Transforming Chronic Disease management through novel National Surveillance Programmes & Disease Registries: The Health Support System (HSS)

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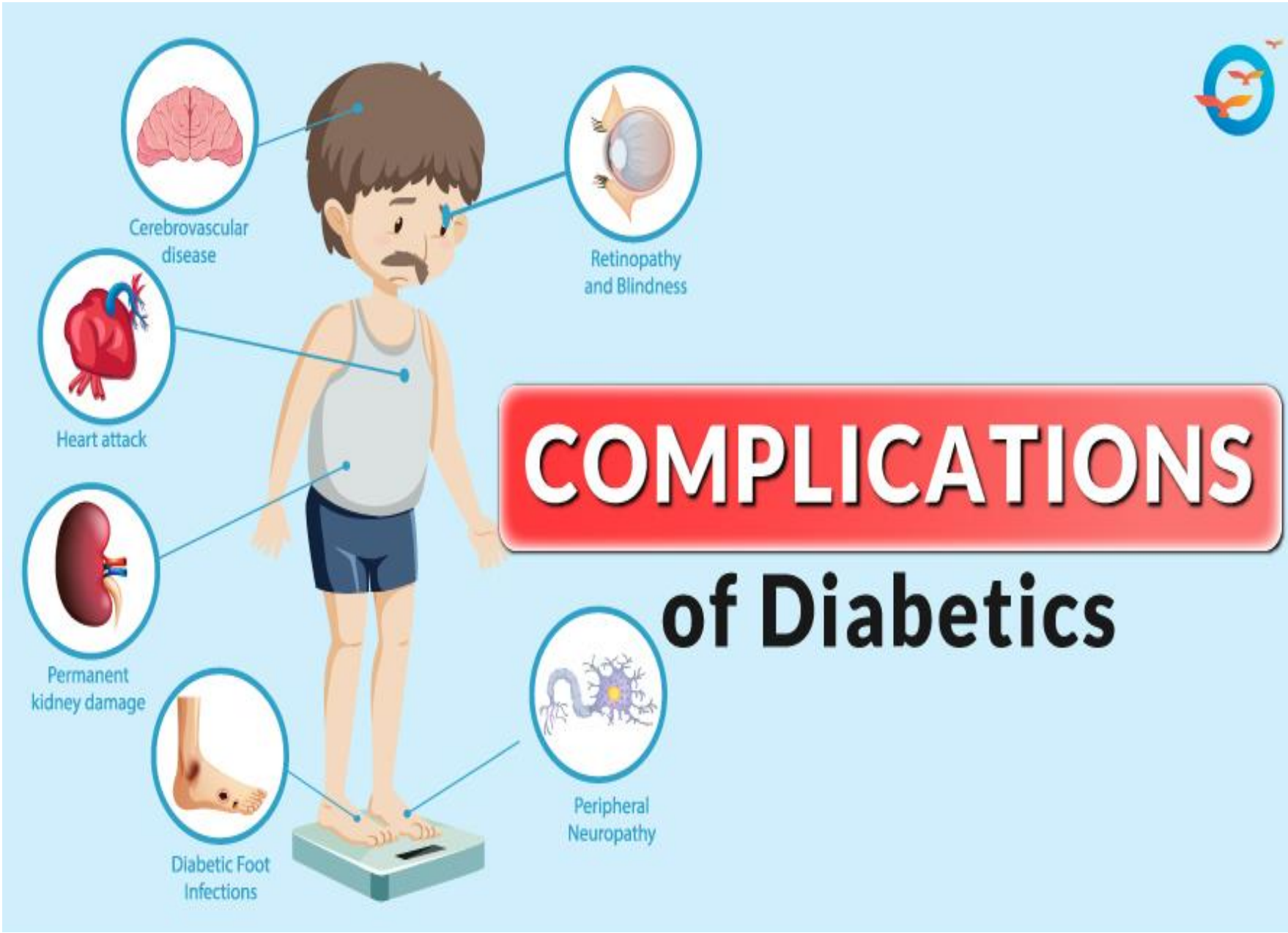
Chronic Disease

- 1.3 million people in Ireland live with one of the following major chronic diseases: Cardiovascular Disease, Chronic Obstructive Pulmonary Disease, Asthma or Diabetes




- Personal impact of suffering with a chronic disease
- Unsustainable pressure on current health services
- Loss of productivity in society

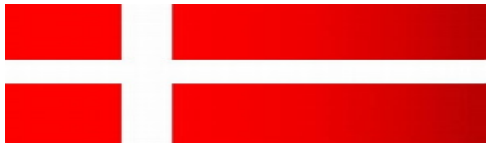

Cerebrovascular disease
Retinopathy and Blindness
Heart attack
Permanent kidney damage
Diabetic Foot Infections
Peripheral Neuropathy
COMPLICATIONS
of Diabetics

