

Kidney Disease: The Basics

Note: Footnotes in body text may not run sequentially due to ongoing updates. However, they do correspond correctly to the numbers in the reference list.

Fast Facts

Kidney disease, also known as chronic kidney disease or CKD, causes more deaths than breast cancer or prostate cancer (NVS 2021 report of 2018 data).¹ It is the under-recognized public health crisis.

- Kidney disease affects an estimated 37 million people in the U.S. (15% of the adult population; more than 1 in 7 adults).^{2,3,4}
- Approximately 90% of those with kidney disease don't know they have it.²
- And 2 of 5 adults with severe kidney disease don't know they have it.²
- 1 in 3 adults in the U.S. (approximately 80 million) is at risk for kidney disease.^{2,5}
- Kidney disease is **more common in women (14%) than men (12%)**.² But for every 2 women who develop endstage kidney disease (ESKD), 3 men's kidneys fail.²
- Kidney disease is a leading cause of death in the U.S.^{1,6,7}
- About 1 in 2 people with very low kidney function (not on dialysis) don't know they have kidney disease.^{2,13}
- Approximately 1 in 3 adults with diabetes and 1 in 5 adults with high blood pressure may have kidney disease.²
- COVID-19 is targeting people with kidney disease, kidney transplant patients, and those at risk for kidney disease. [See **www.kidney.org/covid-19**]

What is Kidney Disease?

Chronic kidney disease (CKD) means your kidneys are damaged and losing their ability to keep you healthy by filtering your blood. In the early stages of the disease, most people do not have symptoms. But as kidney disease gets worse, wastes can build up in your blood and make you feel sick. You may develop other problems, like high blood pressure, anemia, weak bones, poor nutritional health, and nerve damage. Because kidneys are vital to so many of the body's functions, kidney disease also increases your risk of having heart and blood vessel disease. While these problems may happen slowly and without symptoms, they can **lead to kidney failure, which can appear without warning. Once kidneys fail, dialysis or a kidney transplant is needed to stay alive. Kidney failure is also called kidney failure with replacement therapy (KFRT).**

What Causes Kidney Disease?

The two main causes of kidney disease are diabetes and high blood pressure.9

- These two conditions were the primary diagnosis in 76% of kidney failure cases between 2015–2017: 47% of new KFRT patients had a primary diagnosis of diabetes¹⁰, the leading cause of KFRT, while 29% of new KFRT patients had a primary diagnosis of hypertension¹⁰, the second leading cause of KFRT.
- Other conditions that can lead to KFRT are: glomerulonephritis (diseases that damage the kidney's filtering units), which are the third most common type of kidney disease; inherited diseases, such as polycystic kidney disease; malformations at birth that occur as a fetus develops; lupus and other immune diseases; obstructions such as kidney stones or an enlarged prostate; and repeated urinary tract infections¹¹, which can also lead to kidney infections and can cause long-term damage to the kidneys.
 - **People with kidney disease are at greater risk for cardiovascular disease and death** at all stages of kidney disease. Kidney disease and heart disease are linked and have common risk factors, such as diabetes and hypertension. Each condition can lead to or worsen the other.¹²

How is Kidney Disease Treated?

- The best treatment of kidney disease is facilitated by **early detection**, when the disease can be slowed or stopped. Early treatment includes diet, exercise, medications, lifestyle changes, and treating risk factors like diabetes and hypertension. However, once kidneys fail, treatment with dialysis or a kidney transplant is needed.
- **Dialysis** comes in two forms: hemodialysis (HD) or peritoneal dialysis (PD). Both forms remove wastes and extra fluid from your blood. Patients receive hemodialysis usually 3–4 times a week, either at home or at a dialysis center. During hemodialysis, your blood is pumped through a dialysis machine, where it is cleaned and returned to your body. With peritoneal dialysis, your blood is cleaned inside your body every day through the lining of your abdomen using a special fluid that is periodically changed. Peritoneal dialysis can be done at home, at work, at school, or even during travel. Home dialysis is an increasingly popular mode of treatment⁵⁶, and is associated with better outcomes.
- A **kidney transplant** places a healthy kidney into your body from a deceased donor or from a living donor, such as a close relative, spouse, friend, or generous stranger. A kidney transplant, however, is a treatment, not a cure. Antirejection and other medications are needed to maintain the transplant. Per the United States Renal Data System (USRDS), more than 22,000 (22,393) kidney transplants were performed in the United States in 2018.⁵⁷ The active waiting list remains substantially larger than the supply of donor kidneys, which presents a continuing challenge.⁵⁷
- Although it is very important for patients who are nearing the need for dialysis or kidney transplantation to be cared for by a nephrologist, in 2018, 38.8% of incident (newly occurring) KFRT patients (18–44 years) had **received little or no pre-KFRT nephrology care**.⁵⁸

How Many People Require Dialysis or Transplant?

- In 2018, 785,883 Americans had kidney failure, and needed dialysis or a kidney transplant to survive (2 in every 1,000 people).^{2,14} 554,038 of these patients received dialysis to replace kidney function and 229,887 lived with a kidney transplant.^{8,14}
- About 130,000 people started KFRT treatment in 2018^{2,15} of which approximately 128,000 started dialysis as the initial mode of therapy.¹⁶
- In 2018, 22,393 people received a kidney transplant.¹⁷ By the end of 2018, a total of 229,887 Americans were living with a kidney transplant.¹⁸
- While about 100,000 Americans are waiting for a kidney transplant, only 22,817 Americans received one in 2020.^{19,20} About one-third of these transplants came from living donors.²⁰
- Living and deceased kidney donors are crucial: 12 people die every day while waiting for a kidney transplant.²¹
- In 2016, more than 3,600 kidneys from deceased donors were surgically discarded; NKF is making efforts to utilize more of these kidneys for transplantation.^{22,23}
- **People with kidney disease are five to ten times more likely to die prematurely** than they are to progress to KFRT.²⁴ More than 100,000 people with KFRT died in 2018.²⁵
- Without increased investment in prevention, the total number of patients with kidney failure will likely exceed 1 million by 2030.²⁶

Who is at Risk for Kidney Disease?

