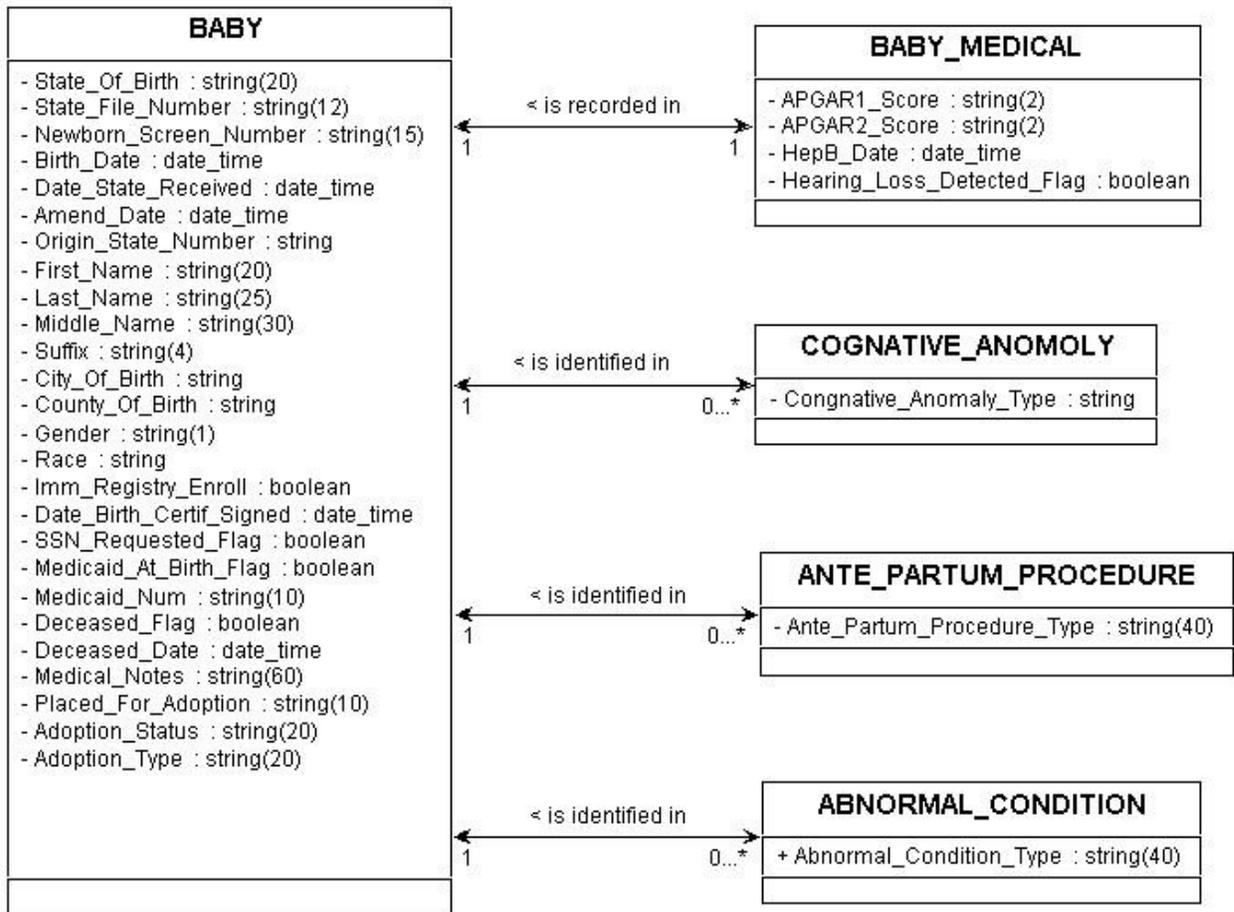


Figure 2.3. VS Medical information about a baby.

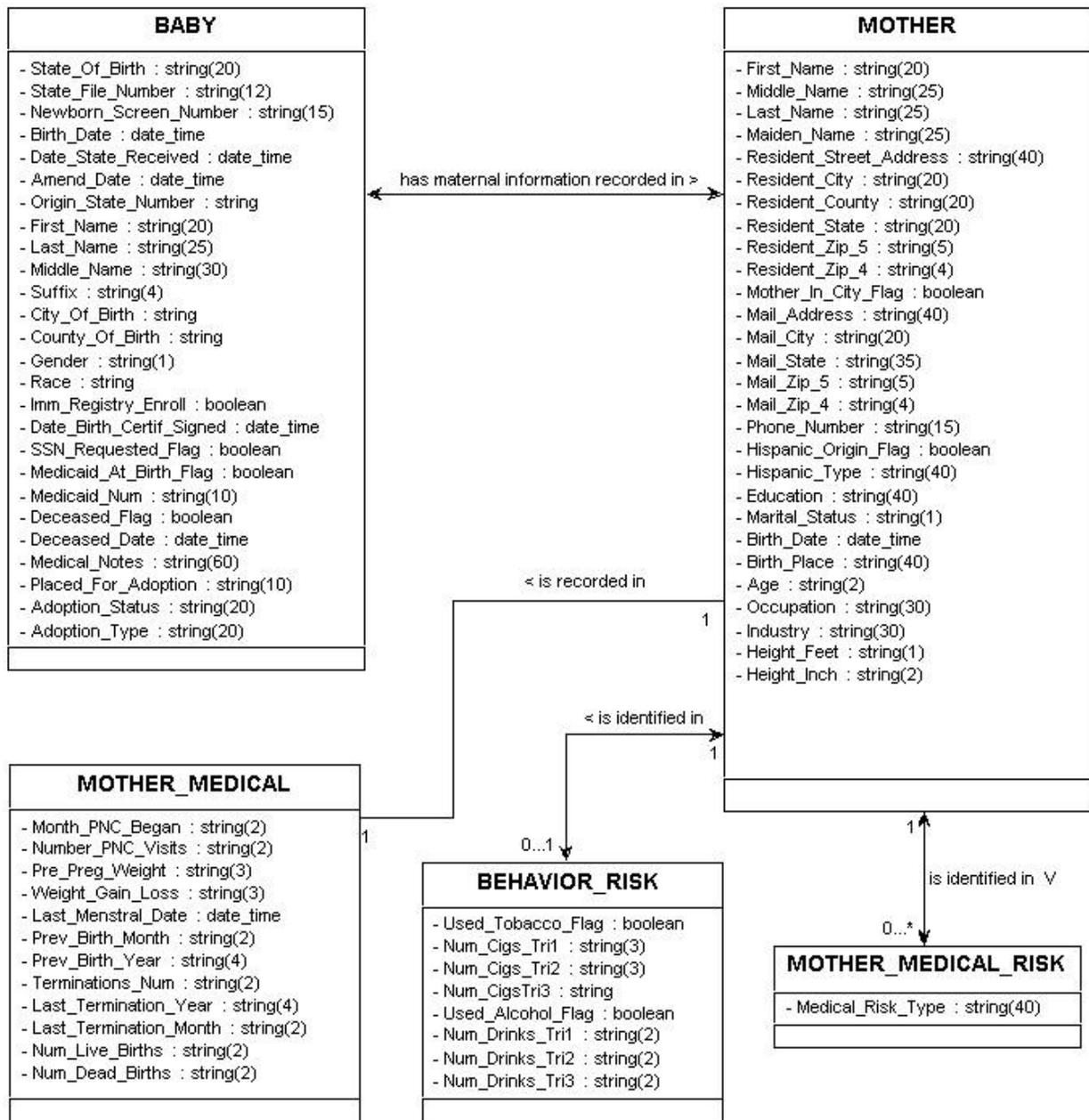


Figure 2.4. VS Mother’s medical information.



Figure 2.5. VS Information regarding the death of a baby.

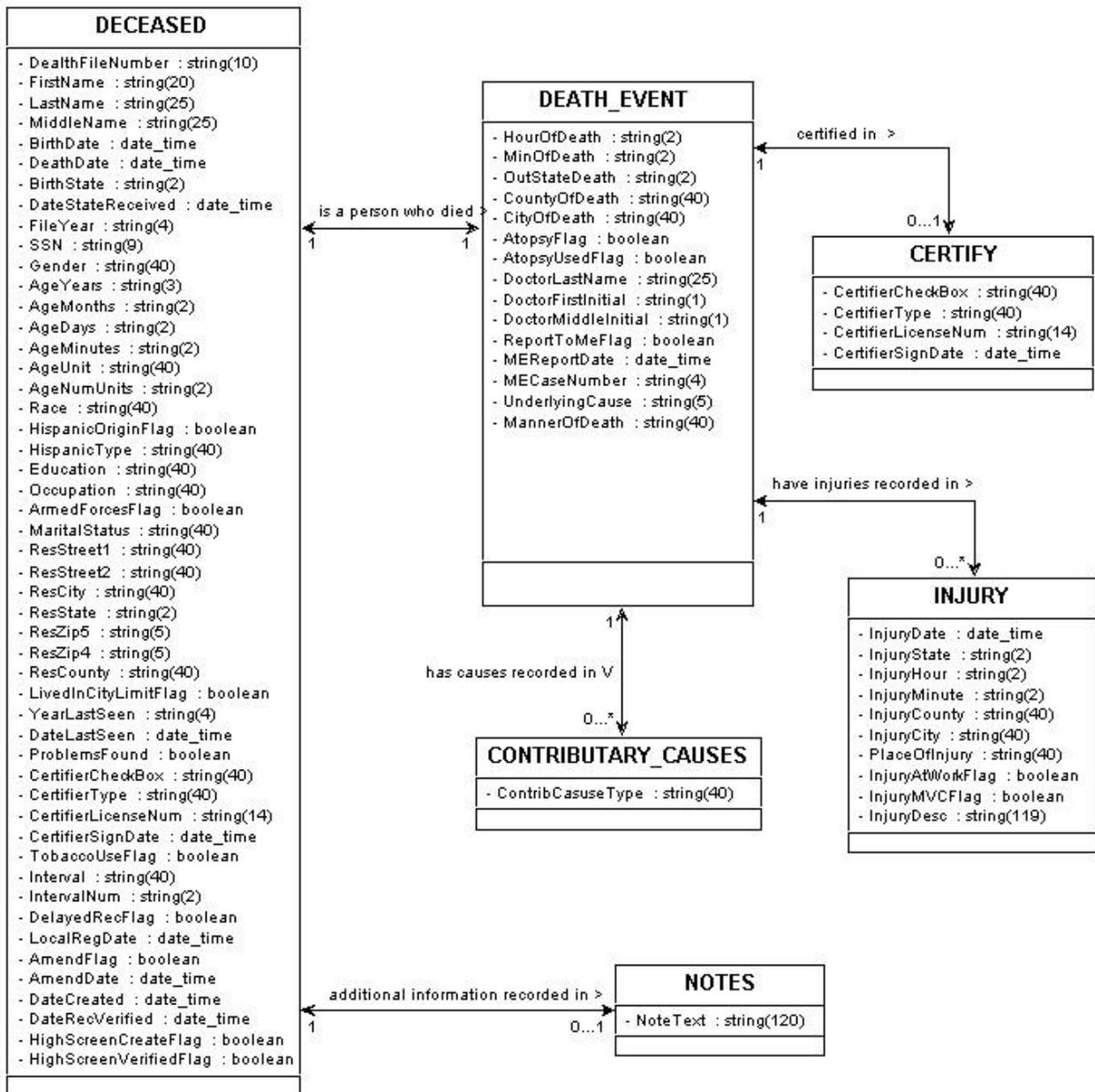


Figure 2.6. VS Additional information regarding the death of a baby.