National Diabetes Registries

- Register: database of people identified with a certain condition

Registry: organisation and process that supports the register

- Operational in many European countries:
  - Scotland (**Scottish Care Information – Diabetes Collaboration**)
  - Scandinavia (Steno Centre in Denmark)



- Evidence that National Diabetes Registries improve outcomes:
  1. Promote the management of diabetes & prevent complications (improving clinical care)
  2. Enable trends to be estimated
  3. Inform service planning & resource allocation
  4. Research

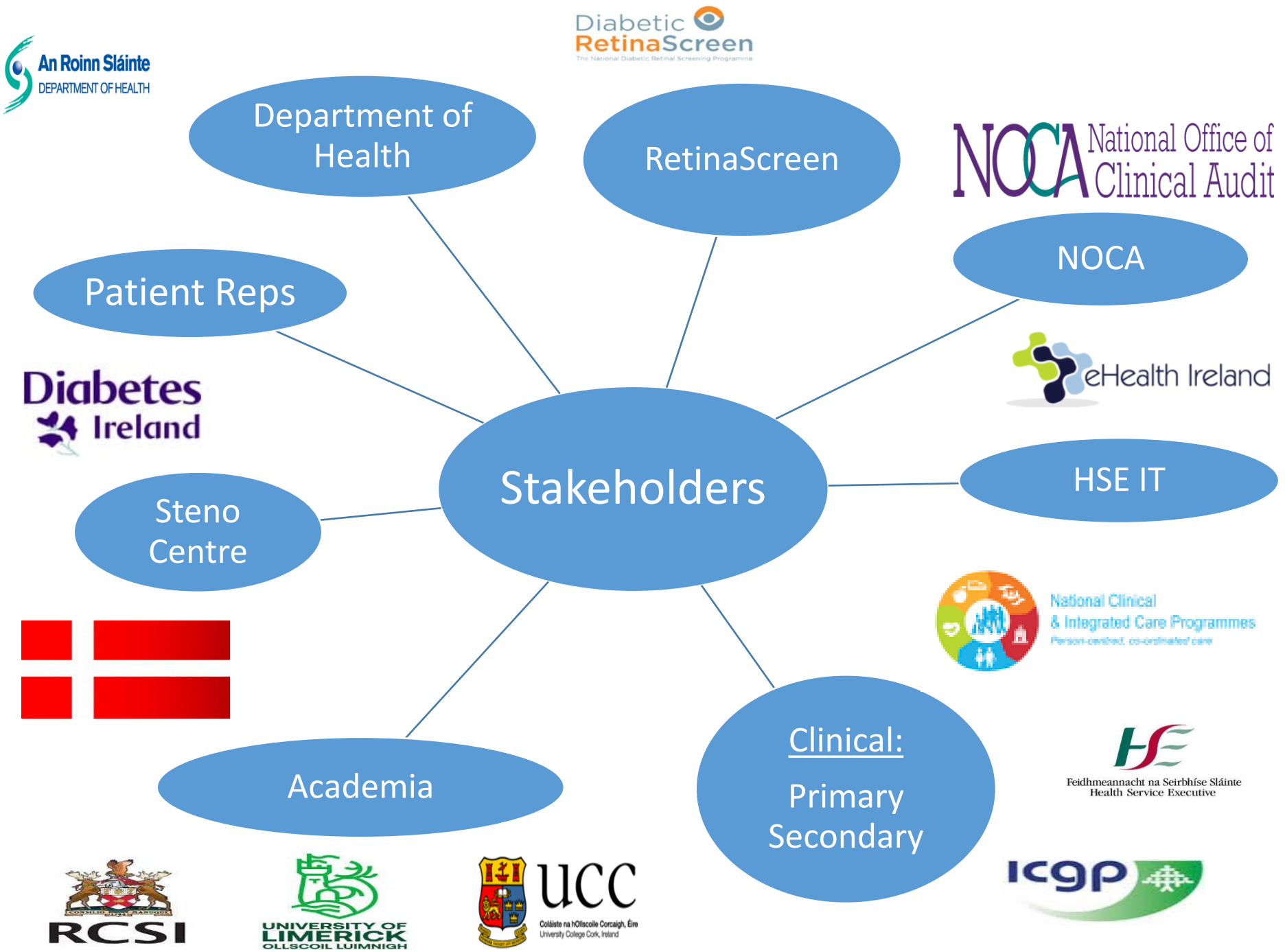
Overall Vision

- Proposal written by ***multidisciplinary*** team of diverse stakeholders

- Funding for a National Diabetes Registry pledged by Department of Health

- Develop a National Diabetes Registry within 5 years

    1. Improve Patient Care
    2. **Collect metrics to monitor trends over time**
    3. **Plan health services**
    4. Generate new knowledge (Research)