- **1 in 3 adults in the U.S. is at risk for kidney disease**.⁵ Some demographic groups are at higher risk. (See "What's Behind Racial Disparities in Kidney Disease?" section.)
- **Risk factors for kidney disease include**: diabetes; high blood pressure; family history of kidney failure; age 60 or older²⁷; obesity; heart disease; past damage to kidneys; and being in minority populations that have high rates of diabetes or high blood pressure, such as Blacks or African Americans, Hispanics or Latinos, Asian Americans or Pacific Islanders, and American Indians or Alaska Natives (Note: current CDC/ NHANES demographic terminology.).^{2,28}

What's Behind Racial Disparities in Kidney Disease?²⁹

People from some groups are more likely to develop kidney disease than others. Many factors can contribute to these groups being at higher risk, ranging from societal to medical reasons.

- A breakdown of kidney disease rates within demographic categories of the general population of the United States for 2015–2018 (USRDS, Prevalence of CKD in U.S. adults within age, sex, race/ethnicity, & risk factor categories) showed: 16.0% Non-Hispanic Black or African American; 15.7% Non-Hispanic White; 11.9% Hispanic or Latino (2018).³⁰
- Among Medicare FFS (fee-for-service) beneficiaries, kidney disease is highest among Blacks or African Americans (33%), followed by American Indians or Alaska Natives (30%), Hispanics or Latinos (28%), and Asian Americans or Pacific Islanders (26%). Whites (23%) beneficiaries had the lowest percentages of kidney disease (2018).³¹
- Non-Hispanic Black or African-American and Hispanic or Latino people experience **more rapid decline of kidney function** than non-Hispanic Whites.^{12,32} Minority communities in general are at increased risk of progressing from CKD to KFRT and of progressing more rapidly.^{12,33}
- Blacks or African Americans are **about 3 times more likely** than Whites to **develop kidney failure**. Blacks or African Americans are 13% of the U.S. population, while representing 35% of those with kidney failure.^{2,34,35}
- Black or African-American race is also associated with increased risk for acute kidney injury (AKI).^{36,37}
- Blacks or African Americans also suffer higher rates of comorbid conditions, such as diabetes and high blood pressure, resulting in higher rates of fair/poor health (age 18+, 22% Blacks or African Americans vs. 16% Whites).³⁸
- Compared to non-Hispanics, Hispanics or Latinos are almost 33% (1.3 times) more likely to receive a diagnosis of kidney failure.^{2,34}
- Native Hawaiians, Pacific Islanders, American Indians and Alaska Natives **also have a higher prevalence of kidney disease** than Whites.^{2,12,28,30,34,39,40}
- There are disparities in the quality of primary care for patients of different racial, ethnic, and socioeconomic groups who have kidney disease and kidney disease risk factors.¹² These disparities are related to patient, clinician, clinical, and systemic factors. Patients receiving dialysis in areas with populations that are largely Black or African American, low-income, or of lower educational attainment, are less likely to have received pre-dialysis care from a nephrologist. One study found that 52% of Hispanic or Latino patients on hemodialysis had not received pre-dialysis care from a nephrologist, compared to 44% of non-Hispanic patients.¹²
- Blacks or African Americans and Hispanics or Latinos are also less likely to be treated with kidney transplantation than Whites.⁴¹
- On average, Black or African-American transplant candidates wait longer than White transplant candidates for kidney, heart, and lung transplants.⁴²
- In 2018, 57% of White patients with KFRT received in-center hemodialysis, versus 72% of Black or African-American patients.⁴³ This may reflect fewer Black or African-American patients utilizing home dialysis options.⁴⁴

How are Children and Adolescents Affected by Kidney Disease?⁴⁵

- **Many children and adolescents have conditions that**, if left untreated, **dramatically increase their risk for kidney disease** and KFRT: about 4% of youths (12–19 yrs) in the U.S. have hypertension, while about 10% have elevated blood pressure.⁴⁶ In children aged 2–19 years, the prevalence of obesity is 18.5% (about 13 million)⁴⁷, and 210,000 people younger than 20 years are living with diagnosed diabetes.⁴⁸ The growing prevalence of these conditions in children means that the incidence and prevalence of kidney disease will likely increase further in the coming years.
- 6,427 children (<18 yrs old) in the U.S. lived with KFRT in 2017.49
- According to one study, children with KFRT are 30 times more likely to die prematurely than healthy children.⁵⁰ In another study, adolescents (<18 yrs old) with KFRT since childhood had a life expectancy of 38 years if they were treated with dialysis during childhood, and 63 years if they received a kidney transplant during childhood.⁵¹
- The primary causes of pediatric KFRT in the U.S. between 2015–2018 were: primary glomerular disease, CAKUT (congenital anomalies of the kidney and urinary tract), cystic/hereditary/congenital disorders, and primary/ secondary glomerular disease/vasculitis.⁵² Urinary tract infections can also lead to kidney infections, which can cause long-term damage to the kidneys.¹¹
- In 2020, 710 children (<18 yrs old) received a kidney transplant.⁵³
- More than 1,000 children (<18 yrs old) are waiting for a donated kidney.⁵⁴
- Recent USRDS data indicates substantial racial and ethnic disparities in KFRT treatment for children and adolescents:
 - White children were twice as likely to receive a kidney transplant as Black or African-American children (20.8% versus 10.0%).
 - More Black or African-American (57.3%) children than White (40.5%) children-initiated hemodialysis (HD).
 - Hispanic or Latino children received a kidney transplant less often than non-Hispanic children (12.0% versus 20.2%) and initiated HD more often and PD less often.
 - The median kidney transplant waitlist time for children, by race: 35.2 months for Black or African-American children; 34.0 months for children of other race groups (not Black, White, or Asian); 23.3 months for White children; and 20.3 months for Asian-American children.⁵⁵

What are the Costs to Treat Kidney Disease?⁵⁹

In 2018, Medicare costs for all people with all stages of kidney disease were \$130 billion.^{60,61,62} In 2018 Medicare spent \$81 billion for people with kidney disease and an additional \$49.2 billion for people with KFRT.^{60,61,62} For 2018, per person per year (PPPY) spending on KFRT patients was \$80,426.^{62,63} Early detection of kidney disease could save a substantial percentage of these costs.

