

## Why is this important?

Data collected will help researchers answer important healthcare questions and come up with new ideas for treatments to study in clinical trials. If you have a disease or condition that researchers want to study more in the future, you may be contacted regarding participation in a study. This contact will come through your specific hospital, clinic or community health center where you receive your care in order to protect your privacy.

## Who in my community is involved in this project?

CAPriCORN has a Patient Community Advisory Committee (PCAC) which is comprised of patients; health professionals; community members who are interested in advocating the patient perspective in health care research; and representatives from advocacy/volunteer health organizations. The PCAC works hand-in-hand with the CAPriCORN researchers to generate research questions that are important and relevant to patients. In addition, the PCAC advises investigators on prioritizing research that takes place within the CAPriCORN network.

## CAPriCORN Partners

Chicago Area Patients and Patient Advocates  
AllianceChicago (formerly Alliance of Chicago Community Health Services)  
Ann & Robert H. Lurie Children's Hospital of Chicago  
Cook County Health & Hospitals System  
Loyola University Health System  
NorthShore University Health System  
Northwestern Medicine  
Rush University Medical Center  
University of Chicago Medicine  
University of Illinois Hospital & Health Sciences System  
Veterans Administration (Jesse Brown VA Medical Center & Edward Hines, Jr. VA Hospital)

## How do I get involved?

Visit [www.CAPriCORNCORN.org](http://www.CAPriCORNCORN.org) for more information, to vote on health issues CAPriCORN should address, and to learn how you can be a part of improving health in your community.

For information on CAPriCORN at (site name), contact (site specific contact information).

9 Million People

1 Region

1 Mission



Chicago Area Patient-Centered  
Outcomes Research Network  
(CAPriCORN)

**Learn More About Your  
Role in Public Health**

## What is CAPriCORN?

CAPriCORN is a Chicago-wide partnership between eight leading healthcare systems, two Veteran's Administration Hospitals, AllianceChicago's health clinics, and all of their patients.

## What is the purpose of CAPriCORN?

The goal: work together to find ways to improve health care and results, focusing on issues affecting people living in and around Chicago. CAPriCORN expects to answer important health questions and with those answers help patients make decisions about what is right for them.

## Who supports CAPriCORN?

CAPriCORN has support from the leadership of all participating institutions, as well as community organizations and local city, county, and state officials, including the Commissioner for Public Health of the City of Chicago, the Cook County Board President, insurance organizations (State of Illinois Medicaid; Blue Cross/Blue Shield), and non-profits such as The Chicago Community Trust, which was instrumental in the initiation of CAPriCORN. CAPriCORN is managed under the Center for Health Information Partnerships at Northwestern University.

## How is CAPriCORN funded?

CAPriCORN is 1 of 13 Clinical Data Research Networks funded by the Patient Centered Outcomes Research Institute (PCORI) to provide a National Patient-Centered Clinical Research Network (PCORnet). PCORI is funded through the Patient-Centered Outcomes Research Trust Fund, which was authorized by Congress as part of the Affordable Care Act of 2010.

## Which health conditions has CAPriCORN studied?

CAPriCORN initially focused on common health conditions such as obesity, asthma, diabetes and anemia, and rare health conditions such as recurrent *Clostridium difficile* (*C. difficile*) and sickle cell disease.

Currently, more health conditions are being selected based on patient needs in the metropolitan Chicago area, and the experience of doctors, patients and researchers in the health systems represented by CAPriCORN and PCORnet partners.

## Why do researchers need health information from patients' medical records?

Your health information is very valuable to advance research, especially when combined with healthcare information from others. Every day, patients and doctors face common questions that have no clear answers, such as:

“When is the best time to take my daily blood pressure medicine?”

“What is the best treatment plan for my 87-year-old father with anemia?”

“Which medication is best for my child with asthma?”

Combining and studying information from a large numbers of patients can provide answers to these and other common health questions. Health information gathered from patients in Chicago and throughout the country will assist researchers in addressing some of the nation's common and often most serious health issues. Health and illness-related information will be compared with characteristics of individuals, such as age, gender, race or ethnic group or geographic area, to test how these attributes affect health.

## How will my health information be shared?

When you see your doctor and agree to be treated at your hospital, clinic, or community health center, your health information is saved at your specific hospital, clinic or community health center to help with your future care and for business and research purposes.

CAPriCORN allows the health information at your health care institution to be shared with information from millions of other patients being seen at the other CAPriCORN partners. This sharing occurs by a secure electronic network that connects the partner institutions and includes multiple levels of protections to keep your health information confidential.

An important security feature is that your name, date of birth, address and other personal information will not be shared or connected with your health information outside of your hospital, clinic or community health center.

CAPriCORN will never allow information that will identify you to be shared outside your health center unless you have given your written permission.

CAPriCORN network is also connected to other similar networks across the country to study specific illnesses on a national level.