An Roinn Sláinte
DEPARTMENT OF HEALTH
Diabetic RetinaScreen
The National Diabetic Retinal Screening Programme
Department of Health
RetinaScreen
NOCA National Office of Clinical Audit
NOCA
Patient Reps
eHealth Ireland
Diabetes Ireland
Stakeholders
HSE IT
Steno Centre
National Clinical & Integrated Care Programmes
Person-centred, co-ordinated care
Clinical:
Primary
Secondary
Academia
Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive
RCSI
UNIVERSITY OF LIMERICK
OLLSCOIL LUIMNIGH
ucc
Coláiste na hOllscoile Corcaigh, Éire
University College Cork, Ireland
icgp

Opportunities:

- SFI-funded research projects:
  - Changing the Direction of Diabetes with Integrated, Population-Level, Data-Driven Decision Making (RCSI)
  - RECONNECT: Chronic disease: discovery, analysis and predictive modelling (UCC/DCU)
- Challenges: Legal, Technical and Governance
- Learn from National Kidney Disease Surveillance System

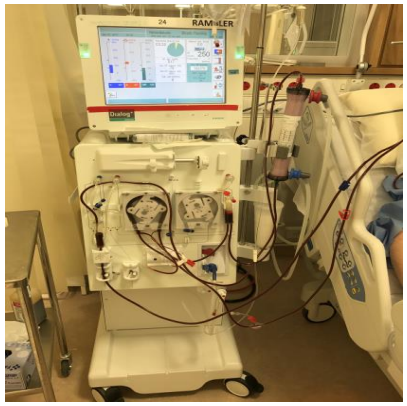
National Kidney Disease Surveillance and Quality Assurance System (NKDSS)

Professor Austin Stack on behalf of the NKDSS Consortium

Research Conference , Department of Health
Evidence for Reform: Where Research meets Policy
7th November 2023

Why focus on Chronic Kidney Disease?

Common: 10% of adults affected (400, 000 adults)



Harmful: 12th leading cause of death

14 % of all Irish hospitalisations

> 500 new patients with Kidney Failure per year

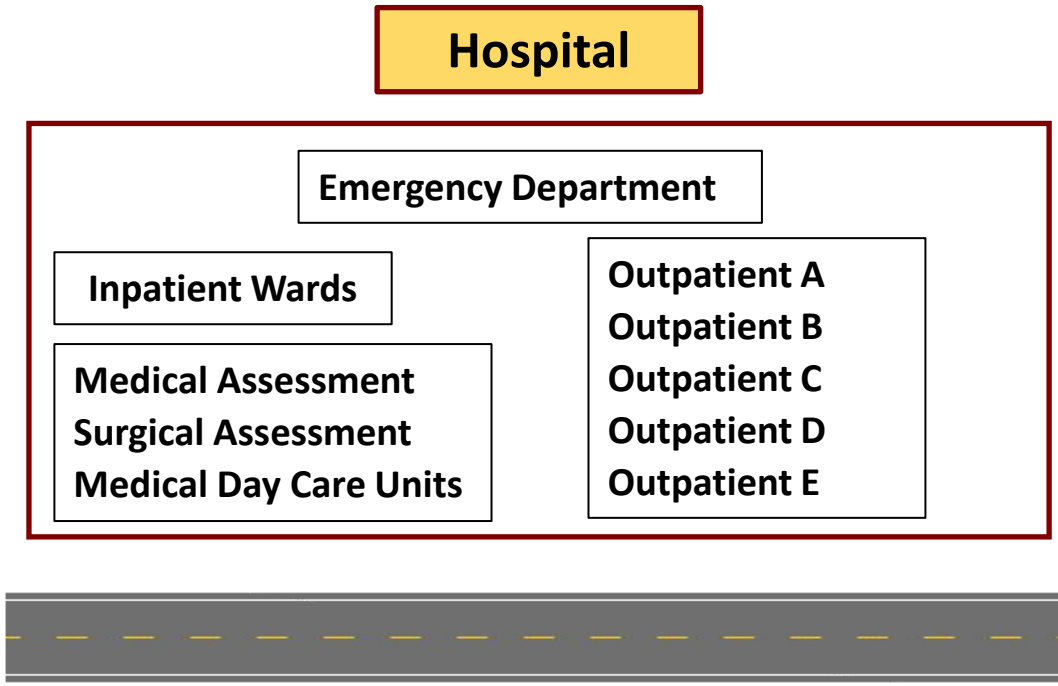
Costly: to patients and to the health system

