

## **Privacy Notice for National Kidney Disease Surveillance System (NKDSSS) and Quality Assurance (QA) Programme**

This is a statement of the practices of the National Kidney Disease Surveillance System (NKDSS) and Quality Assurance (QA) Programme, University of Limerick, The CERC Building, University Hospital Limerick, Limerick Ireland regarding the use of personal data shared with us for this longitudinal study and the steps taken by the University to protect your privacy. The University fully respects your right to privacy and actively seeks to protect your privacy rights. Any personal information collected by the University as part of this health surveillance programme will be treated with the highest standards of security and confidentiality, in accordance with Irish and European Data Protection legislation.

The privacy notice explains the following:

1. How we collect and use your personal data
2. The purpose and legal basis for collecting your personal data
3. How we store and secure personal data
4. What are your rights

## 1. How we collect your personal data?

The data subjects are members of the general population who receive healthcare in the Irish health system. A patient is included if they have a renal panel conducted by a healthcare practitioner. A renal panel is a collection of measurements that provide multi-faceted information about the health of the kidneys.

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 secure data prior to any analysis.

The NKDSS and QA Programme collects information from Laboratory Information Systems, End Stage Kidney Disease 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.

The Health Service Executive (HSE), the National Renal Office (NRO) and Central Statistics Office provide data to the NKDSS and QA programme.

### 1.1. Data collection and processing

The personal data is encrypted at each site by a designated data managers/controllers of Laboratory, HIPE or mortality data before it is securely transferred to the Data Coordination Centre (DCC) situated at University Limerick.

Once securely transferred to the Data Coordination Centre (DCC) files are loaded and decrypted, all files are converted into datasets for processing. A series of data verification steps are completed to ensure data quality and integrity by the Biostatistician /data programmer/ analyst at the Data Coordination Centre (DCC).

All data processing and analysis is conducted within the confines of the DCC, which offers a secure operating IT environment, locked facilities, with verified password-protected access for all members of staff.

Primary data extraction will include identifiable data, which will then be used to link patient level data to hospitalisation data (HIPE), and mortality data (CSO) through the creation of pseudo identifiers.

“Pseudonymisation” of data means replacing any identifying characteristics of data with a pseudonym, or, in other words, a value, which does not allow the data subject to be directly identified.

These pseudo identifiers allow longitudinal linkage of laboratory, hospitalisation and End Stage Kidney Disease data and mortality data in a secure manner.

Prior to conducting an analysis, the above-mentioned datasets are linked. Once, linked/merged all identifiers including the pseudo ID are stripped away and replaced with a random hex character string, the dataset is then shuffled resulting in an analytical dataset that has been irrevocably anonymised dataset.

The final analytical datasets will be completely de-identified protecting the confidentiality of patient data.

## **2. The purpose and legal basis for collecting data**

The major goal of the National Kidney Disease Surveillance System (NKSSS) and Quality Assurance (QA) Programme is to provide meaningful high-quality information on the frequency of kidney disease (acute and chronic) and its complications in the Irish health system.

The lack of integrated clinical information systems and the absence of unique health identifiers prevent linkage of patient records in the Irish health system.

Consequently, up to now, it has not been possible to identify the true occurrence of

kidney disease, or determine the rate of progression of kidney disease, or its clinical impact on health in Ireland without linking personal data from different datasets.

By using pseudo identifiers, we can link episodes of patient care and track the progression of kidney disease, and its complications in the Irish health system.

Due to the large volume of participants (hundreds of thousands of patients) which would be captured by the disease surveillance programme, it was deemed impracticable to seek their consent. Instead, the linkage and processing of personal data for the NSKSS is conducted on the basis that it is necessary for scientific purposes in the public interest. In relying on this basis, and not the explicit consent of data subjects, we have put in place appropriate safeguards to ensure that the rights and freedoms of data subjects are protected. These safeguards include pseudonymisation described in Section 1 above and the security measures set out in Section 3 below.

The Health Research Consent Declaration Committee (HRCDC) has exercised its right under Regulation (8)(4)(b) granted a Conditional Declaration that the public interest in carrying out the health research significantly outweighs the requirement of the Applicant(s) to seek explicit consent of the data subject, whose personal data is being processed for Application: 19-060-AF3; Reference ID: National Kidney Disease Surveillance System and Quality Assurance Programme.

The Scope of the Declaration is for the collection, transfer, pseudonymisation, storage and subsequent linking/merging of the personal data from all data sources named. Data processing that falls under the scope of this declaration is limited to data processing at sites where ethics approval has been fully granted.

Sites include the University Hospital Limerick Group and Saolta Group

### **3. How we store and secure personal data**

The NKDSS and QA is a trusted research data hub (data linkage service). We are trusted by society at large and by health care professionals, to observe the highest standards of security and confidentiality regarding the very sensitive information

**N K D S S**

Data Coordination Centre (DCC),  
National Kidney Disease Surveillance System and QA Programme,  
Clinical Education and Research Centre Building, University Hospital Limerick,  
University of Limerick,  
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which we have in our possession.