- Per type of KFRT treatment, Medicare spent: \$93,191 PPPY for HD, \$78,741 for PD, and \$37,304 for kidney transplant (2018).⁶¹
- In 2018, Medicare spent an estimated \$24,674 PPPY to care for someone with **non-KFRT CKD**, **more than double the spending on the average Medicare beneficiary** (\$12,899).⁶⁴
- Almost 64.3% of new KFRT patients applied for Medicare (2018).65
- In 2018, there were over **500,000 Medicare beneficiaries on maintenance dialysis** (about 1% of Medicare feefor-service population), accounting for 7.2% of the overall claims paid by Medicare.⁶⁶
- Total Medicare Part D spending (2009–2018) rose by 188% for those with CKD (\$4.6 to \$13.1 billion) and by 37% for those without CKD (\$39.5 to \$54.2 billion).⁶⁷
- For kidney transplant recipients, Medicare Part B spent \$2,453 on immunosuppressive drugs, PPPY (2018).68
- Medicare Part D spending was 1.7 times higher for those with CKD (\$5392 PPPY) than for those without CKD (\$3118 PPPY) (2018).⁶⁹
- Medicare Part D spending was 2.4 times higher for patients with KFRT (\$8,173 PPPY) than those without (\$3397 PPPY) (2018).⁷⁰
- There is good news, however, for patients burdened with immunosuppressive drug costs when they are no longer covered by the current 36-month limit. The NKF-supported Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act (S. 3353/H.R. 5534) was passed by both the U.S. House of Representatives and U.S. Senate in December 2020. This bill ensures that transplant patients on Medicare will receive lifetime unlimited coverage for immunosuppressive medications. This legislation represents a significant, positive change in the lives of many kidney patients.^{71,72}
- However, there is still a lot of work to be done: Minority communities may have less access to healthcare than
 other Americans. For example, studies found that about one-third of Hispanics or Latinos, 20% Blacks or African
 Americans, and nearly 1 out of 3 American Indians and Alaska Natives were uninsured.⁷³

How Do You Prevent Kidney Disease?

Early Detection

Early detection is the most effective way to combat kidney disease. There are two simple, quick, and inexpensive tests for kidney disease:

- A kidney damage urine albumin-creatinine ratio (uACR) test, measures the amount of protein called albumin in your urine. Damaged kidneys leak protein into your urine; it should be in your bloodstream.
- A **kidney function blood test, creatinine**, is used to measure your glomerular filtration rate (GFR), which tells how well your kidneys are working to remove wastes from your blood. It is the best way to check kidney function.

Keep Kidneys Healthy^{2,74,75}

- **People with kidney disease should**: •Lower high blood pressure; •Manage blood sugar levels; •Reduce salt intake; •Avoid NSAIDs, a type of painkiller; •Moderate protein consumption; •Get an annual flu shot
- Everyone should: •Exercise regularly; •Control weight; •Follow a balanced diet; •Quit smoking; •Drink alcohol only in moderation; •Stay hydrated; •Monitor cholesterol levels; •Get an annual physical; •Know your family medical history^{2,74,75}

Preventative Medicine Pays Off

A recent report from the Centers for Disease Control and Prevention (CDC) states that between 1996 and 2013, there was a 54% decrease in the incidence of diabetes-related KFRT in Native American and Alaska Natives since the Special Diabetes Program for Indians (SDPI) began in 1997. The CDC estimates that the decrease in KFRT related to diabetes resulted in 2,200 to 2,600 fewer cases of diabetes-related KFRT, and estimates \$436 to \$520 million in savings to Medicare over 10 years.⁷⁶

The National Kidney Foundation (NKF) is the largest, most comprehensive, and longstanding patient-centric organization dedicated to the awareness, prevention, and treatment of kidney disease in the U.S. For more information about NKF, visit www.kidney.org



Note 1: Please direct any queries, updates, suggestions for improvements, or corrections for this sheet to: jamesm@kidney.org

Note 2: The USRDS Annual Data Report (ADR) cites data in several different ways and locations. Follow the instructions at the end of these references to arrive at the correct numbers.

Note 3: KFRT = kidney failure with replacement therapy. Also known as ESRD = end-stage renal disease; ESKD = end-stage kidney disease.

Note 4: Different years are cited, e.g., 2017, 2018, 2019, 2020, because the most up-to-date data available from different sources are being used. Note also that there are varying lags between when data are collected and when they are synthesized, interpreted, and presented. Some studies are done periodically or one-time-only, and not annually.

Note 5: Percentages in some facts may not equal 100 due to rounding.

Note 6: From the USRDS ADR: "Although traditional sources of data used in preparation of the ADR involve an 18-month lag, largely due to processing of Medicare claims, we have used quarterly data extracts from the Centers for Medicare & Medicaid Services' Renal Management Information System—anchored by the ESRD Medical Evidence Report and the ESRD Death Notification—to examine changes in mortality, hospitalization, and onset of ESRD during the early period of the pandemic." "...this year's ADR does not contain data from private insurers. However, we anticipate that future ADRs will include these data and will also incorporate additional data sources to more fully characterize non-Medicare populations with kidney disease."

