

USIDNET Data Use Policy

Introduction

USIDNET is a resource for clinical insight into all primary immunodeficiency diseases. We encourage those who wish to learn more about these conditions to submit a query through our online submission system. Please keep in mind that every query is reviewed, and in some cases we ask for revisions in order to clarify the request. In order to ensure that your query is processed in the most efficient manner, we would like requesters to be aware of the following:

Longitudinal Data

At the present time, USIDNET does not have an abundance of chronological patient data to provide reliable longitudinal analysis of disease. Please keep this in mind when considering queries that are exploring immune deficiency in this manner.

Incidence / Prevalence

USIDNET is a patient-consented research study. It does not encompass all individuals in the United States with a primary immunodeficiency disease. Therefore, the USIDNET registry cannot be used to form conclusions on incidence or prevalence of any primary immunodeficiency diseases.

Requests to Use Data

USIDNET will release the clinical data necessary to successfully satisfy a discrete research question. Each query submitted must be justified by a research initiative, question or hypothesis. USIDNET does not release unlimited clinical information contained within the registry for the purposes of data mining or general review. All queries are reviewed by the USIDNET Steering Committee, and where applicable the pertinent Disease Specific Working Group, to determine whether the fields requested are reasonable and pertinent to the research question presented.

Other uses of USIDNET data can be arranged at the discretion of the Steering Committee, keeping in mind that ultimate use of the data must benefit patients with primary immune deficiency.