

Appendix F: Data Forms

CMS ESRD Forms

- Previous CMS 2728-Chronic Renal Disease Medical Evidence Report
- CMS 2728-ESRD Medical Evidence Report Medicare Entitlement &/or Patient Registration v. 1995
- CMS 2728-ESRD Medical Evidence Report Medicare Entitlement &/or Patient Registration v. 2005
- CMS 2746-ESRD Death Notification (1996)
- CMS 2746-ESRD Death Notification (2004)
- CMS 2744-ESRD Facility Survey
- UB92-CMS 1450-Uniform Bill
- CMS 1500-Health Insurance Claim Form

CDC National Surveillance of Dialysis-Associated Diseases Form

- 1993–2002

Note: The 1996 CDC form is not available. The CDC did not conduct a study in 1998 and the last study was in 2002. Data for the CDC variables are missing after this date.

UNOS Transplant Forms

Transplant Candidate Registration Form

INCLUDES WAITLIST DATA AS WELL AS OTHER CLINICAL AND ORGAN-SPECIFIC INFORMATION COLLECTED PRIOR TO THE TRANSPLANT.

- Adult Kidney Transplant Candidate Registration Worksheet
- Adult Kidney/Pancreas Transplant Candidate Registration Worksheet
- Adult Pancreas Transplant Candidate Registration Worksheet
- Adult Liver Transplant Candidate Registration Worksheet
- Adult Intestine Transplant Candidate Registration Worksheet
- Adult Heart Transplant Candidate Registration Worksheet
- Adult Lung Transplant Candidate Registration Worksheet
- Adult Heart/Lung Transplant Candidate Registration Worksheet
- Pediatric Kidney Transplant Candidate Registration Worksheet
- Pediatric Kidney/Pancreas Transplant Candidate Registration Worksheet
- Pediatric Pancreas Transplant Candidate Registration Worksheet
- Pediatric Liver Transplant Candidate Registration Worksheet
- Pediatric Intestine Transplant Candidate Registration Worksheet
- Pediatric Heart Transplant Candidate Registration Worksheet

- Pediatric Lung Transplant Candidate Registration Worksheet
- Pediatric Heart/Lung Transplant Candidate Registration Worksheet

Transplant Recipient Registration Form

INCLUDES THE PATIENT STATUS AT DISCHARGE, PRE- AND POST-TRANSPLANT CLINICAL INFORMATION, AS WELL AS TREATMENT DATA. THE FORM IS GENERATED WHEN THE PATIENT RECEIVES A TRANSPLANT AND IS REMOVED FROM THE WAITLIST.

- Adult Kidney Transplant Recipient Registration Worksheet
- Adult Kidney-Pancreas Transplant Recipient Registration Worksheet
- Adult Pancreas Transplant Recipient Registration Worksheet
- Adult Liver Transplant Recipient Registration Worksheet
- Adult Intestine Transplant Recipient Registration Worksheet
- Adult Thoracic-Lung Transplant Recipient Registration Worksheet
- Adult Thoracic-Heart Transplant Recipient Registration Worksheet
- Adult Thoracic-Heart/Lung Transplant Recipient Registration Worksheet
- Pediatric Kidney Transplant Recipient Registration Worksheet
- Pediatric Kidney-Pancreas Transplant Recipient Registration Worksheet
- Pediatric Pancreas Transplant Recipient Registration Worksheet
- Pediatric Liver Transplant Recipient Registration Worksheet
- Pediatric Intestine Transplant Recipient Registration Worksheet
- Pediatric Thoracic-Lung Transplant Recipient Registration Worksheet
- Pediatric Thoracic-Heart Transplant Recipient Registration Worksheet
- Pediatric Thoracic-Heart/Lung Transplant Recipient Registration Worksheet

Transplant Recipient Follow-up Form

THIS FORM IS GENERATED AT SIX MONTHS POST-TRANSPLANT AND ON THE TRANSPLANT ANNIVERSARY FOR EVERY LIVING ORGAN RECIPIENT WITH A FUNCTIONING GRAFT. IT INCLUDES PATIENT STATUS AS WELL AS CLINICAL AND TREATMENT INFORMATION. A REDUCED SET OF DATA IS COLLECTED AFTER 5 YEARS. SHOWN HERE ARE THE ADULT AND PEDIATRIC FORMS FOR COLLECTING FOLLOW-UP THROUGH 5 YEARS POST-TRANSPLANT.