References

1 Centers for Disease Control and Prevention (CDC). National Vital Statistics Reports (NVSR). CDC website.

https://www.cdc.gov/nchs/products/nvsr.htm Also:

https://www.cdc.gov/nchs/data/nvsr/nvsr69/nvsr69-13-508.pdf [Volume 69, Number 13; 2021 January 12; Murphy SL, Xu J, Kochanek KD, Arias E, Tejada-Vera B, Division of Vital Statistics; Deaths: final data for 2018]

[Pg.1, Col. 2, & Pg. 9, Col. 1: # 9. Nephritis, nephrotic syndrome and nephrosis (kidney disease); Table 6. Number of deaths from selected causes, by age: United States, 2018. p.36, Row: Malignant neoplasm of breast: 42,950; p.36, Row: Malignant neoplasm of prostate: 31,489; p. 37, Row: Nephritis, nephrotic syndrome and nephrosis: 51,386]

2 Centers for Disease Control and Prevention (CDC). Chronic kidney disease in the United States, 2021. Atlanta, GA: US Department of Health and Human Services, Centers for Disease Control and Prevention; 2021.

https://www.cdc.gov/kidneydisease/publications-resources/ckd-national-facts.html

PDF: https://www.cdc.gov/kidneydisease/pdf/Chronic-Kidney-Disease-in-the-US-2021-h.pdf

3 37 million. Centers for Disease Control and Prevention (CDC); Chronic Kidney Disease (CKD) Surveillance System. Prevalence and incidence. CDC website. https://nccd.cdc.gov/ckd/Default.aspx [•Prevalence of CKD is likely overestimated by single measurements of albuminuria and kidney function (eGFR). In clinical practice, CKD is defined by persistent albuminuria or reduced kidney function for \geq 3 months.*

•In 2015-2016, 14%-15% of adult NHANES participants, representing ~31-34 million noninstitutionalized U.S. civilian residents aged 20 years or older, had evidence of CKD stages 1-4; of these, ~15-18 million had evidence of CKD stage 3 or 4.**

[Prevalence and Incidence > View Prevalence and Incidence Summary > Prevalence of CKD in the General Population > CKD stages among U.S. Adults, 1988-1994 vs. 1999-2006 vs. 2007-2014 vs. 2015-2016;

*"Methods" tab & **"Key Points" tab.] Available at: https://nccd.cdc.gov/CKD/detail. aspx?Qnum=Q8#refreshPosition]

4 USRDS releases 2020 interactive Annual Data Report [news release]. 2020, November 11. https://usrds.org/news/ ["Important findings in this year's Annual Data Report include: A 14.9% prevalence of CKD among US adults."]

5 NOTE: Estimate of 1 in 3 (approx. 80 million) adults at risk for CKD is based on U.S. prevalence of hypertension, diabetes, and obesity. *Without proper treatment, 1 in 3 will develop CKD*.

6 Kochanek KD, Xu JQ, Arias E. (2020 December). Mortality in the United States, 2019; NCHS Data Brief, No. 395, December 2020. Hyattsville, MD: National Center for Health Statistics. https://www.cdc.gov/nchs/products/databriefs/db395.htm PDF : https://www.cdc.gov/nchs/data/databriefs/db395-H.pdf ["The 10 leading causes of death in 2019 remained the same as in 2018, although kidney disease, the eighth leading cause and influenza and pneumonia, the ninth in 2019, switched ranks."]

7 Ahmad FB, Cisewski JA, Miniño A, Anderson RN. Provisional mortality data—United States, 2020. *MMWR Morb Mortal Wkly Rep.* ePub: 31 March 2021. doi: http://dx.doi.org/10.15585/mmwr. mm7014e1external icon

https://www.cdc.gov/mmwr/volumes/70/wr/mm7014e1.htm [FIGURE 2. Provisional number of leading underlying causes of death—National Vital Statistics System, United States, 2020]

8 United States Renal Data System (USRDS). 2020 USRDS annual data report: epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2020.

https://adr.usrds.org/2020/reference-tables

[2020 Annual Data Report; Reference Tables, Vol. 2—ESRD; Ref. Tables D Treatment Modalities; Table D.9 Counts of point prevalent ESRD patients, by mode of therapy: functioning graft. Col. U, Row 59 = **229,887** (TX).]

Also:

United States Renal Data System (USRDS). 2020 USRDS annual data report: epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2020.

https://adr.usrds.org/2020/end-stage-renal-disease/1-

incidenceprevalence-patient-characteristics-and-treatment-modalities

[Volume 2: End-stage renal disease: Chapter 1; Incidence, prevalence, patient characteristics, and treatment modalities; Highlights; Bullet #6: "At the end of 2018, there were **554,038** (70.7%) patients undergoing dialysis and **229,887** (29.3%) patients with a functioning kidney transplant." (Figure 1.6)]

9 U.S. Department of Health and Human Services (HHS); National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). Causes of chronic kidney disease. NIDDK website. 2016, October. https://www.niddk.nih.gov/health-information/kidney-disease/ chronic-kidney-disease-ckd/causes

Also: (diabetes)

Broom D. The silent epidemic that is three times as deadly as COVID. World Economic Forum website. (2020, December 14). https://www. weforum.org/agenda/2020/12/diabetes-silent-epidemic-world-health/ **10** United States Renal Data System (USRDS). 2020 USRDS annual data report: epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2020. https://adr.usrds.org/2020/reference-tables

