



DEEP DATA DIVE – May 2017

Secondary diagnoses are key to understanding disease trends as they provide profound insight into disease trends, factors leading to principal diagnosis and leading cause of death, and are key to patient disease management and provider resource management.

Secondary diagnoses are key to understanding health trends and resource usage as secondary diagnoses are often:

- Possible driving factor leading to principal diagnosis,
- Window to the world of emerging or advancing diseases and disease epidemics,
- Key to managing patient's health and well-being,
- Opportunities to empower people, patients, and families by sharing knowledge and information on disease trends,
- Helpful in provider and health plan resource management and planning, and
- Important to address early on to prevent increases in preventable conditions and deaths.

Sources of Big and Local Data. Hospital inpatient data is the main source of information that is readily available on a national basis covering all patients including all payers and the uninsured. As hospitals are typically the recipient of patients that require advance health interventions for all diseases, the hospital data provides one of the most comprehensive view of advancing diseases and conditions.

The source of hospital information is the claims data which has become increasingly helpful in identifying disease trends through standard ICD codes. The hospital claims diagnosis and procedure codes are highly reliable as a result of:

- Expansion to 25 diagnosis and 25 procedure codes from 9 diagnosis and 6 procedure codes that began in 2006 as hospitals transitioned to HIPAA 837 electronic claim formats. The expansion allows for providers to report on all secondary diagnoses and not force them to pick and choose which ones to report.
- As of October 2007, Medicare required all hospital inpatient claims to report the Present on Admission (POA) codes on diagnoses to distinguish complications and conditions that occurred prior to or during the hospital stay. Since that time, other health plans and state agencies have required the inclusion of POA on inpatient hospital claims. The POA is also used as a determinant in incentive payments as it can identify the conditions that were hospital acquired.

- Improved accuracy of claims data as a result of increased financial incentive payments and fraud oversight and review.

AHRQ HCUP. The most comprehensive source of national inpatient hospital data for all health plans and uninsured is the Agency for Healthcare Research and Quality (AHRQ) Healthcare Cost and Utilization Project (HCUP) that has hospital claims data from 48 states and District of Columbia representing nearly 98% of the U.S. population. The AHRQ HCUP inpatient data is accessible for anyone to analyze hospital information, including secondary diagnoses, through the usage of AHRQ query tools and resources such as HCUPnet [AHRQ HCUP NET](#) and an older query version of AHRQ HCUP Net [AHRQ HUCP NET Older version](#)

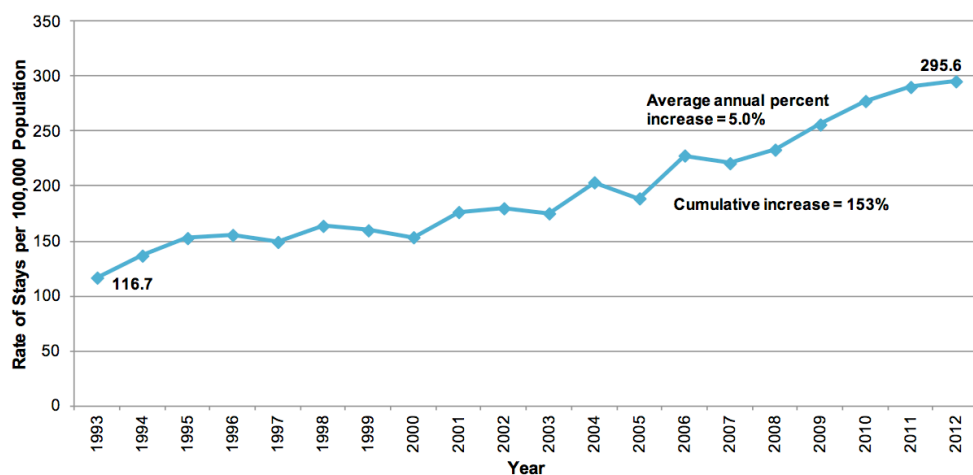
Using the query tools, one can do a deep data dive at a national or state specific level, by specific primary or secondary diagnoses and procedures, patient and provider characteristics, geographic designation, major payer category, and other characteristics over a year or several years. One can display the information in table or graphic format including frequency, rate, charges and costs, discharge status, length of stay, and other key elements.

AHRQ HCUP also has data on emergency room department, ambulatory surgery, and community data. AHRQ HCUP data is available from the date a state started reporting to AHRQ through 2014. As 2015 was the year in which claims reporting switched from ICD-9 to ICD-10, the analytical conversion process of diagnoses is still underway but is expected to be available soon along with guidance on how best to analyze the data pre-ICD-10 and post-ICD-10.

Researchers can request more detailed data directly through the organization providing data in each state or through a formal AHRQ process known as the State Inpatient Data (SID).