Chronic Kidney Disease Collaboration. Global, regional, and national burden of chronic kidney disease, 1990-2017. Lancet. 2020

Overarching Goals

1. To determine frequency of kidney disease and risk factors
2. To measure quality of care delivered to patients
3. To quantify the impact of interventions
4. To support strategic planning and resource allocation

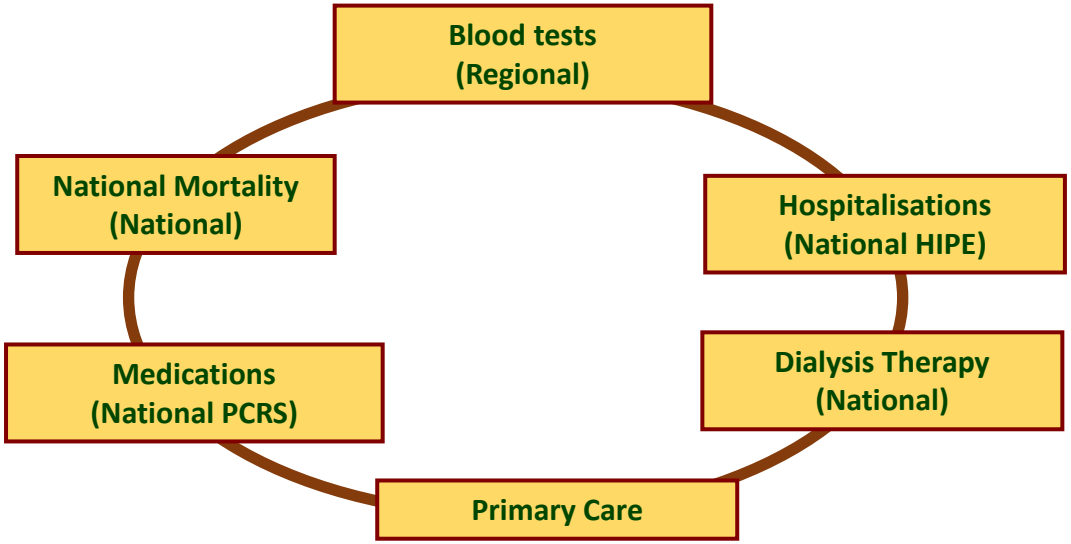
Our entire Health System is in Silos

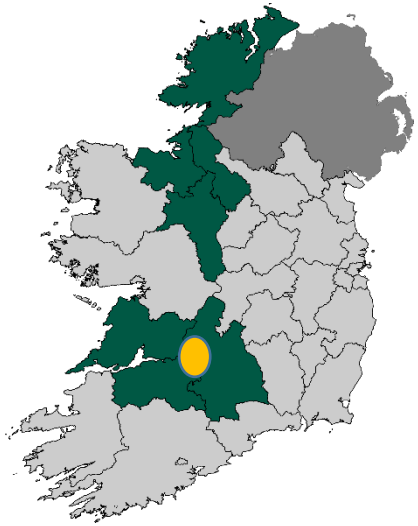


Challenges

- Integration of health data
- Visibility on patient flow
- Visibility on quality of care
- Quality improvement
- Real-time analytics

A Framework to Integrate and link Health Data





PCRS: https://data.ehealthireland.ie/group/pcrs
HIPE: https://data.ehealthireland.ie/group/about/hpo-hipe
KDCPMS: Hussein et al Kidney360 June 2021
CSO: https://www.cso.ie/en/statistics/birthsdeathsandmarriages/mortalitydifferentialsinireland/

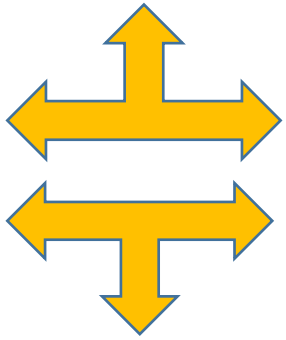
Establish Enduring Partnerships

University of Limerick

Irish State Partners

Health Services Executive (HSE)

1. National Renal Office (HSE)
2. National Health Intelligence Unit (NHIU)
3. Primary Care Reimbursement System (HSE)
4. Hospital Inpatient Enquiry Department (HSE)
5. Central Statistics Office (CSO)