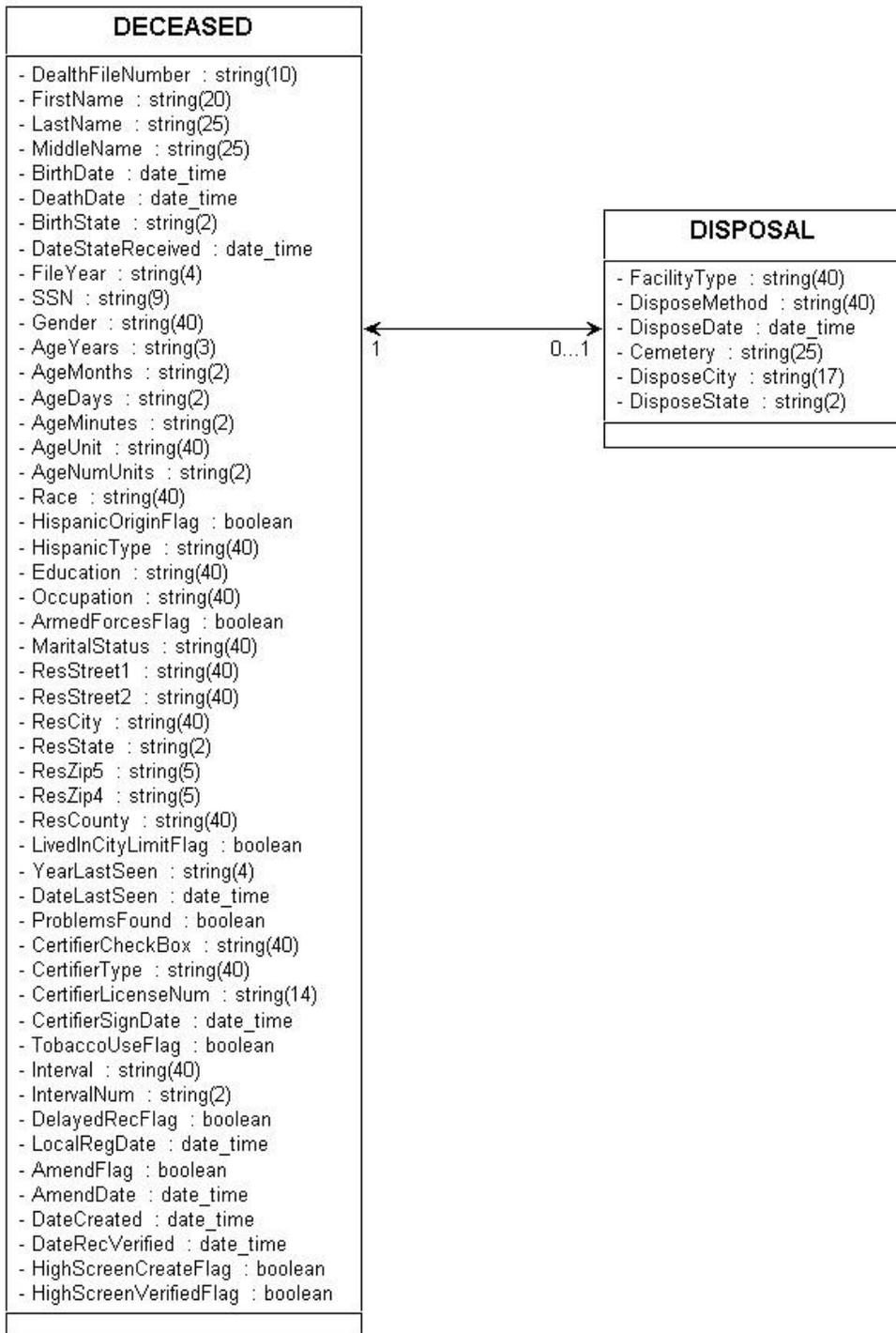


Figure 2.7. VS Disposal of the body of a deceased baby.

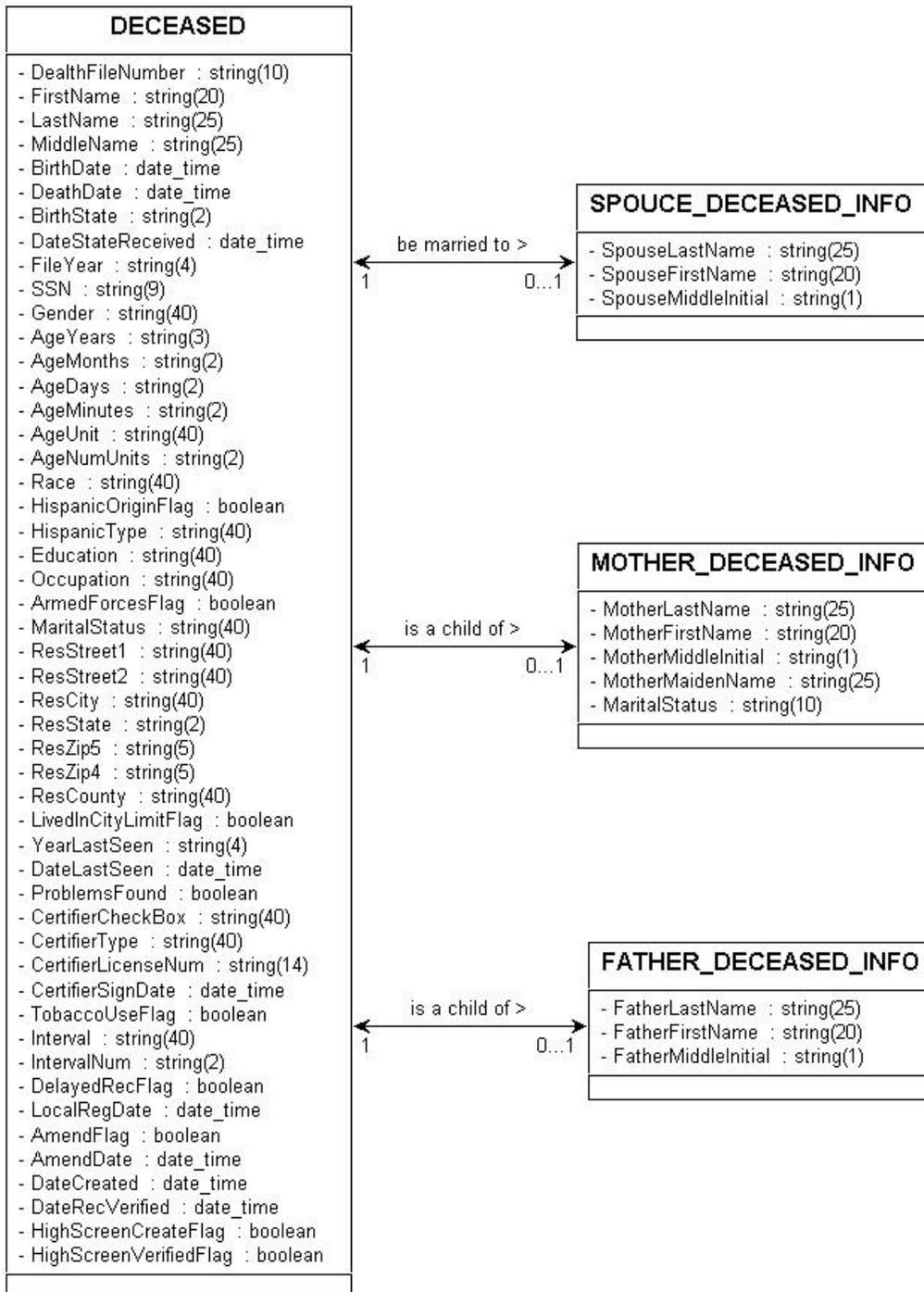


Figure 2.8. VS Information regarding the death of a family member of a baby.