[USRDS 2020 ADR Reference Tables, Vol. 2—ESRD; Ref. Tables A Incidence; Table A.4 Incident counts of reported ESRD patients, by age and primary diagnosis, 2016–2018 combined. Col. X, Row 38 (All patients) 382,398; Col. X, Row 33 (Diabetes) 179,706; Col. X, Row 34 (Hypertension) 110,807.] [Computed from: (Col. X shows all gender and race.) All patients (Col. X, Row 38) = 382,398 / DM (Col. X, Row 33) 179,706; (179,706/382,398) = 47% (0.4699); HTN (Col. X, Row 34) 110,807 (110,807/382,398) = 29% (0.2897)]

11 Ramakrishnan K, Scheid DC. Diagnosis and management of acute pyelonephritis in adults. *Am Fam Physician*. 2005;71:933-942. https://www.ncbi.nlm.nih.gov/pubmed/15768623 Also:

Mayo Clinic. Kidney infection. Mayo Clinic website. https://www.mayoclinic.org/diseases-conditions/kidney-infection/ symptoms-causes/syc-20353387

12 Scholle SH, Onstad K, Hart A, Hwee T; National Committee for Quality Assurance (NCQA). *Chronic kidney disease disparities: educational guide for primary care*. Washington, DC: Department of Health and Human Services (DHHS), Centers for Medicare & Medicaid Services (CMS), Office of Minority Health (OMH); February 2020. [Pages 6 & 10]

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PDF:
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https://www.cms.gov/files/document/chronic-kidney-diseasedisparities-educational-guide-primary-care.pdf

[NOTE: The booklet above is also footnoted and contains sources for more detailed data.]

13 United States Renal Data System (USRDS). 2020 USRDS annual data report: epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2020. https://adr.usrds.org/2020/chronic-kidney-disease/1-ckd-in-the-general-population

[2020 ADR Chapters; Volume 1 CKD; Chapter 1: CKD in the General Population; Figure 1.11; see Stages 1-3 in figure] [Figure 1.11 caption: "Figure 1.11 shows that although awareness among individuals with CKD has increased over time, the vast majority of individuals with kidney disease remain unaware." "Those with more advanced stages of kidney disease were also more likely to be aware than those with earlier stages, although recognition was still low even in stage 3 (16.9%, compared with 61.9% for stage 4 and 86.3% for stage 5 in 2018)."] **14** United States Renal Data System (USRDS). 2020 USRDS annual data report: epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2020. https://adr.usrds.org/2020/reference-tables

[2020 Annual Data Report; Reference Tables, Vol. 2—ESRD; Ref. Tables D. Treatment Modalities. Table D.11 Point prevalent ESRD patients, 2018, by treatment modality. Col. J, Row 59 (All treatment modalities/all populations): **785,883**.] Also:

United States Renal Data System (USRDS). 2020 USRDS annual data report: epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2020.

https://adr.usrds.org/2020/end-stage-renal-disease/1incidenceprevalence-patient-characteristics-and-treatmentmodalities

[2020 ADR Chapters; Volume 2 End Stage Renal Disease; Chapter 1: Incidence, Prevalence, Patient Characteristics, and Treatment Modalities; Highlights: Bullet #6: "At the end of 2018, there were **554,038** (70.7%) patients undergoing dialysis and **229,887** (29.3%) patients with a functioning kidney transplant (Figure 1.6)."; Table 1.3 Unadjusted and adjusted prevalence of ESRD, 1990-2018. Column: Number of prevalent ESRD patients/N, Row/Year: 2018: **785,883**. "In 2018, the number of prevalent patients with ESRD in the U.S. exceeded 785,000 (Table 1.3)."]

15 United States Renal Data System (USRDS). 2020 USRDS annual data report: epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2020. https://adr.usrds.org/2020/reference-tables

[2020 Annual Data Report; Reference Tables; Volume 2—ESRD: A. Incidence; Table A1 Incident counts of reported ESRD by age, sex, race, ethnicity & primary cause of ESRD. Col. U, Row 60 (2018/U.S.): 129,604] ["Incident counts," i.e., starting ESRD.] Also:

Centers for Disease Control and Prevention (CDC). Chronic kidney disease in the United States, 2021. Atlanta, GA: US Department of Health and Human Services, Centers for Disease Control and Prevention; 2021.

https://www.cdc.gov/kidneydisease/publications-resources/ckd-national-facts.html

PDF: https://www.cdc.gov/kidneydisease/pdf/Chronic-Kidney-Disease-in-the-US-2021-h.pdf

[Pg. 3, Col. 1, Facts About ESRD, bullet #1: "In 2018, about 131,600 people in the United States started treatment for ESRD."]

16 United States Renal Data System (USRDS). 2020 USRDS annual data report: epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2020. https://adr.usrds.org/2020/reference-tables

[2020 Annual Data Report; Reference Tables; Volume 2—ESRD: D. Treatment Modalities; Table D.2 Counts of incident ESRD patients by initial mode of therapy: all dialysis. Col. U, Row 60 (2018/All populations): 127,925] **17** United States Renal Data System (USRDS). 2020 USRDS annual data report: epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2020. https://adr.usrds.org/2020/reference-tables [2020 Annual Data Report; Reference Tables; Volume 2 – ESRD: E.