AHRQ HCUP Trends. To illustrate disease trends, AHRQ HCUP provides a special Statistical Brief highlighting key disease or performance trends. Below is a graph from the August 2014 Statistical Brief #177 “Hospital Inpatient Utilization Related to Opioid Overuse Among Adults, 1993–2012” Brief that highlights the upward trend of opioid hospitalizations. AHRQ hopes that by sharing the Statistical Briefs that others will replicate the analysis for their own state or community to assess trends and possible interventions.

Figure 1. Rate of hospital inpatient stays related to opioid overuse* among adults, 1993–2012



* Opioid overuse was identified using all-listed diagnoses.

Source: Agency for Healthcare Research and Quality (AHRQ), Center for Delivery, Organization, and Markets, Healthcare Cost and Utilization Project (HCUP), Nationwide Inpatient Sample (NIS), 1993–2012.

(The trend is definitely upward even with additional secondary diagnoses reported starting in late 2006/early 2007)

AHRQ was also writing about the upward trends in septicemia in October 2011 Statistical Brief # 122 “Septicemia in U.S. Hospitals, 2009.” Within that brief, AHRQ highlighted the upward trends of septicemia and analyzed it by principal and secondary diagnoses, noting that septicemia was more often noted as a secondary rather than a principal.

<https://www.hcup-us.ahrq.gov/reports/statbriefs/sb122.pdf>

In-patient Hospitalizations for Patients with Septicemia Discharges and Rate of Discharges Per 100,000 Population

2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
1,126,092	1,195,288	1,278,451	1,418,620	1,459,070	1,661,475	1,772,819	1,834,785	2,014,204	2,252,586
381.1	400.6	424.4	466.5	475.6	537.1	569.0	584.6	637.1	706.5

Source: AHRQ HCUP Net

The table above also illustrates the upward trend of septicemia in inpatient hospitalizations using the Clinical Classification Software on the AHRQ HCUP Net on-line query system.

State Data. With the exception of two states, almost all states have an inpatient data base of which many provide access to information for consumers and researchers. The data typically includes inpatient hospitalization and many now include information on emergency department visits, observation stays, and ambulatory surgery. For more information, contact your state public health department or go to the AHRQ contact web site <https://www.hcup-us.ahrq.gov/partners.jsp> to contact your state data reporting organization which can include state agencies, hospital associations, or not for profit organizations. In many state, the National Association of Health Data Organizations www.nahdo.org provides guidance and support to

state agencies and other organizations on how best to direct and oversee valid and reliable reporting of data.

In addition to hospital data, most states have a wealth of data that can be used to help supplement one's analysis on disease trends. Often time information is readily available on number and type of providers, vital health statistics, performance metrics for Medicaid and other health plans, and on and on.

As noted in the April Project Patient Care Newsletter, the All Payer Claims Databases (APCD) are providing consumers in several states with access to price and quality data on a range of inpatient, outpatient, and clinic services. www.projectpatientcare.org

Local Data. Information can also be readily available for public sharing of results at a practice, hospital, health system, and community level. By engaging local providers and public health agencies in being transparent with their community health data, one can also get a sense of local disease patterns and the success of local provider and community interventions.

Utilizing National and State Data Sources to Create a Story – Example of Chronic Kidney Disease

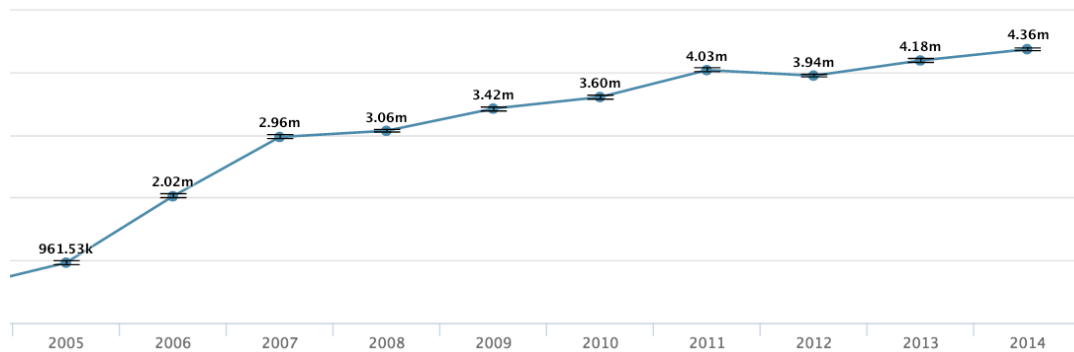
One of the diseases that is quickly advancing without an overall integrated intervention approach is chronic kidney disease (referred also to as chronic renal failure). While we have seen an increase in patients hospitalized with chronic renal failure, we are primarily seeing an increase in treatment and treatment centers when patients are experiencing chronic renal failure and not as much of an increase in early detection.