3. Early Hearing Detection and Intervention (EHDI) Data

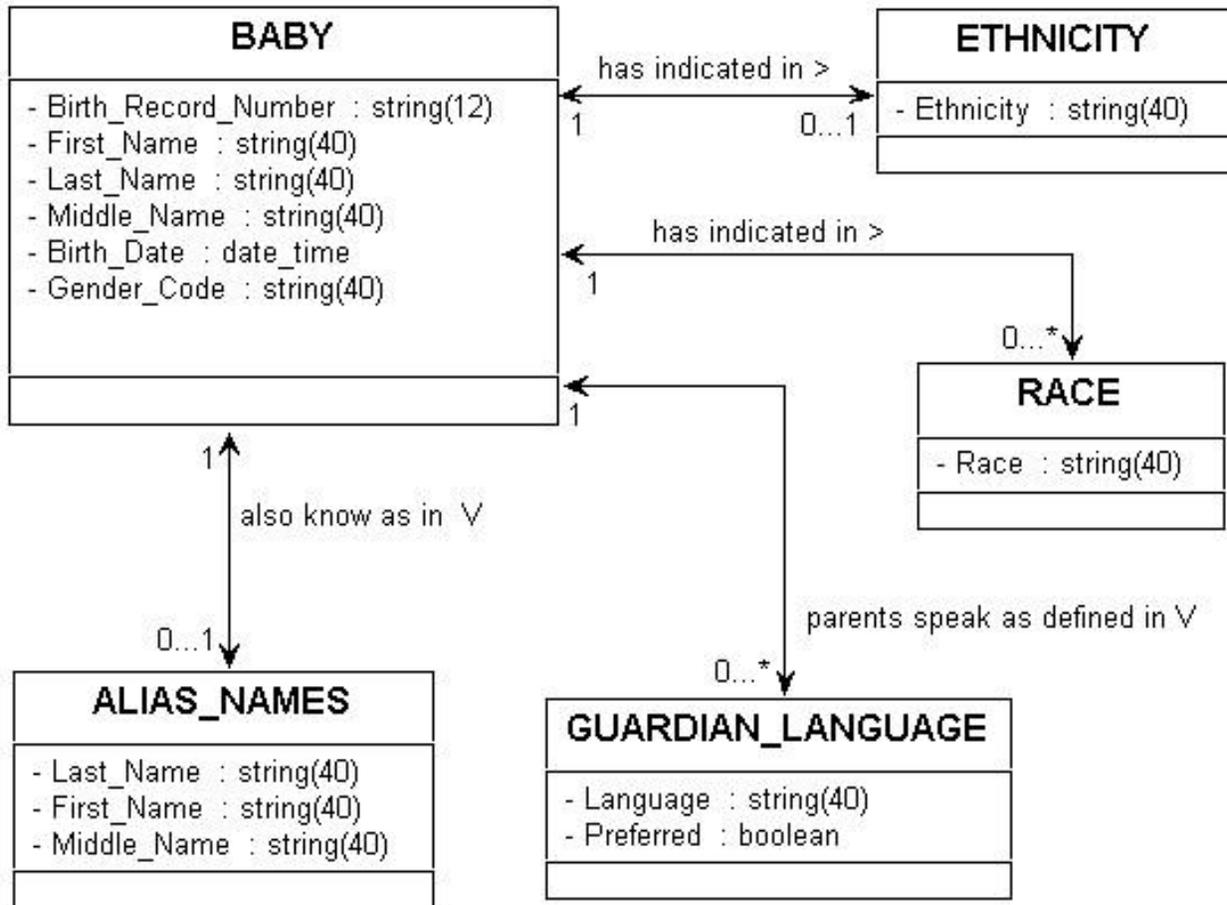


Figure 3.1. EHDI Demographic information for a baby.

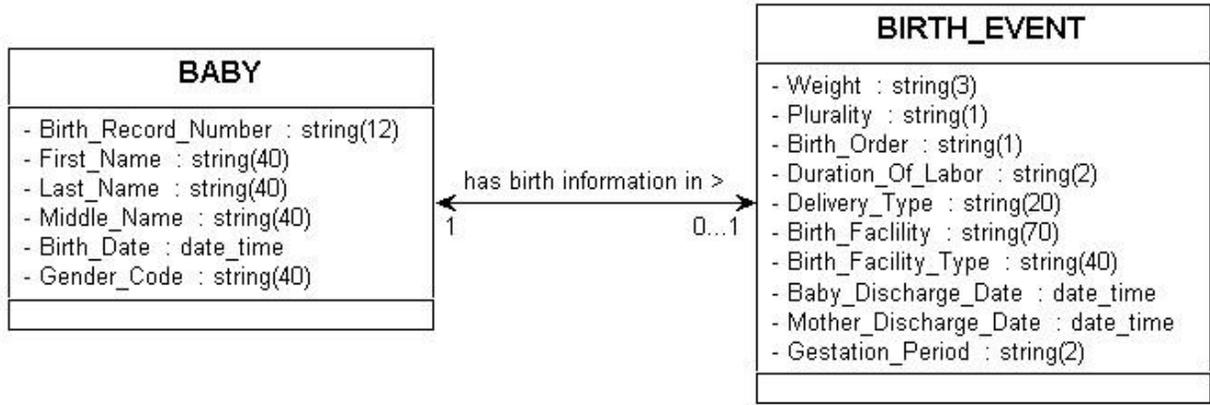


Figure 3.2. EHDI Demographic information for a baby.

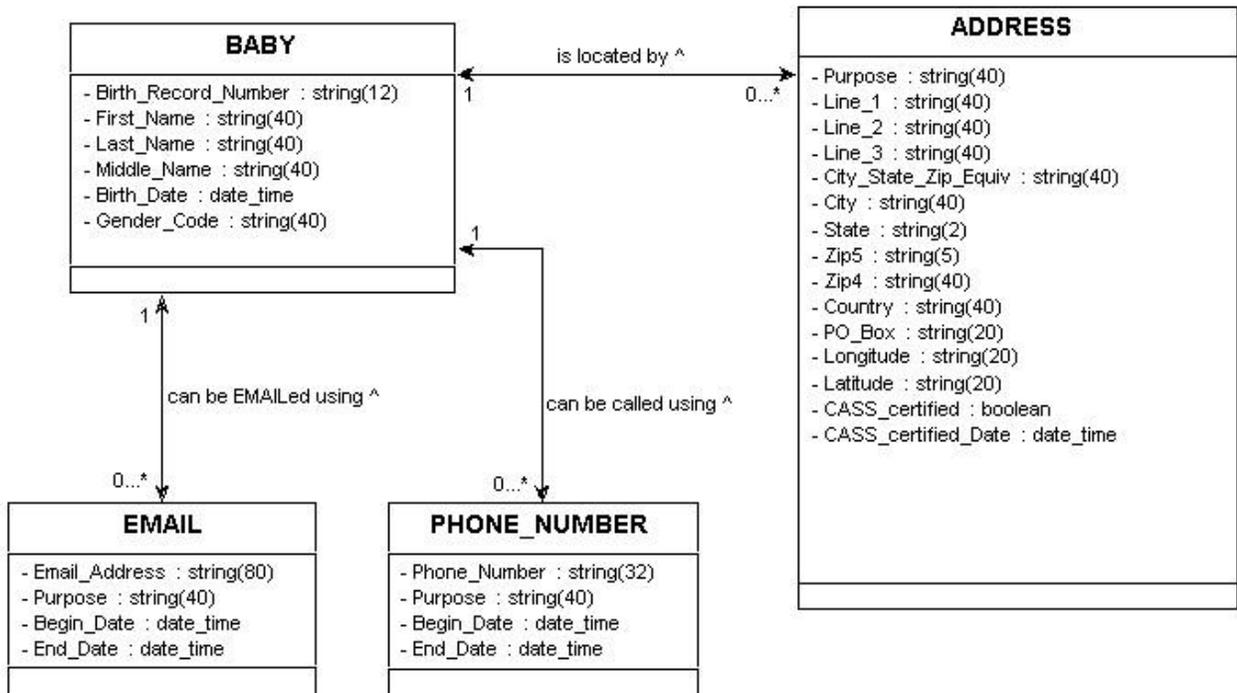


Figure 3.3. EHDI Locator information for a baby.

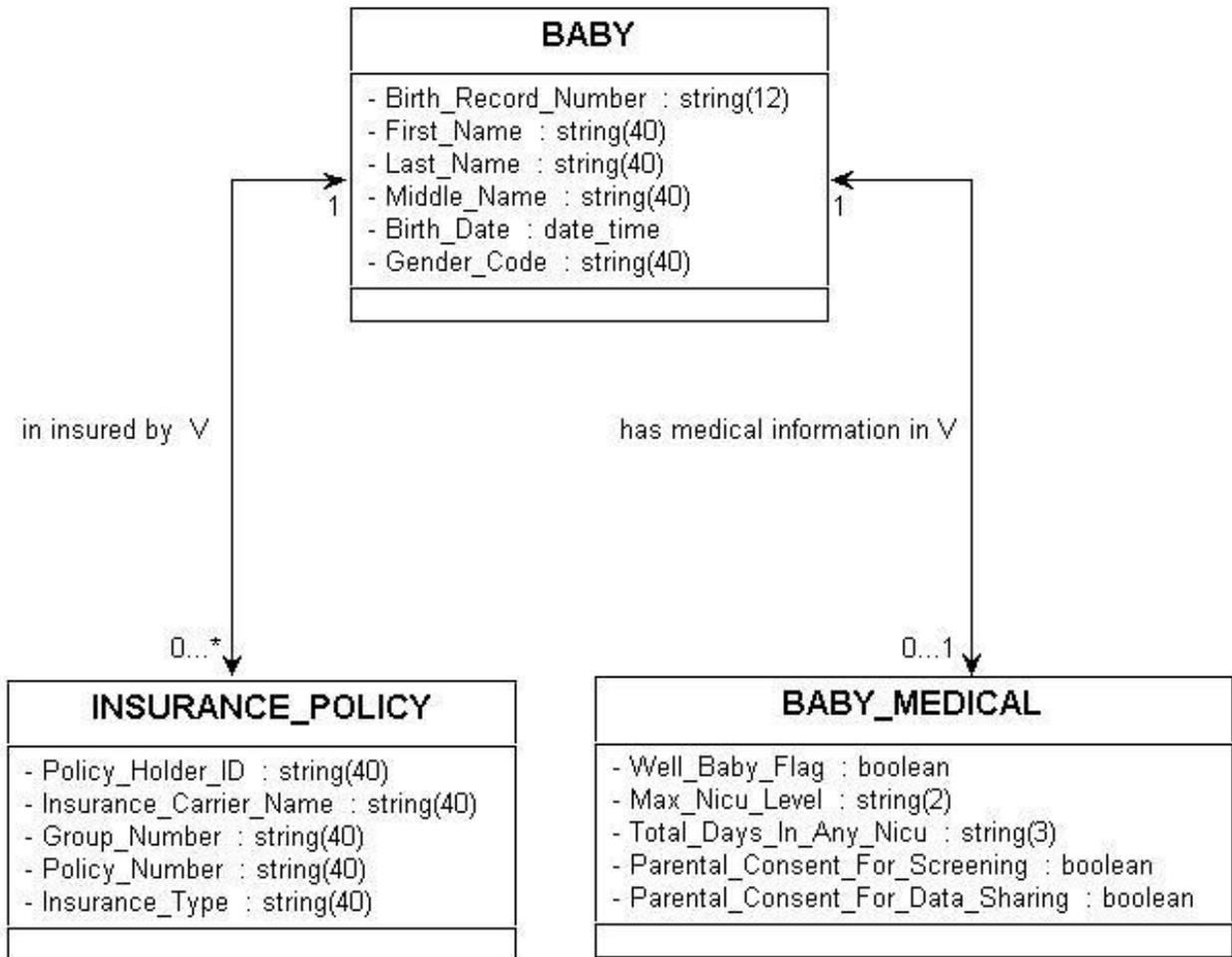


Figure 3.4. EHDI Medical and insurance information for a baby.