Transplantation: Process; Table E.8 Counts of renal transplants, by donor type, all donor types. Col. X, Row 101 (2018/AII): 22,393] **18** United States Renal Data System (USRDS). 2020 USRDS annual

data report: epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2020. https://adr.usrds.org/2020/reference-tables [2020 Annual Data Report; Reference Tables; Vol. 2—ESRD; Ref. Tables D. Treatment Modalities. Table D.9 Counts of **point prevalent** ESRD patients, by mode of therapy: functioning graft. Col. U, Row 59 (2018/All populations: 229,887]

19 U.S. Department of Health & Human Services (HHS); Organ Procurement and Transplantation Network (OPTN). National data. OPTN website.

https://optn.transplant.hrsa.gov/data/view-data-reports/national-data/ [From dropdown menus, select: Step 1: Choose Category: Waiting List; Count: Candidates; Step 2: Choose a report: Overall by Organ; Change report: Candidates; Column: Kidney = 91,154 (3/2021)]

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https://optn.transplant.hrsa.gov/data/view-data-reports/national-data/ [From dropdown menus, select: Step 1: Choose Category: Transplant; Choose Organ: Kidney; Step 2: Choose a report: Transplants by Donor Type; Change Report: Organ: Kidney.] [2020: All donor types: 22,817; Deceased donor: 17,583; Living donor: 5,234 (3/2021)]

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Available at: BlackDemographics website. https://blackdemographics. com/are-african-americans-at-risk-for-the-coronavirus/ [See table: Black Adult Health Risks: Age 18 and Up: Have Fair/Poor Health Status] **39** Na'ai D, Raphael KL. CKD in Native Hawaiians and Pacific Islanders: trouble in paradise. *CJASN*. 2019 November;14(11):1661-1663. doi: doi. org/10.2215/CJN.03260319

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[Bullet #4: "Although the total number of white Americans on organ transplant waiting lists is about 1.4 times greater than that of Black/ African Americans, the number of candidates waiting for a kidney transplant is almost the same between Black/African Americans and white Americans."] [Source: HRSA. U.S. Organ Procurement and Transplantation Network (OPTN). Based on OPTN data as of February 20, 2020. https://optn.transplant.hrsa.gov/data/view-data-reports/ national-data/]

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https://adr.usrds.org/2020/end-stage-renal-disease/1-incidenceprevalence-patient-characteristics-and-treatment-modalities [2020 ADR Chapters; Volume 2; End Stage Renal Disease: Chapter 1 Incidence, Prevalence, Patient Characteristics, and Treatment Modalities; Highlights; Bullet #12: "Whereas 57% of White patients with prevalent ESRD received in-center hemodialysis at the end of 2018, 72% of Black patients received in-center hemodialysis (Figure 1.14)."] **44** African Americans face barriers to alternative modes of renal replacement therapy. *Nephrology News and Issues (NNI)*. (2020, January 13). Healio website. https://www.healio.com/news/ nephrology/20200113/african-americans-face-barriers-to-alternative-modes-of-renal-replacement-therapy

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[2020 ADR Reference Tables; Volume 2; B. Prevalence; Tab B.1 Prevalent counts of reported ESRD: on December 31 of each year, by age, sex, race, ethnicity and primary cause of ESRD, All patients, U.S. and territories. Column U, Rows 6-9] [Column U, Row 6 (0-4) 862 + Row 7, (5-9) 1,331 + Row 8 (10-13) 1702 + Row 9 (14-17) 2532 = 6,427] **50** McDonald SP, Craig JC for the Australian and New Zealand Paediatric Nephrology Association. Long-term survival of children with end-stage renal disease. *N Engl J Med*, 2004;350:2654–2662. doi: 10.1056/NEJMoa031643

https://www.nejm.org/doi/full/10.1056/NEJMoa031643 ["A total of 1634 children and adolescents were followed for a median of 9.7 years. The long-term survival rate among children requiring renal-replacement therapy was 79 percent at 10 years and 66 percent at 20 years. Mortality rates were 30 times as high as for children without end-stage renal disease."]

51 Kramer A, Stel VS, Tizard J, Verrina E, Rönnholm K, Pálsson R, Maxwell H, Jager KJ. Characteristics and survival of young adults who started renal replacement therapy during childhood. *Nephrol Dial Transplant*. 2009 March;24(3):926-933. Epub 2008 Oct 7. doi: 10.1093/ndt/gfn542.

https://www.ncbi.nlm.nih.gov/pubmed/?term=18840894 https://pubmed.ncbi.nlm.nih.gov/18840894/

["The average life expectancy was 63 years for young adults with a functioning graft and 38 years for those remaining on dialysis."]

52 United States Renal Data System (USRDS). 2020 USRDS annual data report: epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2020. https://adr.usrds.org/2020/end-stage-renal-disease/7-%20esrd-among-children-and-adolescents

[2020 ADR Chapters; Volume 2; End Stage Renal Disease: Chapter 7; ESRD among Children and Adolescents; Figure 7.4 Distribution of primary cause of ESRD in children with incident ESRD, by age, 2015-2018]

53 U.S. Department of Health and Human Services (HHS); Organ Procurement and Transplantation Network (OPTN). HHS-OPTN website.

https://optn.transplant.hrsa.gov/data/view-data-reports/national-data/ [Home>> Data>> View Data Reports>> National Data>> From dropdown menus, select: Step 1: Choose Category: Transplant; Step 2: Choose a report: Transplants by Recipient Age; Change Report: Organ; Kidney; 2020: (age) (<1) 0 + (1-5) 184 + (6-10) 129 + (11-17) 397 = 710]

54 U.S. Department of Health and Human Services (HHS); Organ Procurement and Transplantation Network (OPTN). HHS-OPTN website.

https://optn.transplant.hrsa.gov/data/view-data-reports/national-data/ [Home>> Data>> View Data Reports>> National Data>> From dropdown menus, select: Step 1: Choose Category: Waiting List; Count: Candidates; Column: Kidney: (<1) 0 + (1-5) 222 + (6-10) 245 + (11-17) 649 = 1,116 (3/2021)] **55** United States Renal Data System (USRDS). 2020 USRDS annual data report: epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2020. https://adr.usrds.org/2020/end-stage-renal-disease/7-%20esrd-among-children-and-adolescents

[2020 ADR Chapters; Volume 2; End Stage Renal Disease: Chapter 7; ESRD among Children and Adolescents; Highlights; **Bullet # 3:** "At onset of ESRD, there was substantial racial and ethnic disparity in ESRD treatment modality (Figure 7.3). White children were twice as likely to receive a kidney transplant as Black children (20.8% versus 10.0%). A substantially higher percentage of Black (57.3%), compared with White (40.5%) children initiated hemodialysis (HD). Hispanic-Latino children received a kidney transplant at ESRD onset less often than did non-Hispanic children (12.0% versus 20.2%) and initiated HD more often and PD less often than non-Hispanic children."; **Bullet #14**: "The median time to receive a kidney transplant from initial waitlisting varied substantially by race: 35.2 months for Black children, 34.0 months for children of other races, 23.3 months for White children, and 20.3 months for Asian children (Figure 7.19)."]