Academic Partners

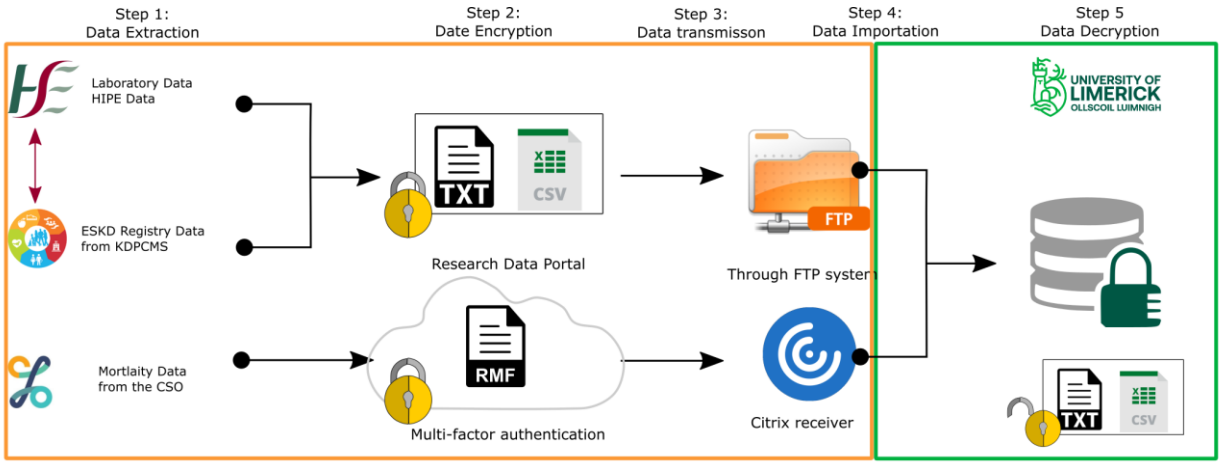
1. University of Limerick
2. University College Cork
3. University College Dublin
4. University of Michigan
5. University of Cincinnati
6. Johns Hopkins University
7. CDC-Surveillance System, USA

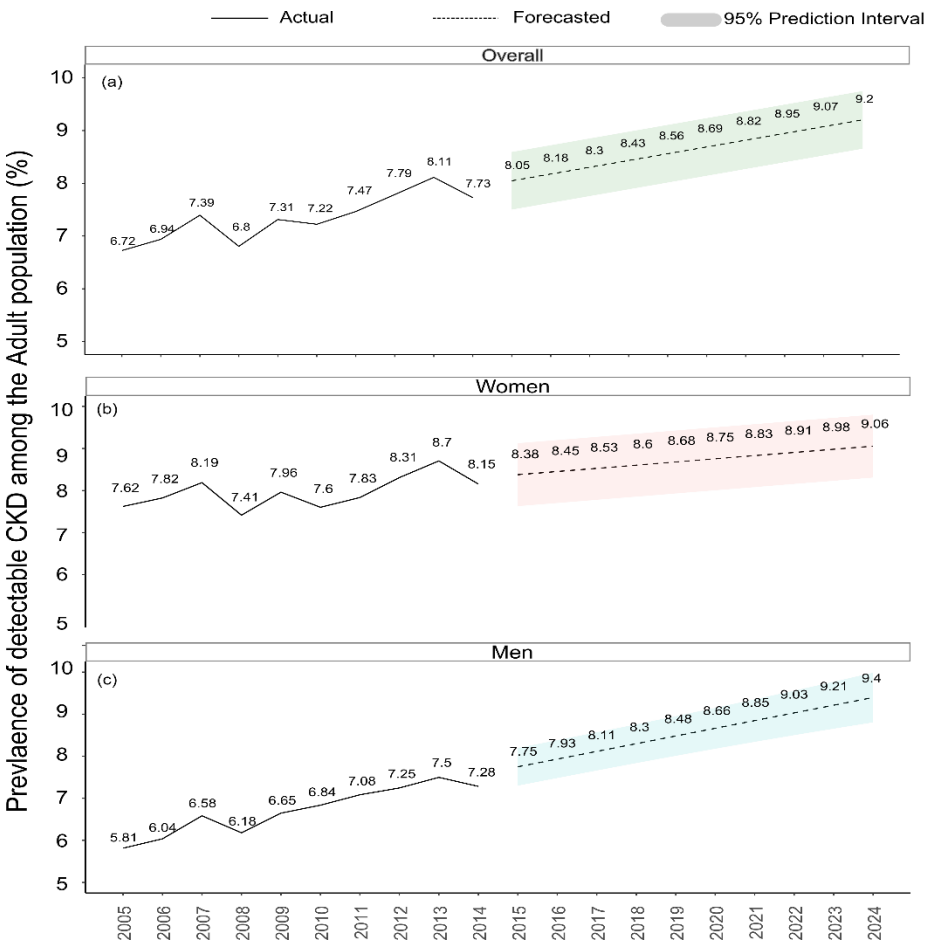
Governance Regulators

Data Protection Office (DPO)
Health Services Executive (HSE)
Central Statistics Office (CS0)
Regional Ethics Committees
Health Research Consent Declaration Committee (HRCDC)