Strict procedures are in place for the proper handling, care, and transportation of patient-level data. Information governance procedures, policies and safeguards in place within the DCC align with those outlined in the document titled An "As Is" Analysis of Information Governance in Health and Social Care Settings in Ireland to ensure that personal information is handled legally, securely, efficiently and effectively.

### **3.1. Basic Principles**

All staff concerned with the collection, processing and output of personal data for the NKDSS and QA programme are employees of the University of Limerick. On taking up duty they are required to

- Sign an undertaking of confidentiality, which will remain binding both during the period that the DCC is active and at any and all times thereafter including both before and/or after the termination of their employment with the University of Limerick.
- Read, agree to, and observe the rules set out in the current Information Governance Policy
- Any Confidential Information that comes into their possession or knowledge in any manner whatsoever is confidential and they shall maintain it as confidential.
- They must not in any form or manner, either directly or indirectly, discuss, disclose or communicate any Confidential Information to any individual or organisation other than the Director of the DCC, a member of staff of the DCC or such other individual designated by the Director of the DCC as having access to this information.

- They must ensure that Confidential Information is stored securely and will not store/transport it on unencrypted portable
- They observe the security precautions currently operating within the DCC and University of Limerick

### **3.2. Physical Security**

The offices of the DCC is hosted at the Clinical Education and Research Building at University Hospital Limerick, a facility which is jointly owned by the Health Services Executive and the University of Limerick. This facility is a closed secure facility with no public access. The DCC premises are protected by swipe access locks and by electronic alarms.

### **3.3. Electronic Security**

A dedicated, secure server is specifically designated for the collection, storage and processing of patient level clinical information. The server is situated within the secure facilities of Information Technology Division (ITD) who oversee security arrangements, policies and procedures within the University.

The University of Limerick Information Technology Division (ITD), oversee the "Security Policies and Procedures," for data transfer and management within the University of Limerick. Regular backups of network data are made on a weekly, monthly, and yearly basis

### **3.4. Retention**

A key objective of the NKDSS Programme is to examine trends in the occurrence of kidney disease and its clinical impact on patient's outcomes. Therefore, it is important to collect, link, and analyse longitudinal integrated data on patients to meet these important goals.

The data that is collected will be retained for as long as necessary to meet the identified purposes and, when no longer required, will be destroyed. Personal data will be retained for 15 years after an individual's death to ensure it has linked to all necessary laboratories, registry and hospitalisation records.

Retention of this data over long periods of time allows for the identification and examination of trends in disease and outcomes which will ultimately lead to better strategic planning of services, and assessment of treatment interventions to improve the healthcare system.

Data subjects can expect their data to be accessed and processed by a very limited select group of approved individuals who will link and pseudonymise data prior to any data analysis. They can expect that no personal data will be transferred to third parties or used outside the scope of the National Kidney Disease Surveillance and Quality Assurance (QA) Programme in accordance with regulatory guidelines.

The purpose of a data processing and linkage is not to make decisions about an individual that would result in harm to the individual, such as being denied access to appropriate health services and/or benefits to which the individual is entitled.

#### **4. What are your rights**

Under the General Data Protection Regulation (GDPR) you have rights in relation to how your personal data is collected and processed. In general, under GDPR you have the right to:

- Know if your data is being used
- Know how your data is being used
- Receive a copy of your data

- Have inaccuracies corrected
- Restrict the use of your data
- Have your data deleted
- Withdraw consent where collection and processing is based on consent

There are, however, a number of scenarios where your rights, as described above, are restricted with regard to personal data held in the NKDSS and QA programmes.

Due to the secure manner in which data is collected for the NKDSS and QA programme it is not always possible for us to identify data relating to particular individuals and this restricts our ability to take direct action in certain circumstances. Furthermore, where your personal data remains in the source datasets obtained from, for example Laboratory Information Systems or the Hospital In-Patient Inquiry Scheme, it is possible that your data will be contained in future imports from these sources. Finally, it may not be possible for us to delete your data or restrict processing of your data where this would seriously impair the achievement of the objectives of the NKDSS and QA programmes.

If you have any questions/concerns about this, please contact us at <https://www.nkdss.ie/contact/>.

Given that, the national data collections are a reflection of the records held in Irish hospitals it may be possible for you to exercise your right to receive a copy of your data and have inaccuracies corrected by contacting the hospital directly. Any amendments made to your medical records while the national data collection is still open will be reflected in that national data collection. However, once the database is considered to be closed then changes will be made only if there is a major problem identified.

#### **4.1. How can I make a request to exercise my rights?**

If you wish to exercise any of your rights, as described above, you should contact <https://www.nkdss.ie/contact/> and/or [dataprotection@ul.ie](mailto:dataprotection@ul.ie).

If you would like to make a request relating to records held by your hospital forms are available for this purpose at <https://www.hse.ie/eng/gdpr/data-requests>.

#### **Changes to the privacy notice**

We regularly review and, where necessary, update our privacy information.

#### **Contact**

If you have any queries relating to the processing of your personal data for the purposes outlined above or you wish to make a request in relation to your rights you can contact <https://www.nkdss.ie/contact/>