56 United States Renal Data System (USRDS). 2020 USRDS annual data report: epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2020. https://adr.usrds.org/2020/end-stage-renal-disease/1-incidence-prevalence-patient-characteristics-and-treatment-modalities [2020 ADR Volume 2; End Stage Renal Disease: Chapter 1; Incidence, Prevalence, Patient Characteristics, and Treatment Modalities; Highlights; Bullet #2: "The number of patients with incident ESRD who initiated in-center hemodialysis ranged from 111,000 to 113,000 for the fourth consecutive year in 2018. Meanwhile, the number of patients who initiated peritoneal dialysis and who received a preemptive transplant reached an all-time high of 18,631 (Figure 1.2)." (See also Figure 1.6.)]

57 United States Renal Data System (USRDS). 2020 USRDS annual data report: epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2020. https://adr.usrds.org/2020/end-stage-renal-disease/6-transplantation [2020 ADR Volume 2; End Stage Renal Disease; Chapter 6; Transplantation; Highlights; Bullet #1: "In 2018, the cumulative number of kidney transplants reached an all-time high of 22,393, an increase of 6.5% since 2017 (Figure 6.9). However, the kidney transplant rate among ESRD patients increased only slightly between 2017 and 2018, from 3.5 to 3.6 transplants per 100 patient-years."; Bullet #3: "The total number of individuals with ESRD on the kidney transplant waiting list hit an all-time high in 2014 (Figure 6.2). Since that time, it has decreased, but the decrease has been predominantly among those with inactive status, with only a small decline in those on the waiting list with active status."]

58 United States Renal Data System (USRDS). 2020 USRDS annual data report: epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2020. https://adr.usrds.org/2020/end-stage-renal-disease/1-incidence-prevalence-patient-characteristics-and-treatment-modalities [2020 ADR Volume 2; End Stage Renal Disease: Chapter 1 Incidence, Prevalence, Patient Characteristics, and Treatment Modalities; Highlights; Bullet # 13: "Pediatric patients were most likely to receive pre-ESRD nephrology care (75.5%), and patients aged 18-44 years were least likely (61.2%) (Figure 1.16)." (i.e., 38.8% of 18-44 years did not)]

59 Baseline/general reference: Centers for Medicare & Medicaid Services (CMS). CMS Office of the Actuary releases 2018 National Health Expenditures (press release). CMS website; Newsroom. December 05, 2019. https://www.cms.gov/newsroom/press-releases/ cms-office-actuary-releases-2018-national-health-expenditures ["Medicare spending: (21 percent of total health care spending) grew 6.4 percent to \$750.2 billion in 2018, which was faster than the 4.2 percent growth in 2017."]

60 United States Renal Data System (USRDS). 2020 USRDS annual data report: epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2020. https://adr.usrds.org/2020/chronic-kidney-disease/6-healthcare-expenditures-for-persons-with-ckd

[2020 ADR Volume 1 Chronic Kidney Disease; Chapter 6 Healthcare Expenditures for Persons with CKD; Highlights; Bullet #1: "Medicare fee-for-service (FFS) spending for beneficiaries with CKD who did not have ESRD exceeded \$81 billion in 2018 and represented 22.3% of Medicare FFS spending (Tables 6.1 and 6.2)."]

61 United States Renal Data System (USRDS). 2020 USRDS annual data report: epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2020. https://adr.usrds.org/2020/end-stage-renal-disease/9-healthcare-expenditures-for-persons-with-esrd [2020 ADR Volume 2; End Stage Renal Disease: End Stage Renal Disease: Chapter 9 Healthcare Expenditures for Persons with ESRD; Highlights; Bullet #1: "Total Medicare-related expenditures for beneficiaries with ESRD rose to \$49.2B in 2018."; Bullet #7: "In unadjusted terms, PPPY spending in Medicare FFS beneficiaries with ESRD increased from \$86,939 to \$93,191 for HD, from \$67,196 to

ESRD increased from \$86,939 to \$93,191 for HD, from \$67,196 to \$78,741 for PD, and from \$33,613 to \$37,304 **(also Ref. Table K.9)** for kidney transplant (Figure 9.9)."] 62 Centers for Disease Control and Prevention. Chronic Kidney Disease Initiative. Chronic kidney disease basics. CDC website. https://www.cdc.gov/kidneydisease/basics.html ["Costs: •Overall Medicare costs for people with CKD were over \$81.8 billion in 2018, or \$23,700 per person. •Total Medicare spending (excluding prescription drugs) for patients with ESRD or kidney failure reached \$36.6 billion in 2018, or \$80,000 per person, accounting for about 7% of the Medicare paid claims costs."]