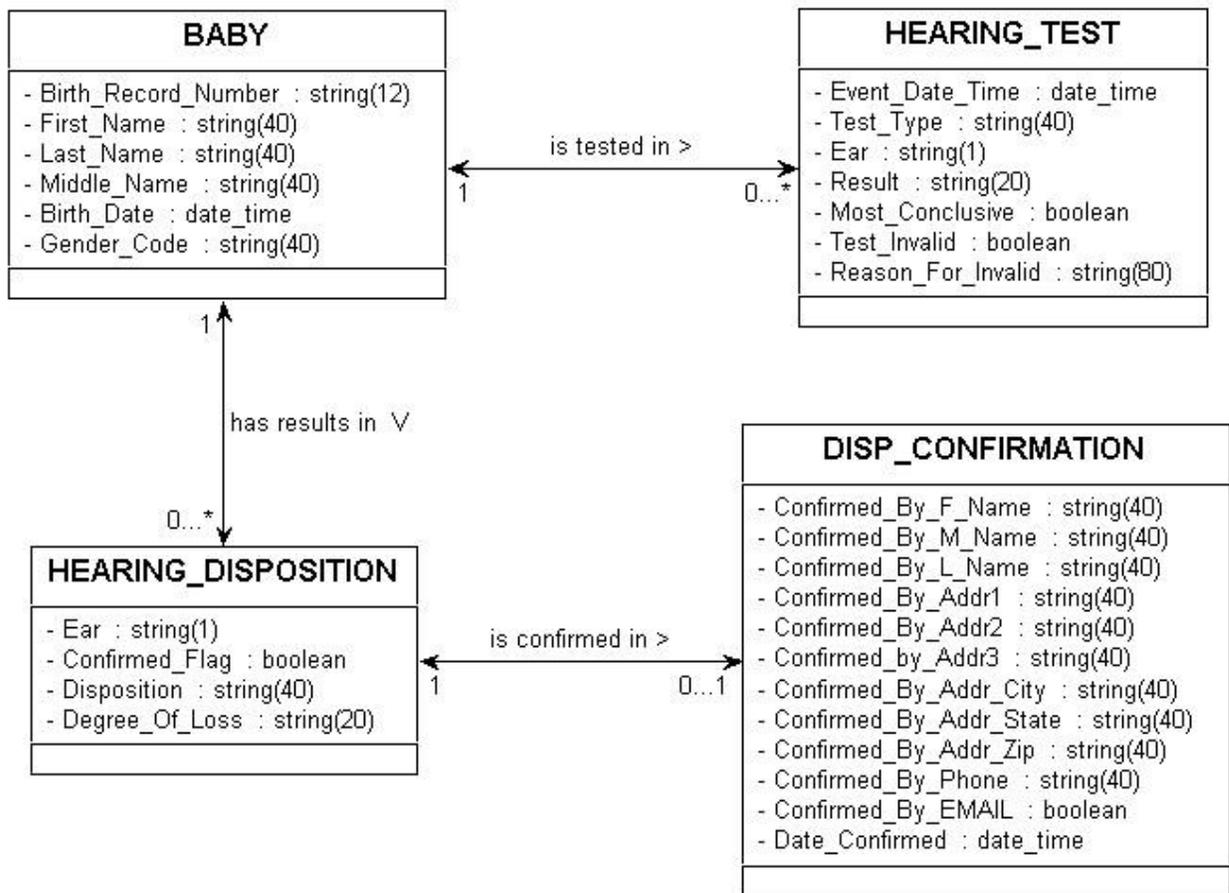


Figure 3.5. The details of EHDI hearing testing for a baby.

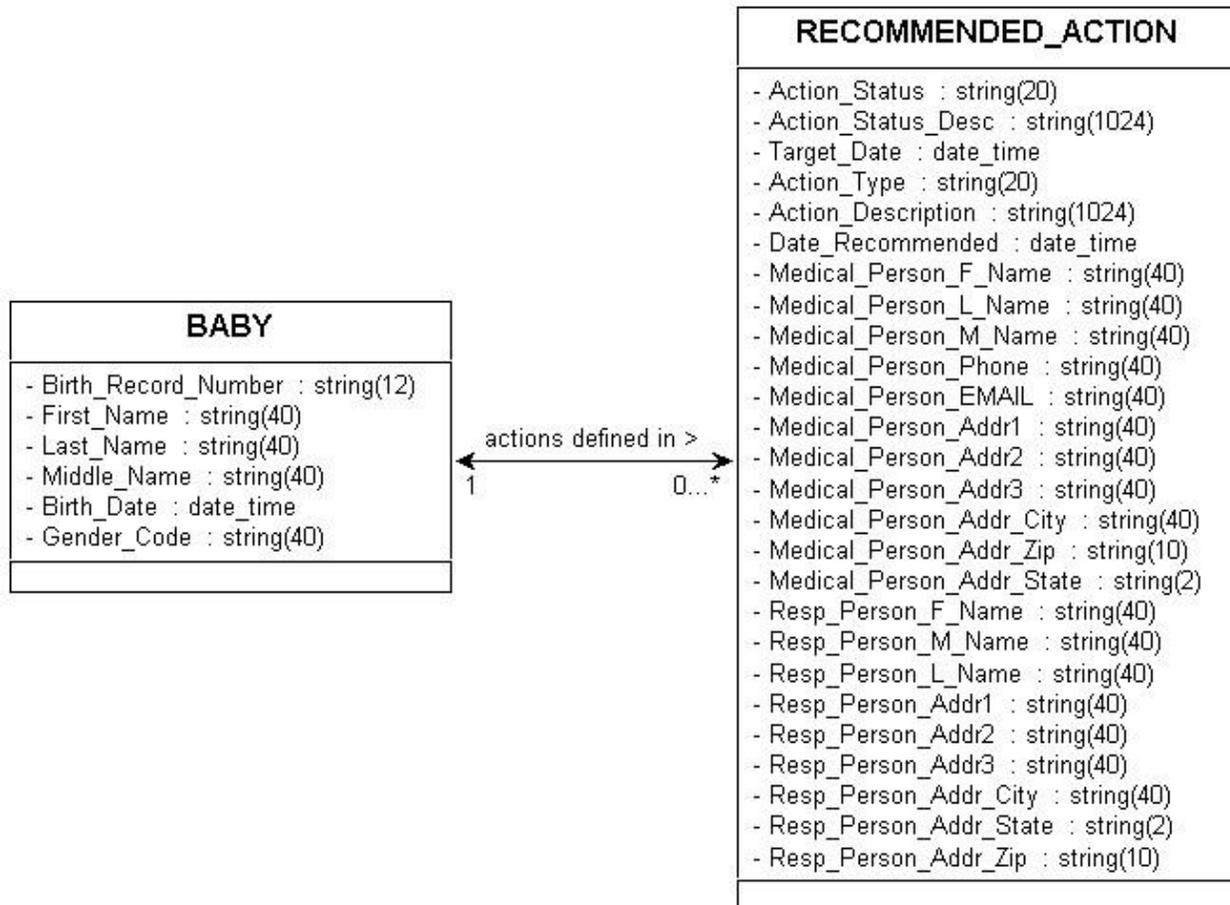


Figure 3.6. EHDI Recommended action(s) for follow-up of hearing testing.

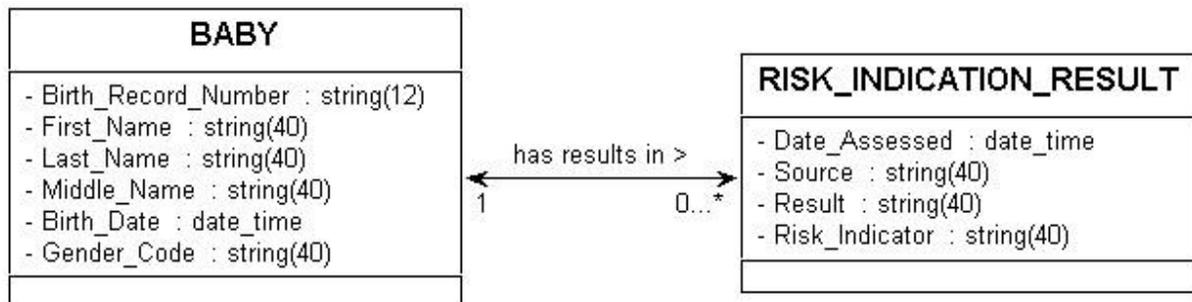


Figure 3.7 EHDI Indicators of risk for a hearing loss of a baby.