- Adult Kidney Transplant Recipient Follow-Up Worksheet
- Adult Kidney-Pancreas Transplant Recipient Follow-Up Worksheet
- Adult Pancreas Transplant Recipient Follow-Up Worksheet
- Adult Liver Transplant Recipient Follow-Up Worksheet
- Adult Intestine Transplant Recipient Follow-Up Worksheet
- Adult Thoracic Lung Transplant Recipient Follow-Up Worksheet
- Adult Thoracic Heart Transplant Recipient Follow-Up Worksheet
- Adult Thoracic Heart Lung Transplant Recipient Follow-Up Worksheet
- Pediatric Kidney Transplant Recipient Follow-Up Worksheet
- Pediatric Kidney-Pancreas Transplant Recipient Follow-Up Worksheet
- Pediatric Pancreas Transplant Recipient Follow-Up Worksheet
- Pediatric Liver Transplant Recipient Follow-Up Worksheet
- Pediatric Intestine Transplant Recipient Follow-Up Worksheet
- Pediatric Thoracic Lung Transplant Recipient Follow-Up Worksheet
- Pediatric Thoracic Heart Transplant Recipient Follow-Up Worksheet
- Pediatric Thoracic Heart Lung Transplant Recipient Follow-Up Worksheet
- Adult Post-Transplant Malignancy Worksheet
- Pediatric Post-Transplant Malignancy Worksheet
- Adult Post-Transplant Malignancy Worksheet
- Pediatric Post-Transplant Malignancy Worksheet
- Liver Recipient Explant Pathology Worksheet
- Recipient Histocompatibility Worksheet
- Deceased Donor Registration Worksheet
- Living Donor Registration Worksheet
- Living Donor Follow-Up Worksheet
- Donor Histocompatibility Worksheet

Special Study Data Forms

Case Mix/Adequacy Study

- Confidential Report

CAPD Peritonitis Study

- Confidential Report

Data Validation Study

- Transplant Information
- Patient History
- Dialysis Treatments
- Hospital Stay Information

EPO & Quality of Life Study

- Health Status Measurement
- Social Worker Questionnaire
- Physician Questionnaire
- Six-month Follow-up

Pediatric ESRD Growth & Development Study

- Patient History

Renal Biopsy Study

- Prognosis After ESRD

USRDS Dialysis Morbidity and Mortality Study Forms

DMMS Wave I Special Study Data Forms

- Instructions: USRDS Dialysis Morbidity & Mortality Study
- Dialysis Facility/Unit Questionnaire
- Vascular Access Questionnaire
- Vascular Access in Incident Patients
- USRDS DMMS-Core Confidential Report
- Anemia Questionnaire
- USRDS DMMS-Anemia Confidential Report
- Nutrition Questionnaire
- USRDS DMMS-Nutrition Confidential Report
- Patient Tracking form

DMMS Wave II Special Study Data Forms

- Cover Sheet & Patient Consent form
- Instruction Manual
- Dialysis Facility/Unit Questionnaire Instructions
- Dialysis Patient Questionnaire
- Medical Questionnaire Confidential Report
- USRDS DMMS Prospective Follow-up Study-Instructions
- Cover Sheet for Medical Update Questionnaire
- Medical Update & Questionnaire
- Cover Sheet & Patient Consent form
- Dialysis Patient Questionnaire
- Patient Tracking & Identification form

DMMS Wave III-IV Special Study Data Forms

- Instruction Manual for Clinical Questionnaire
- Clinical Questionnaire

- Confidential Report: Clinical Questionnaire
- Patient Tracking

DMMS FACS Special Study Data Forms

- Dialysis Facility/Unit Questionnaire

Glossary

Definitions are taken from *Dorland's Illustrated Medical Dictionary* or *On-line Medical Dictionary*.

ARF ACUTE RENAL FAILURE Sudden decrease in glomerular filtration rate accompanied by azotemia. ARF may or may not require renal replacement therapy; ARF patients who require dialysis may or may not recover renal function with short-term dialysis.

CAPD CONTINUOUS AMBULATORY PERITONEAL DIALYSIS A method of dialysis in which dialysate is always present in the abdomen and is usually exchanged every two hours. Normal treatment length is 48 to 72 hours.