63 United States Renal Data System (USRDS). 2020 USRDS annual data report: epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2020. https://adr.usrds.org/2020/reference-tables

[2020 ADR Reference Tables, Volume 2—ESRD; K. Expenditures for ESRD Patients; Section K: Medicare Costs for ESRD patients; K.5. Per person per year spending (\$): all ESRD patients, with unknown modalities dropped (model 1). Row 61, All/Column Q, 2018: \$80,426]

64 United States Renal Data System (USRDS). 2020 USRDS annual data report: epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2020. https://adr.usrds.org/2020/reference-tables

[USRDS 2020 ADR Reference Tables, Volume 1—CKD: K. Expenditures; K.1 Per person per year estimated costs (\$): all fee-for-service non-ESRD Medicare patients; Row 40, All/Column U, 2018: \$12,899; Row 38, CKD/Column U, 2018: **\$24,674**; also, Table K.2 Per person per year estimated costs (\$): fee-for-service non-ESRD Medicare patients with chronic kidney disease (CKD): Row 41, All/Column U, 2018: **\$24,674**]

65 United States Renal Data System (USRDS). 2020 USRDS annual data report: epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2020. https://adr.usrds.org/2020/end-stage-renal-disease/9-healthcare-expenditures-for-persons-with-esrd

[2020 ADR Volume 2 End Stage Renal Disease: Chapter 9 Healthcare Expenditures for Persons with ESRD; Figure 9.3a "Sources of medical coverage for patients with incident ESRD, 2009-2018, by treatment modality; 2018; Non-Medicare: 35.7%; Medicare Advantage 23.8%; MSP: 5.8%; MPP: dual Medicare/Medicaid: 10.3%; MPP Medicare only: 24.4%....**Total Medicare-related: 64.3%;** non-Medicare 35.7%"]

66 United States Renal Data System (USRDS). 2020 USRDS annual data report: epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2020. https://adr.usrds.org/2020/end-stage-renal-disease/9-healthcare-

expenditures-for-persons-with-esrd

[2020 ADR Volume 2 End Stage Renal Disease; Chapter 9 Healthcare Expenditures for Persons with ESRD; Introduction; Paragraph #2: "At the end of 2018, there were over 500,000 patients receiving maintenance dialysis, who represent approximately 1% of the U.S. Medicare fee-for-service (FFS) population but account for approximately 7.2% of Medicare FFS spending."] **67** United States Renal Data System (USRDS). 2020 USRDS annual data report: epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2020. https://adr.usrds.org/2020/end-stage-renal-disease/10-prescription-drug-coverage-in-patients-with-esrd [2020 ADR; Volume 2 End Stage Renal Disease; Chapter 10 Prescription Drug Coverage in Patients with ESRD; Highlights; Bullet #1: "Between 2009 and 2018, total Medicare Part D spending rose by 188% in those with CKD (\$4.6 to \$13.1 billion) and by 37% in those without CKD (\$39.5 to \$54.2 billion)."

68 United States Renal Data System (USRDS). 2020 USRDS annual data report: epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2020. https://www.usrds.org/reference.aspx

[2020 ADR Reference Tables; Volume 2; K. Expenditures for ESRD Patients; Table K.b Medicare payments (\$) per person per year: 2018, by claim type (model 1); Column G, Transplant/Row 50, Immunosuppressive drugs = \$2,453]

69 United States Renal Data System (USRDS). 2020 USRDS annual data report: epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2020. https://adr.usrds.org/2020/chronic-kidney-disease/7-prescription-drug-coverage-in-patients-with-ckd

[2020 ADR Volume 1 CKD; Chapter 7 Prescription Drug Coverage in Patients with CKD; Highlights; Bullet #6: "In 2018, per person per year Medicare Part D spending was 1.7 times higher for those with CKD (\$5392) than for those without CKD (\$3118) (Figure 7.7)."]

70 United States Renal Data System (USRDS). 2020 USRDS annual data report: epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2020. https://adr.usrds.org/2020/end-stage-renal-disease/10-prescription-drug-coverage-in-patients-with-esrd

[2020 ADR Volume 2 End Stage Renal Disease: Chapter 10 Prescription Drug Coverage in Patients with ESRD; Highlights; **Bullet # 6**: "In 2018, Medicare Part D spending was 2.4 times higher for patients with ESRD (\$8173) than those without (\$3397) (Figure 10.7)." (**Bullet #5**: "Per person per year Part D spending also increased in beneficiaries with ESRD until 2017, after which there was a large decrease (Figure 10.5)...")] **71** National Kidney Foundation. National Kidney Foundation Applauds House Passage of Landmark Immunosuppressive Drug Coverage Bill (news release). National Kidney Foundation website; Press Room. (2020, December 8).

https://www.kidney.org/news/national-kidney-foundation-applaudshouse-passage-landmark-immunosuppressive-drug-coverage-bill Also:

Congressional Budget Office. (2020, November 2). Congressional Budget Office cost estimate: at a glance: H.R. 5534, Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act of 2020.

https://www.cbo.gov/system/files/2020-11/hr5534.pdf Congressional Budget Office. Frequently asked questions about CBO Cost Estimates. CBO website. https://www.cbo.gov/about/products/ ce-faq

72 National Kidney Foundation. NKF Applauds Immunosuppressive Drug Coverage Legislation Passed in the U.S. Senate (news release). National Kidney Foundation website; Press Room. (2020, December 22). https://www.kidney.org/news/national-kidney-foundationapplauds-landmark-immunosuppressive-drug-coverage-legislationpassed

Also:

Congressional Budget Office. (2020, November 2), Congressional Budget Office cost estimate: at a glance: H.R. 5534, Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act of 2020. https://www.cbo.gov/system/files/2020-11/hr5534.pdf Congressional Budget Office. Frequently asked questions about CBO Cost Estimates. CBO website. https://www.cbo.gov/about/products/ ce-faq

73 Office of Disease Prevention and Health Promotion (ODPHP); Healthypeople.gov. Access to health services. Office of Disease Prevention and Health Promotion website.

https://www.healthypeople.gov/2020/topics-objectives/topic/socialdeterminants-health/interventions-resources/access-to-health [NOTE: The webpage above is also footnoted and contains sources for more detailed data.]

74 Centers for Disease Control and Prevention (CDC). (2021, February 18). Live well with chronic kidney disease. CDC website. https://www.cdc.gov/kidneydisease/publications-resources/live-wellwith-chronic-kidney-disease.html

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