4. Newborn Screening Data

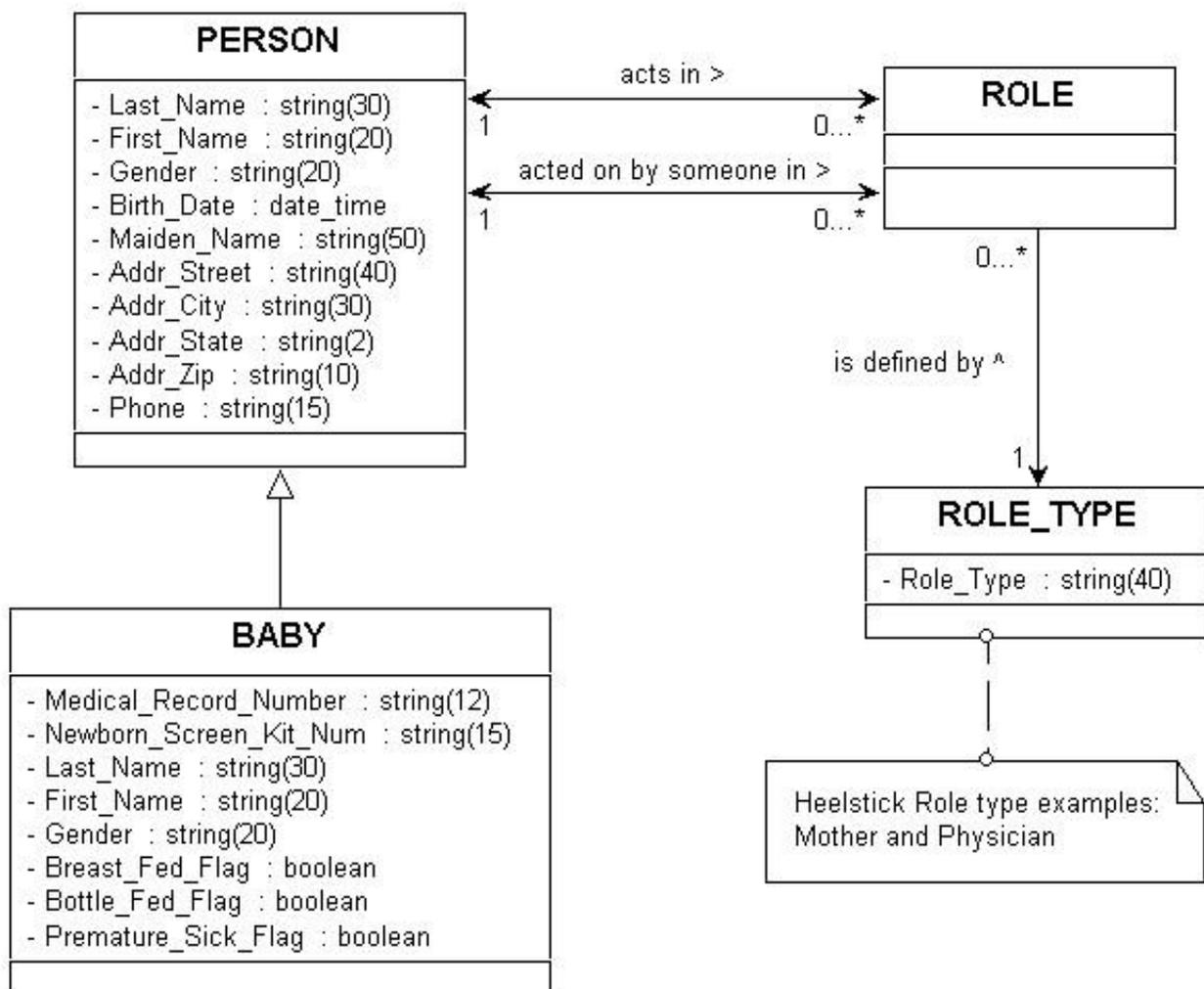


Figure 4.1. Demographic data that may be shared by Heel-Stick, now known as Newborn Screening.

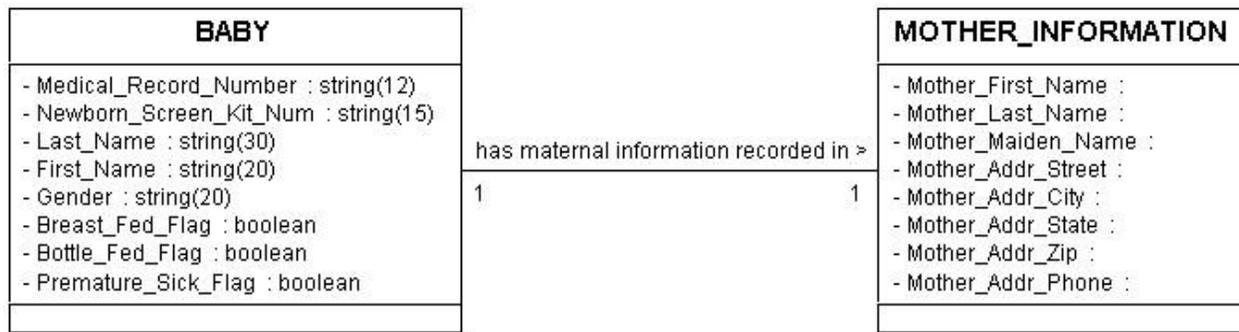


Figure 4.2. Newborn Screening demographic information about a baby’s mother.

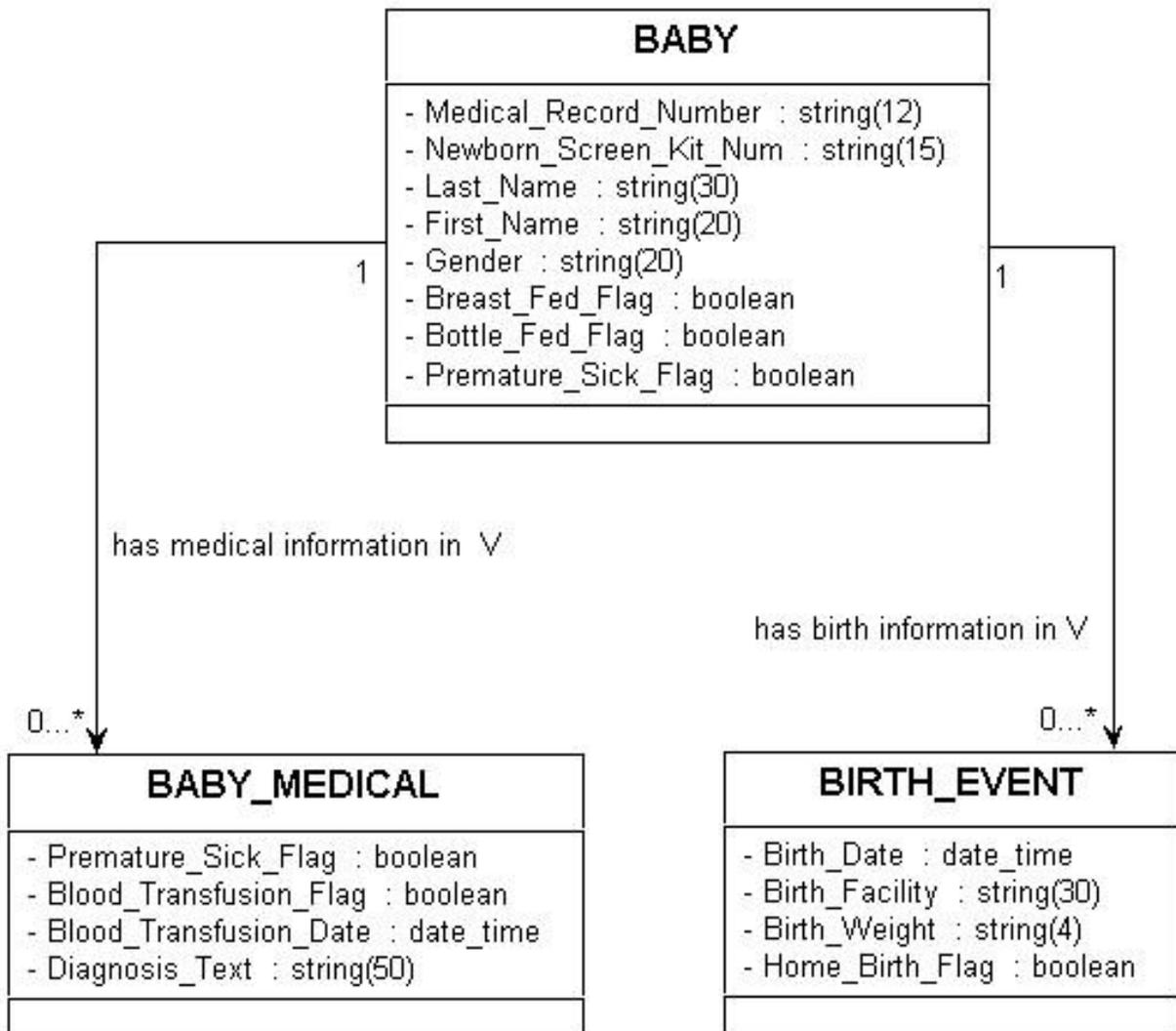


Figure 4.3. Medical information of a baby that may be shared by Newborn Screening.

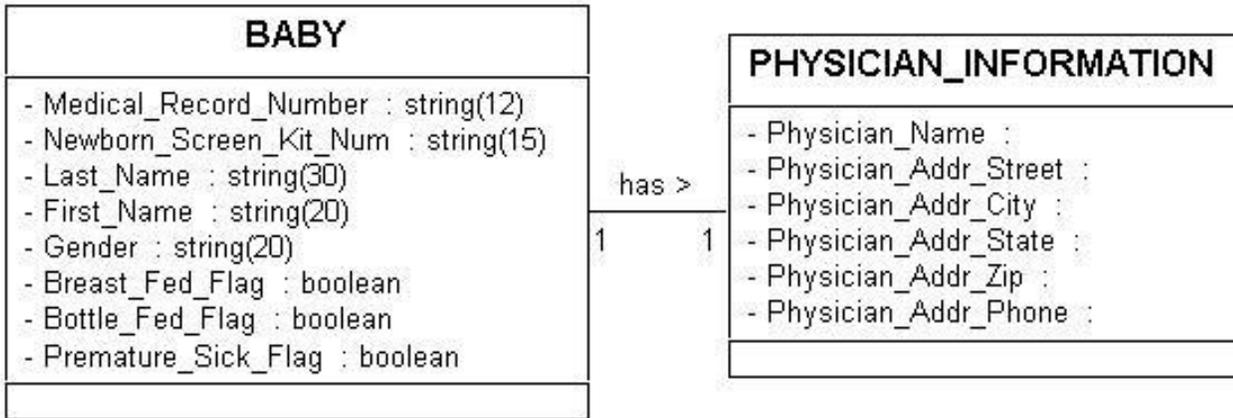


Figure 4.4. Newborn Screening information about a baby’s physician.

