Ollscoil Luimnigh
University of Limerick

Frequently Asked questions

What is the purpose of the NKDSS and QA programme?

Chronic kidney disease is a common chronic condition that adversely affects patient lives and reduces life expectancy. Between 10-15 % of adults in Ireland are affected, both men and women. They experience considerable suffering, high rates of hospitalisation and their likelihood of dying is far greater (up to 5-fold) than those without kidney disease. The average life expectancy on dialysis is between 5-10 years.

It is imperative for the public good to better understand the burden of kidney disease in Ireland, its impact on our citizens, in order to improve their lives. The purpose of the programme is to

1) provide meaningful high-quality information on the frequency of kidney disease (acute and chronic) and its complications in the Irish health system,
2) assess the quality of care provided to patients with kidney disease, and the effectiveness of different treatments for kidney disease.
3) identify areas or regions where the burden of disease is high and where greater attention should be focused.
4) identify areas of good clinical practice and areas where clinical care is suboptimal in the health system.

How are participant's included?

Participants are included if they are adult patients who receive health care at sites who provide data to the NKDSS and QA programme (UHLG and SAOLTA). A patient is included if they have a **renal panel** conducted which is a collection of measurements that provide multi-faceted information about the health of the **kidneys.** This routine test can play a role in early detection, diagnosis, and monitoring of kidney problems.

Who is conducting the study?

The NKDSS and QA programme is conducted by the University of Limerick

How will information be used?

The purpose of processing of patient-level data is to provide a more complete profile of the patient’s health status in the Irish Health system in order to improve our understanding of kidney disease in Ireland.

There is a major lack of information on the epidemiology of CKD in Ireland. These deficits in knowledge are due to the: 1) lack of integrated clinical information systems and the 2) absence of unique health identifiers preventing linkage of patient records.

The NKDSS uses a novel combination of deterministic and probabilistic matching to link regional and national datasets in the absence of a unique identifier and generates health datasets to address these deficits in our knowledge.

This programme provides a cost-effective solution for describing the natural history of kidney disease and its clinical consequences in the Irish health system. It will provide a better understanding of this complex illness and it will help inform national policy on prevention efforts and management practices.

The results of linkage with the creation of integrated datasets are expected to contribute to:

a) Improvements in the identification of kidney disease in the Irish health system and

b) across demographic and clinical subgroups

c) Better understanding of the impact of kidney disease on risk of hospitalisation and mortality in the Irish health system

d) Improvements in our scientific understanding of the epidemiology of kidney disease

e) and its complications over time

f) Promotion and protection of the health of individuals and communities

g) Improvements in health system policy planning, management and resource allocation in the Irish health system