Technical, Ethical, Information Governance Framework

- Data Protection Office
- HSE Data Sharing Agreements
- CSO Data Sharing Agreements
- Ethical Approvals by region
- Health Research Consent Declaration (HRCDC)
- Data linkage algorithms





CKD defined as mean eGFR <60 ml/min/1.73 m², using CKD-EPI
N=579,452, Population estimates derived from 2012 and 2016 census data

Predict Growth of Chronic Kidney Disease

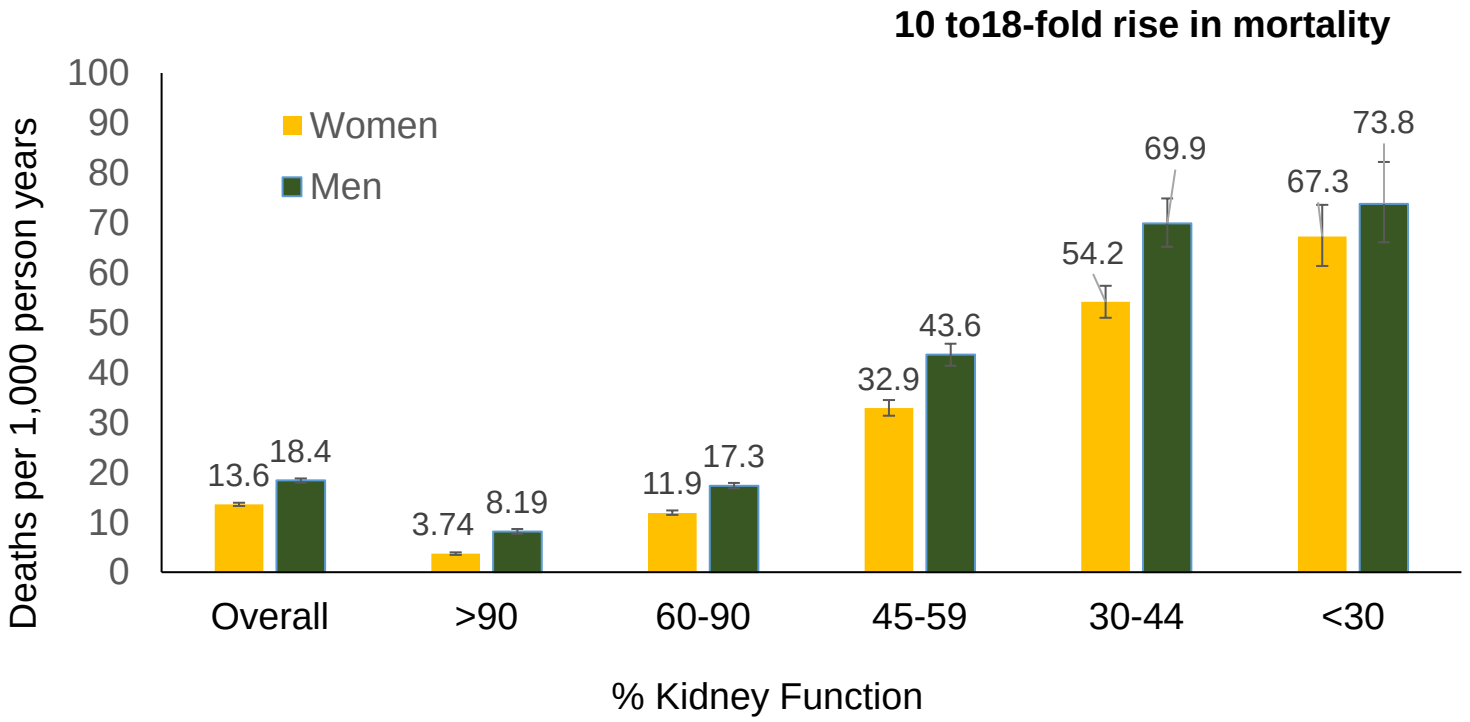
By 2024, CKD predicted to rise to 9.2 %

Mainly driven by growth in the elderly

(Age 75+ , a 5% rise)