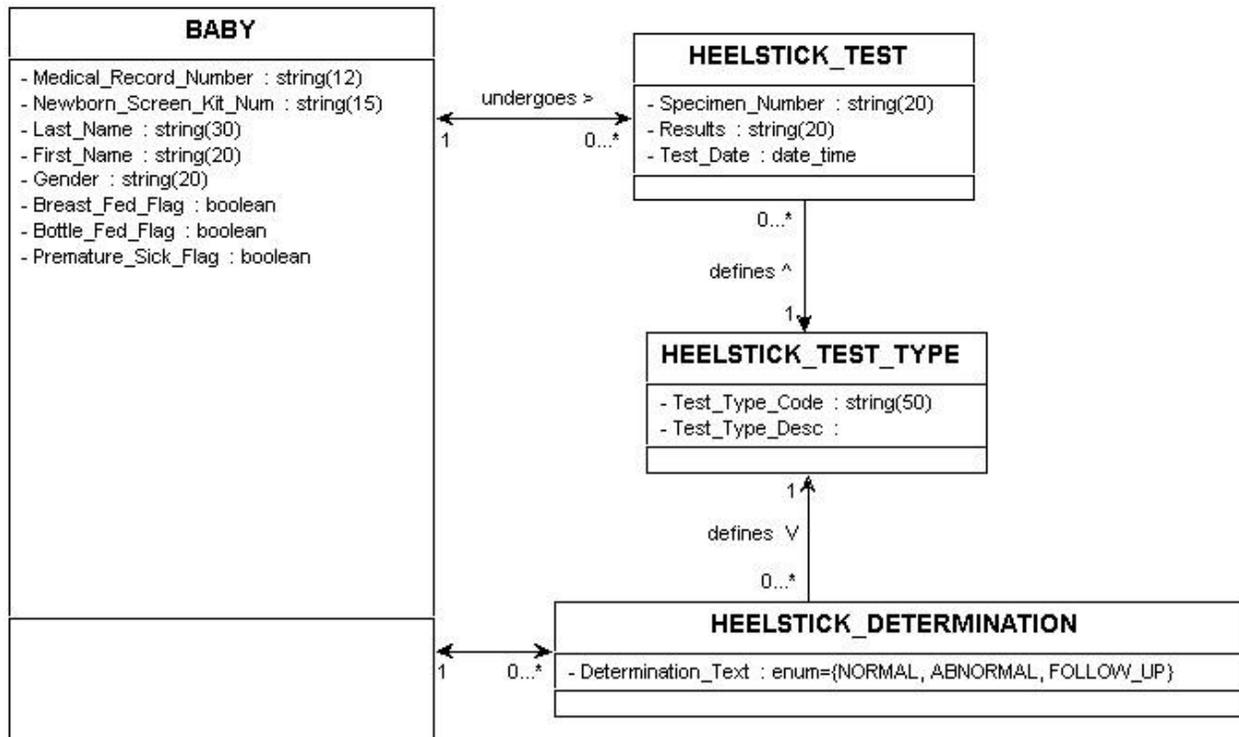


Figure 4.5. Newborn Screening test data.

5. Utah Statewide Immunization Information System (USIIS) Data

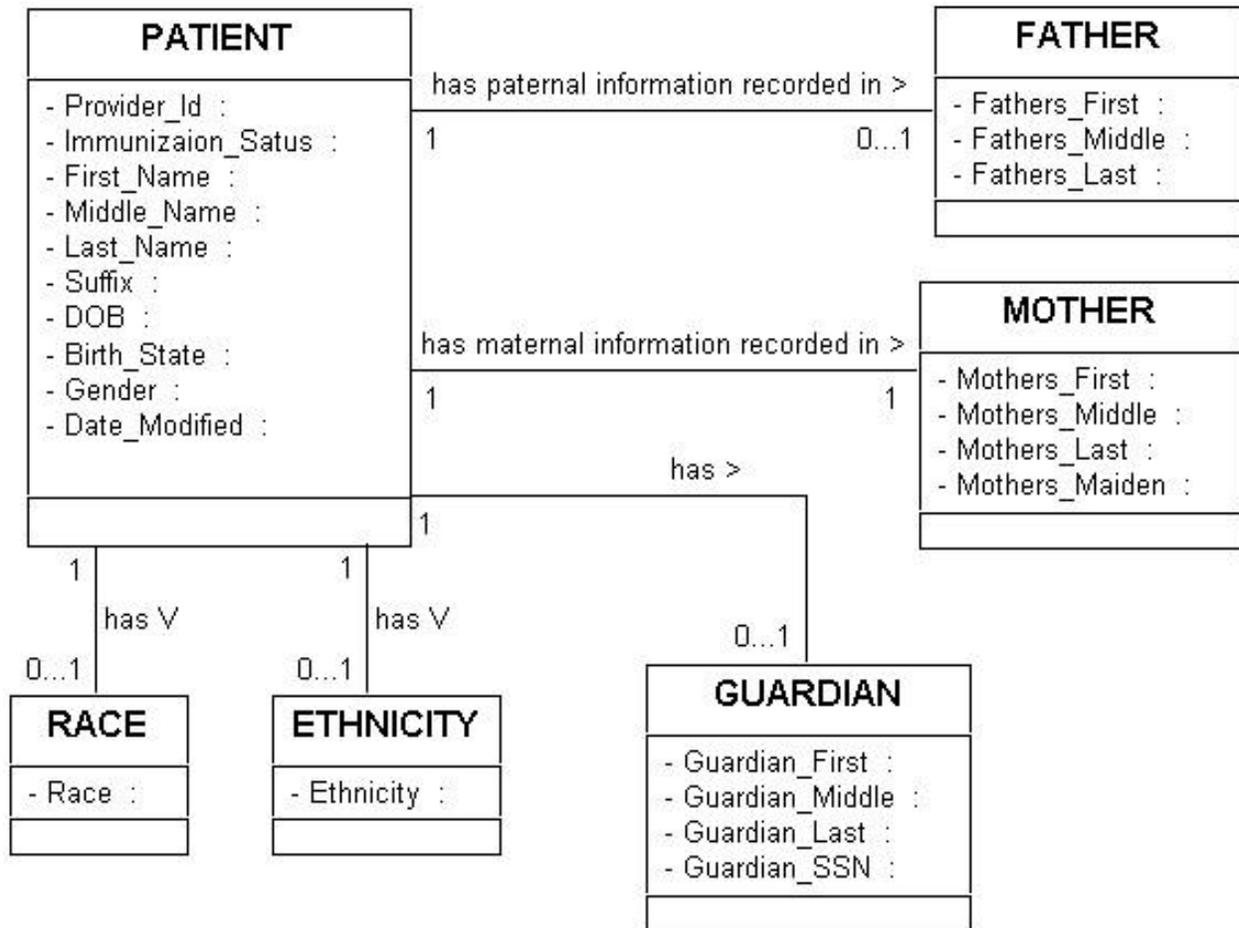


Figure 5.1. USIIS Patient demographic information.

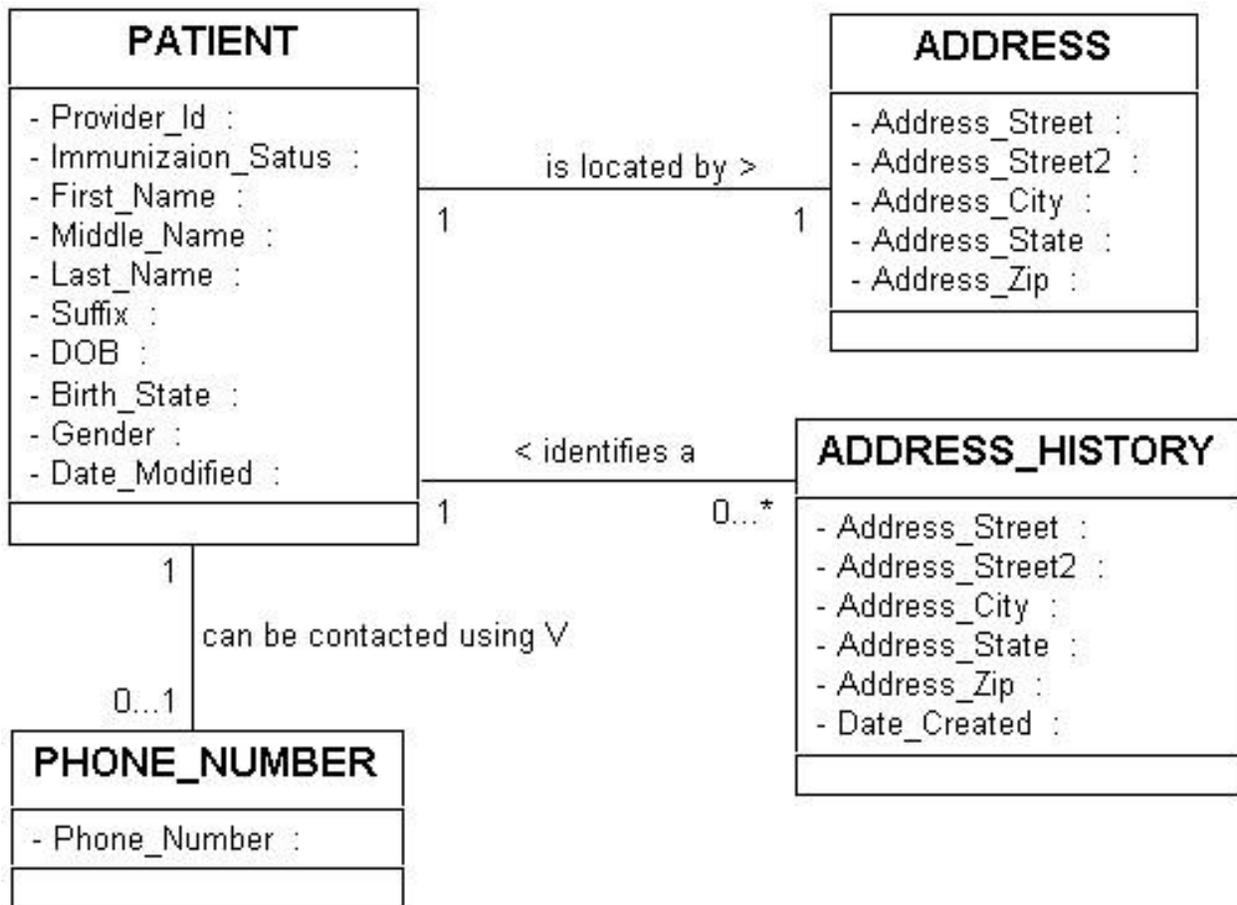


Figure 5.2. USIIS Patient location information.