According to the CDC, <https://nccd.cdc.gov/CKD/help.aspx?section=F#wrapper> “Chronic kidney disease (CKD) is a condition in which the kidneys are damaged and cannot filter blood as well as possible. This damage can cause wastes to build up in the body and lead to other health problems, including cardiovascular disease (CVD), anemia, and bone disease. People with early CKD tend not to feel any symptoms. The only ways to detect CKD are through a blood test to estimate kidney function and a urine test to assess kidney damage. CKD is usually an irreversible and progressive disease, and can lead to kidney failure over time if it is not treated. Once detected, CKD can be treated through medication and lifestyle changes to slow down the disease progression, and prevent or delay the onset of kidney failure. However, the only treatment options for kidney failure are dialysis or a kidney transplant.”

To explore this in greater detail, we will look at some national trends and also view it from a state perspective.

AHRQ HCUP. In terms of national trends, we can see from the AHRQ HCUP Net the growth pattern in chronic renal failure while keeping in mind the impact of expanded reporting of secondary diagnoses in 2006/2007 as a result of HIPAA requirements.

Number of Discharges of Chronic Renal Failure In-Patient Hospitalizations All Diagnoses from 2005-2014



Source: AHRQ HCUP NET

Number of Discharges and Rate of Discharge per 100,000 Hospitalizations Chronic Renal Failure In-Patient Hospitalizations All Diagnoses from 2005-2014

2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
961,534	2,020,679	2,964,886	3,064,117	3,417,294	3,601,412	4,030,919	3,941,966	4,184,108	4,362,947
325.4	677.2	984.3	1,007.6	1,114.0	1,164.3	1,293.7	1,255.9	1,323.5	1,368.3

Source: AHRQ HCUP

Note: Remember HIPAA expanded to 25 diagnoses and 25 procedures in late 2006

CKD Data from USRDS. The United States Renal Data System (USRDS) gathers information from many sources to identify key trends and characteristics that are helpful in identifying patient risk factors for CKD.

While CKD is estimated to affect almost 15% of the entire U.S. population, awareness is very low. In recent studies through the Behavioral Risk Factor Surveillance System revealed a range of awareness from 1.8% in Virginia to 4.0% in Arizona. Given the overall prevalence of CKD in the U.S. population of about 14%, these numbers are consistent with limited awareness of CKD among those who have the condition.

As mentioned previously, the majority of people with CKD do not know they have the disease and therefore are not under any treatment regiment to manage their CKD so that they might avoid advancing from Level 1 to Level 5.

Dialysis In-Centers. According to the USDRS, in 2016 there were an estimated 660,000 Americans being treated for kidney failure with 468,000 patients on dialysis and 193,000 with a functioning transplanted kidney. Of the dialysis patients, 39% are 65 years and older with 44% between the ages of 45-64. <https://www.kidney.org/news/newsroom/factsheets/End-Stage-Renal-Disease-in-the-US>

While dialysis can be conducted at home based upon the treatment needed, over 89% of dialysis is still being conducted at dialysis in-centers. Patients typically received dialysis three times a week for four hours each treatment.

Dialysis Centers are required to report data on all in-center patients to Medicare for public reporting. Public data on dialysis centers is located on Dialysis Center Compare and includes information on location, number of stations, operating hours, ownership, quality performance results, and re-admission data. Since Dialysis Centers were the first facility type to come under Medicare's Value Based Purchasing program, it also includes results on in-center dialysis programs. There is also an overall star rating for the dialysis centers.

Expansion of Dialysis Centers Continue. Dialysis in-centers continue to expand with over 6,800 operating in the United States. These centers are located as free-standing facilities or are embedded in hospital or other facility campuses.

To demonstrate the growth in dialysis in-centers, consider that at the end of 2015 in Illinois, there were 235 Dialysis in-centers and today there are 297 Dialysis in-centers, representing a growth of over 26% in the span of less than two years. While the number of centers increases, in 2015 in Illinois, the number of kidney transplant patients declined as did the in-center usage rate.