[1] Stack et al: Data from Kidney Disease Surveillance Programme in Ireland 2017

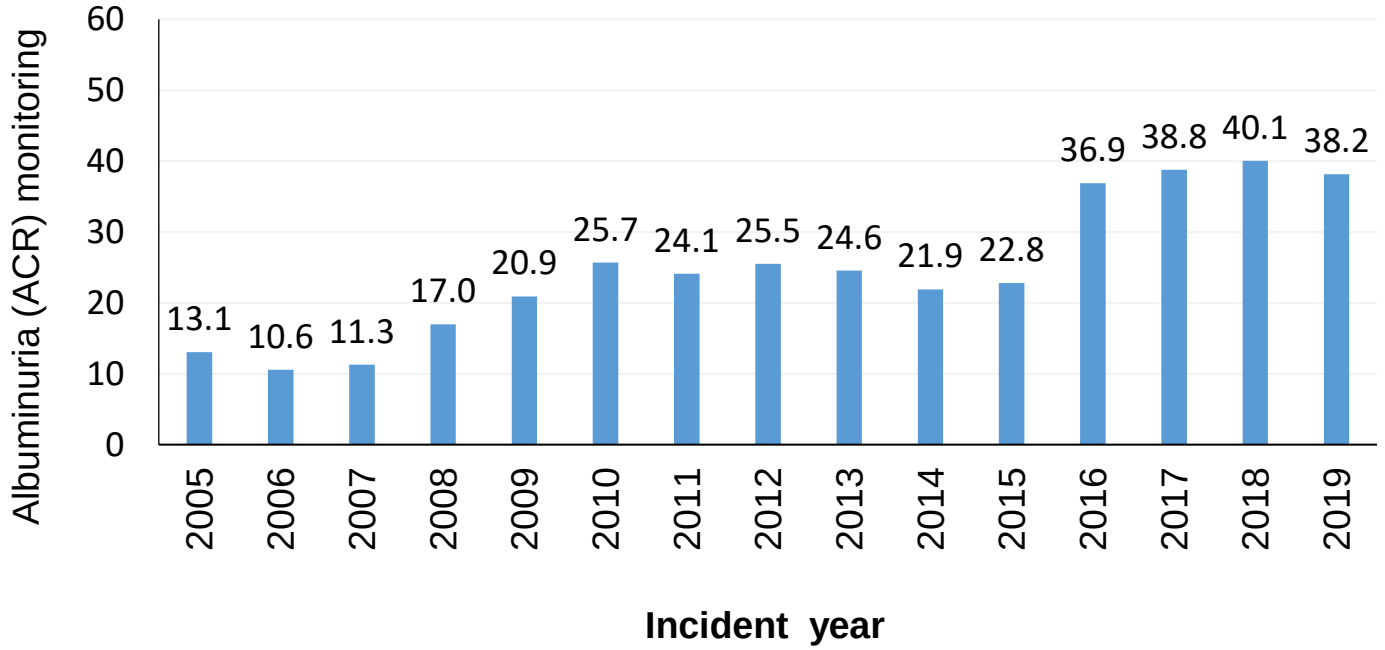
Quantify the impact on overall Death Rates



N= 125, 890 patients
N= 93, 515 hospitalisations

Stack et al European Renal Association 19TH May 2022

Determine screening among high-risk patients (Diabetes)



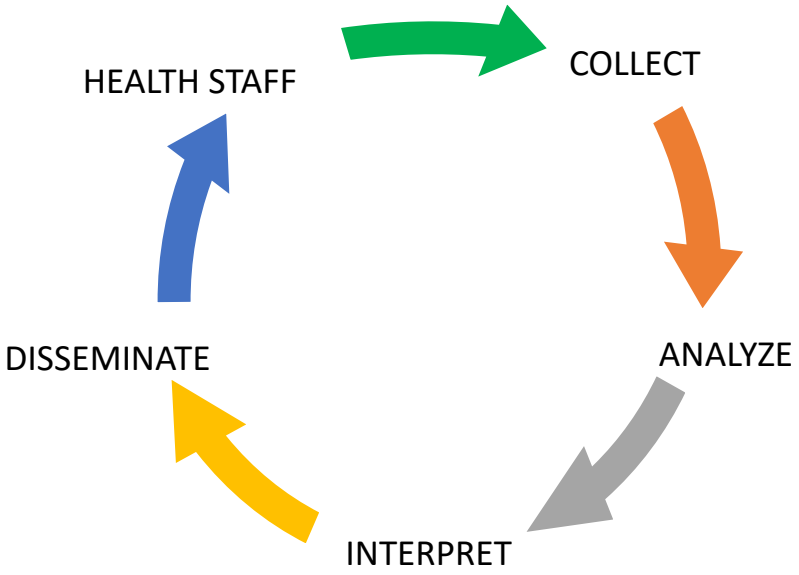
N= 16,272 adult incident diabetic patients, age 18)
Diabetes: Two consecutive measures of Fasting plasma glucose >=7mmol/L or HBA1C >= 48 mmol/mol or Random plasma glucose >=11.1 mmol/L.