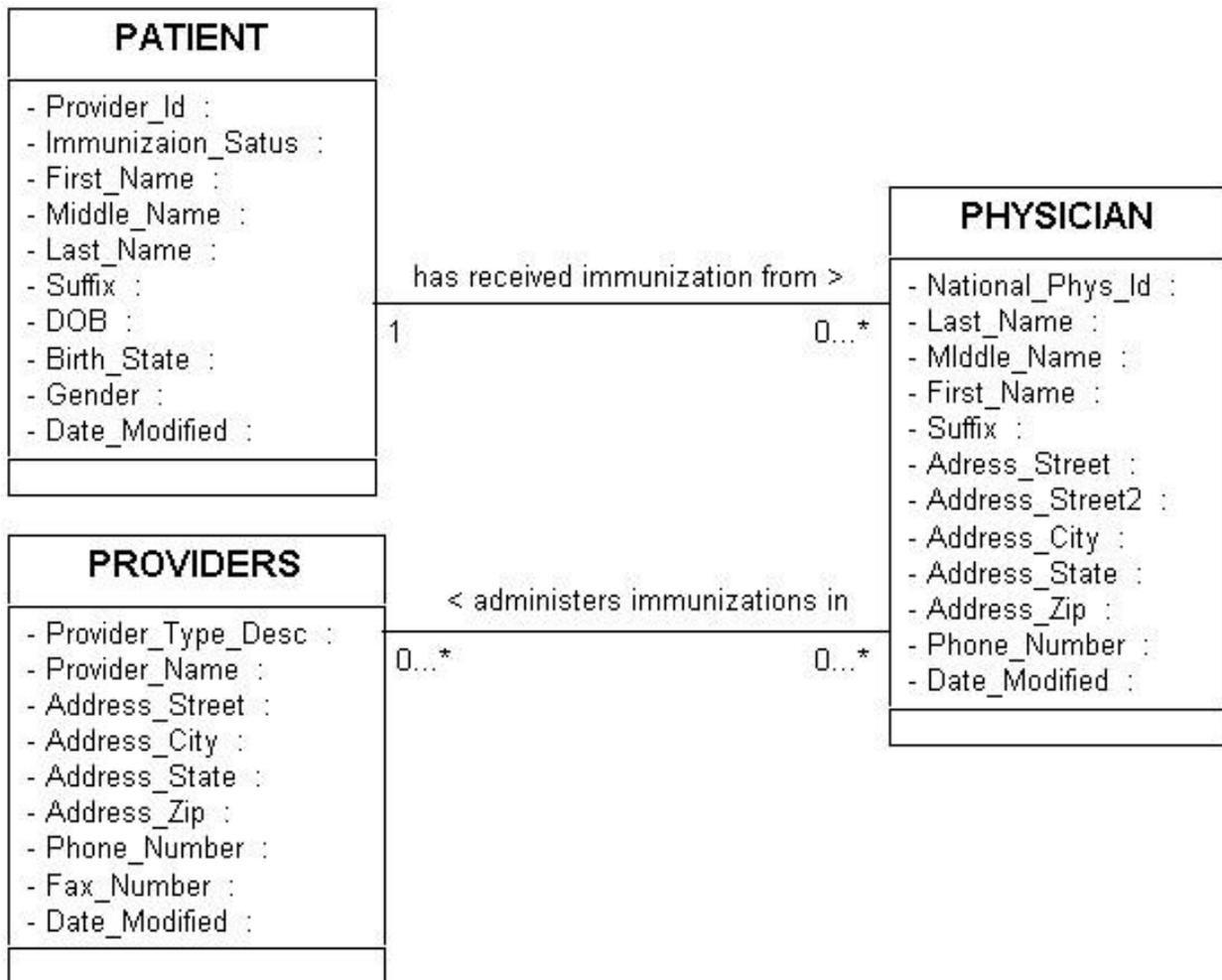


Figure 5.3. USIIS Patient’s physician information.

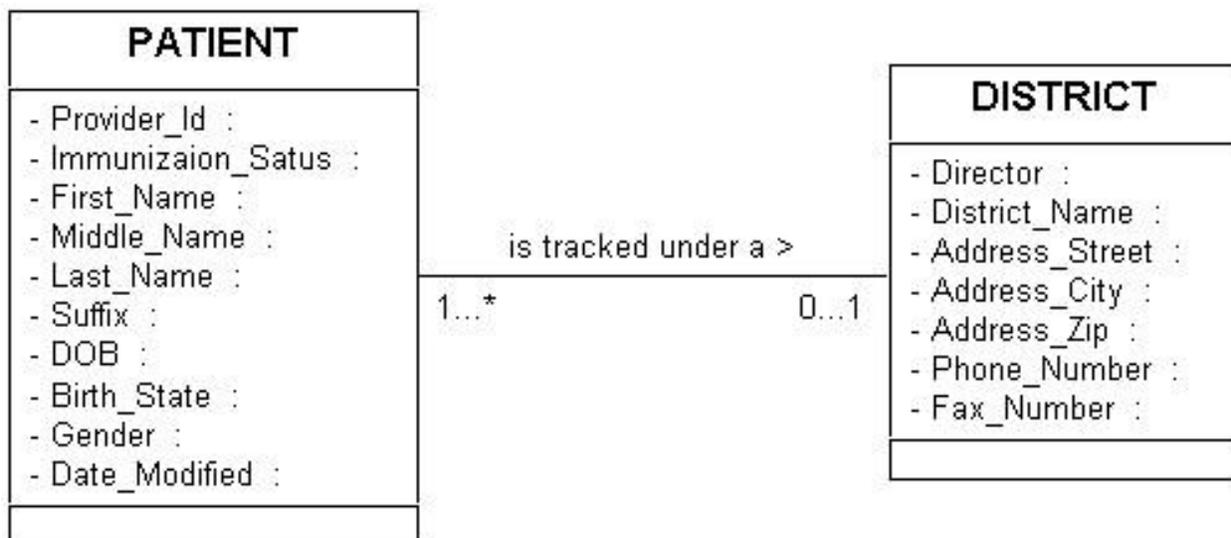


Figure 5.4. USIIS Patient’s school district information.

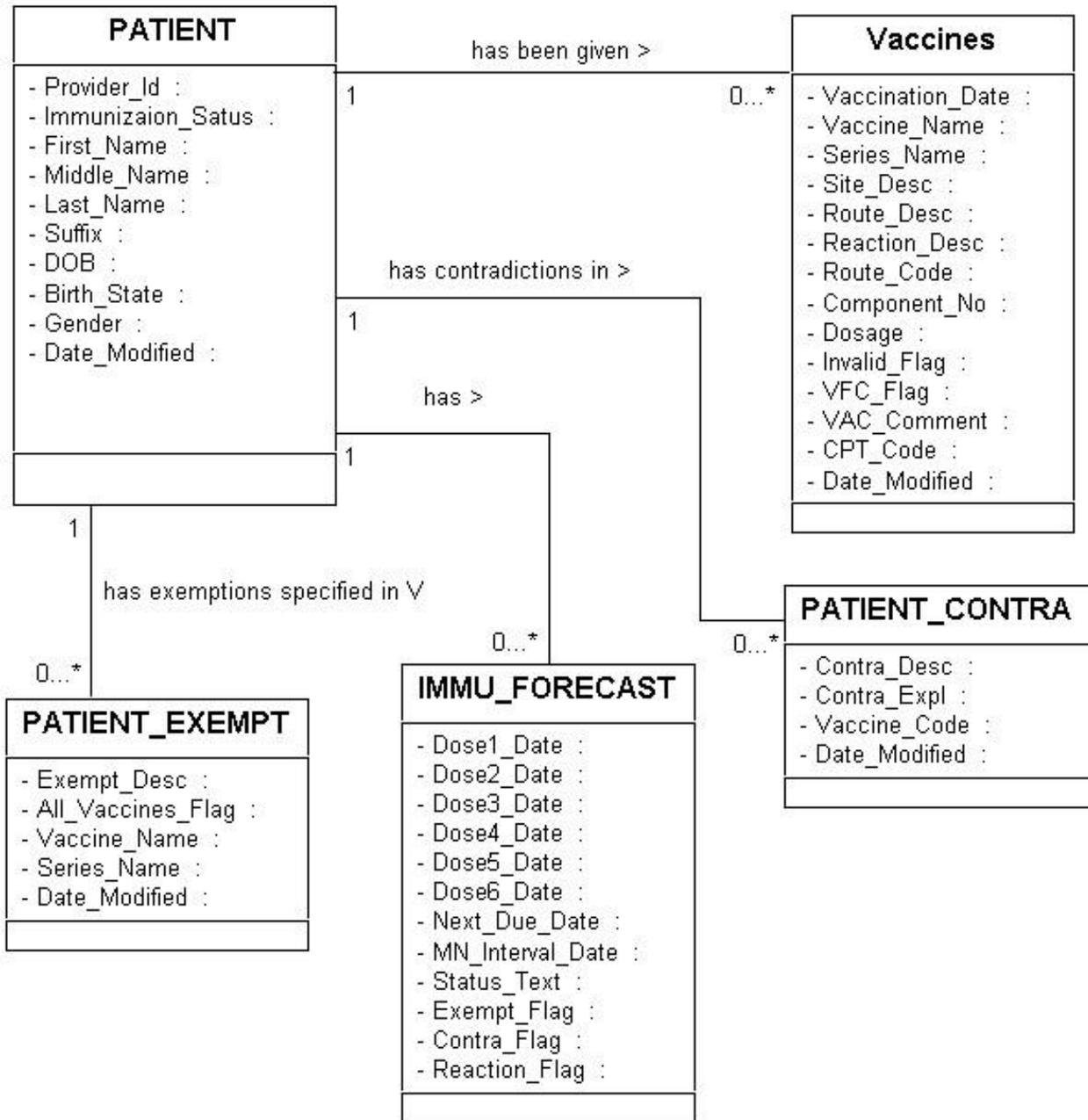


Figure 5.5. USIIS Patient’s immunization information.

