

## Data We Collect

The data subjects are members of the general population who receive healthcare in the Irish health system. The principal use of the data collected by the NKDSS and QA Programme is surveillance of kidney disease and its clinical impact in the Irish Healthcare system.

Data subjects can expect their data to be accessed and processed by a limited select group of approved individuals who will link and anonymise data prior to any analysis

The National Kidney Disease Surveillance System (NKDSS) and Quality Assurance (QA) Programme collects information from Laboratory Information Systems, dialysis registers, the Hospital In-Patient Enquiry Scheme (HIPE) and National Mortality data to provide a more complete profile of the patient's health status through the Irish Health system

**Laboratory Information Systems** includes clinical and demographic data. Clinical information includes serum and urine biochemical and haematological test results. Demographic information collected includes patient names, patient addresses, medical record number, gender, month and year of birth, and county of residence

### **End Stage Kidney Disease (ESKD) Registers**

ESKD Registers capture data on all patients who develop ESKD and require dialysis or kidney transplantation. Data collected includes patient demographics, the date and type of first dialysis, the primary modality of renal replacement therapy. More recently, deployment of the renal information system (Kidney Disease Clinical Patient Management System) captures dialysis data.

**HIPE** is a health information system that collects demographic, clinical and administrative information on discharges and deaths from acute hospitals nationally. The information collected includes clinical, administrative and demographic data. Clinical information includes details of diagnoses and procedures carried out on each patient. Administrative information includes items such as dates and times of admission and discharge, type of admission, source of admission and discharge location. Demographic information collected patient surnames, Medical Record Number, gender, month and year of birth, county of residence.

**National Mortality data** includes, full name, date of death, address of residence of deceased, place of death, cause of death, occupation of deceased, age of deceased, sex of deceased, marital status of deceased.