Similar to the physical growth of in-center dialysis facilities, the net revenue of centers continues to rise as dialysis treatment and associated hospitalizations now represents 8% of the Medicare budget and 1% of the overall federal budget <http://catalyst.nejm.org/the-big-business-of-dialysis-care/>

Illinois has one of the most comprehensive set of information on dialysis centers that is required by the Illinois Health Facilities and Services Review Board (IHFSRB). IHFSRB oversees the Certificate of Need program for almost all health facility types. Illinois Dialysis Centers must report quarterly their staffing, utilization, transplants, and patient characteristics by age, gender, race and ethnicity, and payer source. There are a number of financial elements that also are reported including net revenue which continues. All of the information is publicly available in [report form and excel spreadsheets](#)

**Illinois Number of Dialysis In-Center Patients and Net Revenue For Dialysis Centers
2013-2015 Calendar Year Data from Dialysis Center Illinois State Summary Profile Reports**

	2015		2014		2013	
	Number and Percent of Patients	Net Revenue and Percent	Number and Percent of Patients	Net Revenue and Percent	Number and Percent of Patients	Net Revenue and Percent
Medicaid	1,375 (5.4%)	\$414,073,330 (17.0%)	1,979 (7.9%)	\$417,454,808 (18.0%)	2,646 (11.0%)	\$509,032,412 (14.9%)
Medicare	17,420 (68.7%)	\$885,543,801 (36.3%)	17,532 (69.7%)	\$853,050,705 (36.8%)	16,712 (69.4%)	\$1,119,435,387 (32.7%)
Commercial	5,788	\$1,016,171,175	4,801	\$904,301,979	3,707	\$813,708,498

	(22.8%)	(41.7%)	(19.1%)	(39.0%)	(15.4%)	(23.8%)
Private Pay	267 (1.1%)	\$30,589,620 (1.3%)	356 (1.4%)	\$81,686,313 (3.5%)	635 (2.6%)	\$78,988,474 (2.3%)
Other Public	522 (2.1%)	\$91,706,604 (3.8%)	493 (2.0%)	\$61,925,562 (2.7%)	383 (1.6%)	\$901,449,957 (26.3%)
TOTAL	25,372	\$2,438,084,531	25,161	\$2,318,419,366	24,083	\$3,422,614,728
Charity	148 (0.6%)	\$22,329,532 (0.9%)	203 (0.8%)	\$39,834,169 (1.7%)	149 (0.6%)	\$264,357,596 (7.7%)

Source: Illinois Health Facilities Planning Board Dialysis Center State Summary Profiles for 2013, 2014, and 2015
<https://www.illinois.gov/sites/hfsrb/InventoriesData/FacilityProfiles/Pages/default.aspx>

“I Felt Like I Fell Off of A Cliff” This is how many patients describe their feeling when they first hear they are going on dialysis and had never been told their CKD level or had the blood and urine tests or test results communicated to them.

“I never knew – no one told me” is also a common response as often time as we now know, CKD is not diagnosed and the patients as we know do not show symptoms of CKD.

What we do know is that there are patients at higher risk for CKD and those include patients with diabetes, hypertension, opioid abuse, or are black.

In Illinois, 41% of the in-center dialysis patients are black but they only represent 14% of the Illinois population. The disproportionate share of blacks on dialysis is reflective of a nation-wide trend which has been linked at times to higher percentages of hypertension and diabetes in the black population along with social determinants.

While the occurrence of CKD patients on dialysis was more prevalent among the under age 65 at a national level, in Illinois we found that trend to have changed slowly with 50% of the patients on in-center dialysis under the age of 65. Dialysis patients no longer reflect an elderly population, but an increasingly younger age population.

Bending the CKD Level 5 Growth Rate. We know that with interventions, CKD can be managed so that a person does not advance to Level 5 and be on dialysis. This would require a re-direct of our attention and focus to prevention and sharing and discussing test results with patients in a meaningful way that they understand and can be engaged in shared decision-making. By increasing kidney transplants, we know that CKD Level 5 patients that receive a kidney transplant live longer than if they remain on dialysis.

Here are some suggestions to help reduce the number of patients needing dialysis:

- Empower patients to understand the importance of early CKD testing and understanding of test results.
- Test results should be shared by physicians and discussed with patients with the goal of developing a joint physician-patient care plan.

- Clinicians should be aware of the high-risk factors for CKD and encourage their patients with high risk factors to undergo the blood and urine tests to monitor their kidney function routinely.
- As kidney transplant patients have an average life span of X years after the transplant and dialysis patients have an average life span of five years from the beginning of dialysis, clearly communicate the value that a kidney transplant can have for a patient.
- Encourage more people to sign their donor cards and to increase the number of kidney donors.
- Continue to track CKD trends geographically and by key factors.
- Encourage patients and families of loved ones with CKD to explore transplant options.
- If a patient or family member is going on dialysis at an in-center or wanting to switch dialysis providers, there are some key quality measurements available to use in selecting a dialysis in-center at Medicare Dialysis Compare. Medicare Dialysis Compare reflects all patients regardless of payer or uninsured status and information on quality and organizational information.

As a nation, we have the opportunity to reverse the rising trends we see in CKD patients on dialysis. We know that early detection and disease management can prevent most patients from needing dialysis, but that will only happen if we raise the awareness of patients, families, and clinicians and we all are working together to reverse the rising dialysis unsustainable trend.

Project Patient Care
Pat Merryweather
pmerryweather@p4ps.net
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