6. Early Intervention (EI) Data

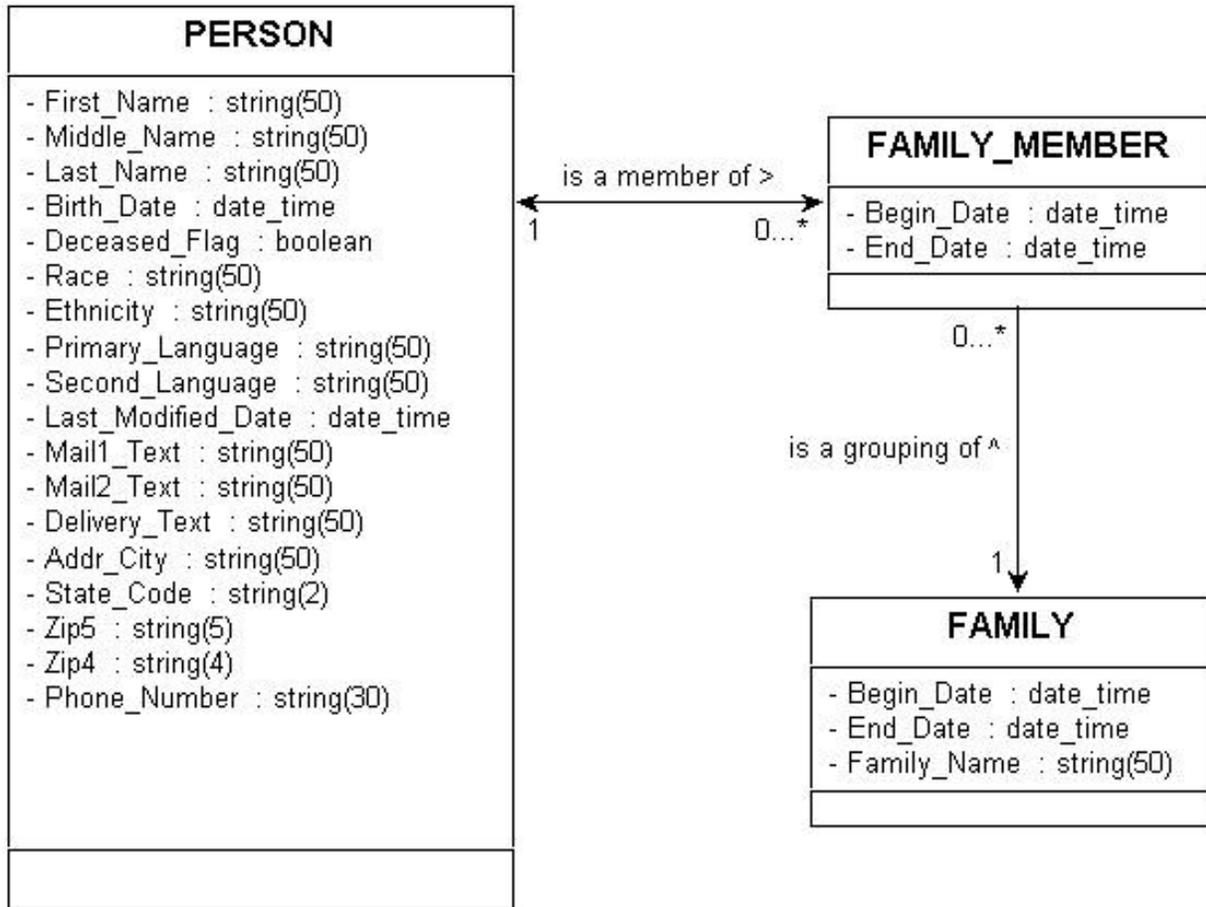


Figure 6.1. Data about the family members of a child served by EI.

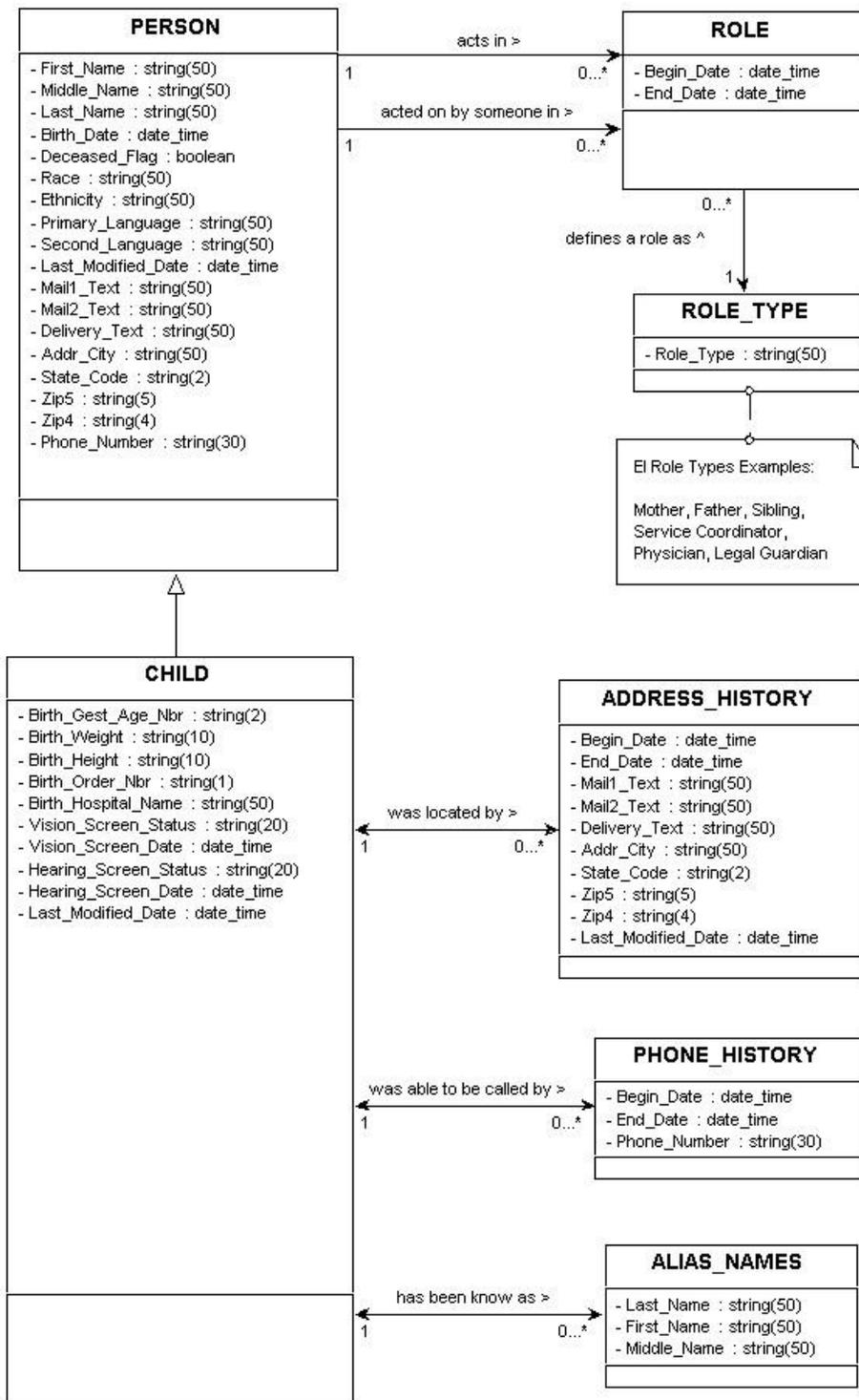


Figure 6.2. Demographic information of child served by EI.

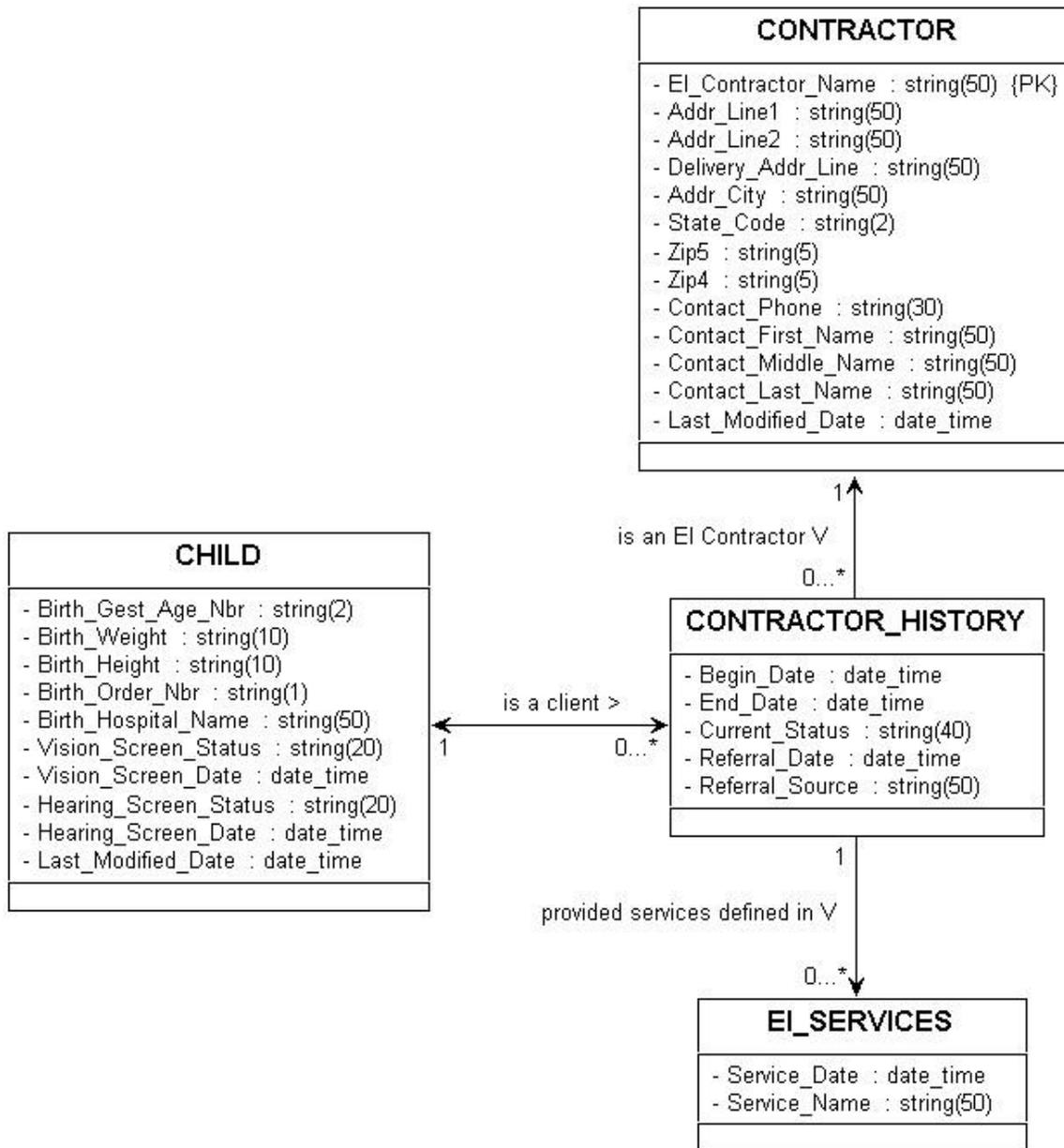


Figure 6.3. Services provided by EI.

7. Summary

Data shared by the five Participating Programs (EHDI, VS, Newborn Screening, USIIS and EI) were presented in this document. This document could be utilized to specify useful services offered by each of the participating program. The participating programs could then utilize these services via the Charm Server.