CCPD CONTINUOUS CYCLER-ASSISTED PERITONEAL DIALYSIS A method of dialysis in which the patient is connected to a cyclor machine, usually at bedtime, and dialysate in the patient's abdomen is replaced with fresh dialysate 3 to 5 times during the night.

CDC CENTERS FOR DISEASE CONTROL & PREVENTION Recognized as the lead federal agency for protecting the health and safety of people at home and abroad, the CDC serves as the national focus for disease prevention by developing and applying programs designed to improve the health of the people of the United States.

CKD CHRONIC KIDNEY DISEASE A condition of deteriorating kidney function classified by five stages that define increasing evidence of kidney damage shown by microalbuminuria and estimated glomerular filtration rate.

CMS CENTERS FOR MEDICARE & MEDICAID SERVICES Created in 1977 as the Health Care Financing Administration (HCFA) and renamed in June 2001, this federal agency is responsible for the administration of the nation's largest healthcare programs, Medicare and Medicaid.

CMS-2728 MEDICAL EVIDENCE REPORT Provides source data about ESRD patients, including information on patient demographics, primary cause of renal disease, comorbidity, laboratory values, dialysis treatment, transplant, dialysis training, employment status, and initial insurance coverage.

CMS-2744 ESRD FACILITY SURVEY Data collected annually by CMS from all facilities certified to provide Medicare-covered renal dialysis and transplantation. The survey includes the entire United States and encompasses the full calendar year, with geographical data to the facility's ZIP code level. Each record contains facility information and information on the number of patients served, dialysis treatments provided, and kidney transplants performed, for Medicare and non-Medicare patients.

CMS-2746 DEATH NOTIFICATION A form used to report ESRD patient demographic information and information on the primary cause of death.

CHAIN PROVIDER A Chain, as applied to the USRDS Annual Data Report, is defined as follows: from 2001 to 2007 inclusive, a Chain is defined as a business entity that owns 20 or more dialysis units located in more than one state. After 2007 a USRDS Chain is defined as a business entity that owns 20 or more dialysis units (there is no state restriction). In addition, the USRDS defines a small Dialysis Operation (SDO) as a Chain with less than 100 dialysis units. A Large Dialysis Operation (LDO) is a chain with 100 or more dialysis units. The Annual Data Report will compare the data of each LDO and the sum of ALL SDOs in the numerous graphical displays. There may be graphical displays between just the SDOs.

CHF CONGESTIVE HEART FAILURE A risk factor for and complication of kidney disease.

CWF COMMON WORKING FILE SYSTEM The Medicare Part A and Part B benefit coordination and claims validation system, through which CMS maintains institutional and physician/supplier claims-level data. CWF claims records are the data sources for most claims and utilization files used by the USRDS.

DM DIABETES MELLITUS A condition of impaired ability to metabolize carbohydrates, protein, and fat, both a complication of kidney disease and a risk factor for ESRD and heart disease.

EGHP EMPLOYER GROUP HEALTH PLAN A source of data on CKD patients aged less than 65 years and continuously enrolled in a fee-for-service plan for two consecutive years.

ESRD END-STAGE RENAL DISEASE A condition in which kidney function is not adequate to support life.

ESRD NETWORKS Eighteen geographically defined organizations under contract to CMS serving as liaisons between the federal government and providers of ESRD services. The Network Organizations oversee the quality of patient care, collect data to administer the national Medicare ESRD program, and provide technical assistance to ESRD providers and patients.

EPO ERYTHROPOIETIN A hormone secreted chiefly by the adult kidney; it acts on the bone marrow to stimulate red cell production. Erythropoietin is available as a therapeutic agent used to treat anemia resulting from chronic renal failure and other conditions.

FOR-PROFIT FACILITY A dialysis facility owned, leased, or by any other means, controlled by a single business entity.

FREESTANDING FACILITY; INDEPENDENT UNIT A dialysis facility licensed to provide only outpatient and home maintenance dialysis.

HCFA HEALTH CARE FINANCING ADMINISTRATION See CMS, Centers for Medicare & Medicaid Services.

HD HEMODIALYSIS Removal of uremic toxins from the blood by virtue of the difference in rates of their diffusion through a semipermeable membrane while being circulated outside the body.

HOSPITAL-BASED FACILITY A dialysis facility attached to or located in a hospital and licensed to provide outpatient dialysis services.

INCIDENT PATIENT A patient starting renal replacement therapy for ESRD during a given calendar year. Excludes patients with acute renal failure, patients with chronic renal failure who die before receiving treatment for ESRD, and patients whose ESRD treatment is not reported through CMS.

NCH NATIONAL CLAIMS HISTORY 100% NEARLINE FILE Contains all Common Working File (CWF) Part A (provider) and Part B (physician/supplier) Medicare claims and adjusted claims information.

NIDDK NATIONAL INSTITUTE OF DIABETES AND DIGESTIVE AND KIDNEY DISEASES A part of the NIH that conducts and supports research on internal medicine diseases, including kidney, urologic, and hematologic diseases.

NIH NATIONAL INSTITUTES OF HEALTH The federal focal point for medical research in the United States and one of eight health agencies of the Public Health Services, part of the Department of Health and Human Services.

PD PERITONEAL DIALYSIS A type of dialysis in which fluid (dialysate) is introduced into the abdominal cavity and uremic toxins are removed across the peritoneum.

PERIOD PREVALENT PATIENT A patient receiving treatment for ESRD at some point during a given time period, usually six or twelve months. Patients may die during the period or be point prevalent at the end of the period.

POINT PREVALENT PATIENT A patient reported as receiving treatment for ESRD on a particular day, such as December 31 of a given year.

PMMIS/REBUS/REMIS PROGRAM MEDICAL MANAGEMENT AND INFORMATION SYSTEM FOR ESRD/RENAL BENEFICIARY AND UTILIZATION SYSTEM/RENAL MANAGEMENT INFORMATION SYSTEM The major source of data for the USRDS. This CMS file incorporates data from the Medical Evidence Report (CMS-2728), the Death Notification (CMS-2746), the Medicare Enrollment Database, Medicare inpatient and outpatient claims, the SIMS database, and the UNOS Transplant Database.

PREVALENT PATIENT A patient receiving renal replacement therapy or having a functioning kidney transplant (regardless of when the transplant was performed). Excludes patients with acute renal failure, patients with chronic renal failure who die before receiving treatment for ESRD, and patients whose ESRD treatments are not reported through CMS.

REUSE A process by which a hemodialyzer is cleaned and disinfected, allowing multiple uses on the same patient.

SAF STANDARD ANALYSIS FILES CMS files containing final action Medicare Part A claims data, including Inpatient, Outpatient, Home Health

Agency, Hospice, Skilled Nursing Facility, Clinical Laboratory, Durable Medical Equipment, and 5% Sample Beneficiary.

SAS® STATISTICAL ANALYSIS SYSTEM Format chosen for the USRDS SAFS because it is widely used, easily transported, and largely self-documenting. SAS is a commercially available data management and statistical analysis software system that runs on most computers, from mainframes to PCs, and it is almost universally available on university computer systems. The USRDS SAFS take full advantage of the program's ability to incorporate a large amount of documentation into the file.

SHR STANDARDIZED HOSPITALIZATION RATIO Used to compare hospitalization rates for a selected group of patients by computing the ratio of the group's observed hospitalization rate to the expected hospitalization rate for the national ESRD population.

SIMS STANDARD INFORMATION MANAGEMENT SYSTEM A database generated by the ESRD Networks used by the USRDS to provide detailed treatment history and to follow non-Medicare patients more closely.

SMR STANDARDIZED MORTALITY RATIO Used to compare dialysis patient mortality rates from year to year. Mortality rates for a subgroup of patients are compared to a set of reference rates, with adjustments for age, race, gender, and diabetes as a cause of ESRD.

STR STANDARDIZED TRANSPLANTATION RATIO Used to compare the transplant rate of a sub-group of patients to the national transplant rate.

TRANSPLANT CENTER A hospital unit licensed to provide transplantation and other medical and surgical specialty services for the care of kidney transplant patients, including inpatient dialysis furnished directly or under arrangement.

UNOS UNITED NETWORK FOR ORGAN SHARING A private, non-profit organization that maintains the organ transplant list for the nation and coordinates the matching and distribution of organs to patients awaiting transplant.

WAIT-LIST A list maintained by UNOS of patients awaiting an organ transplant.