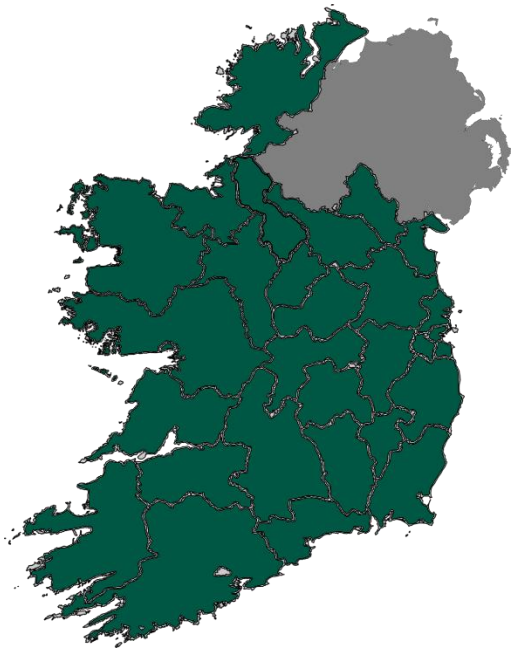
NKSS

Stack et al :Preliminary data Kidney Disease Surveillance System 2022

National Kidney Disease Surveillance System (NKDSS)

Learning health system:





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NKDSS

Key learnings to date

- **Registries** – excellent source of deep clinically rich longitudinal data on patient cohorts

- But traditional approach creates **siloes** - single disease focus, manual processes, duplication of structure & effort.

- Interest in evolving “registry type” solutions for **many other conditions** – diabetes, renal, cardiac, COPD, heart failure, inherited conditions, dementia, congenital, rare diseases …….

- **Challenges**

    1. Legal underpinnings - data sharing, consent etc.
    2. Governance – ownership, location (inside/outside HSE), organisational structure
    3. Technical infrastructure
    4. Data collection & access to available data
    5. Data quality, coding, classification, structured v unstructured
    6. Analytical capacity to fully exploit the potential of data – advanced analytics, AI etc.
    7. Display & user access
    8. Underuse of available data
    9. Data re-association - many identifiers v IHI/PPSN – process & environment (e.g. DASSL approach)
    10. Scope of functions – wide v narrow
    11. Absence of an overarching framework

What the functions should be

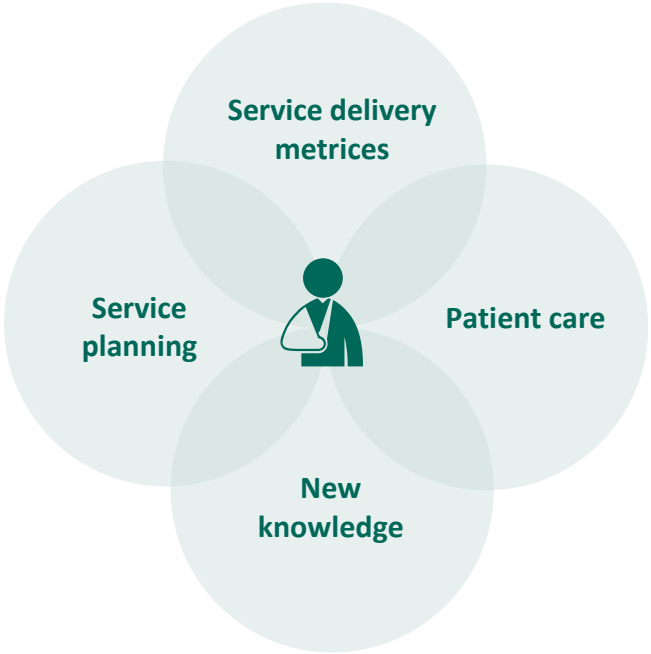
Four essential functions (~ data quality/availability)

1) **Patient care** (direct/indirect)

2) **Service metrics** (activity, trends, QA/QI)

3) **Service planning** (projections, evaluation of impact, epidemiology, modelling)

4) **New knowledge/research/policy**



The way forwards - legal basis

Core legal underpinnings for registry type solutions are provided by the four pieces of legislation

1. The **Health Act 2004 -** mandates the HSE "to use the resources available to it in the most beneficial, effective and efficient manner to improve, promote and protect the health and welfare of the public."

2. **General Data Protection Regulation** (GDPR) - processing of data (including personal and sensitive data) is lawful, without specific consent, if carried out in the exercise of official authority vested in the controller.#

3. Use of the Individual Health Identifier (IHI) aligns with primary and secondary purposes as defined in **The Health Identifiers Act 2014**.

4. Generation of new knowledge through scientific study may require the invocation of the **Health Research Regulations (2018)**.

5. **Health Information Bill** – will provide further underpinnings to include appropriate data sharing across the health sector (public + private), directing data to be collected, data standards etc.

Digital policies & frameworks – EU, DOH, HSE

The way forwards – technical phases & data flows

Phased development

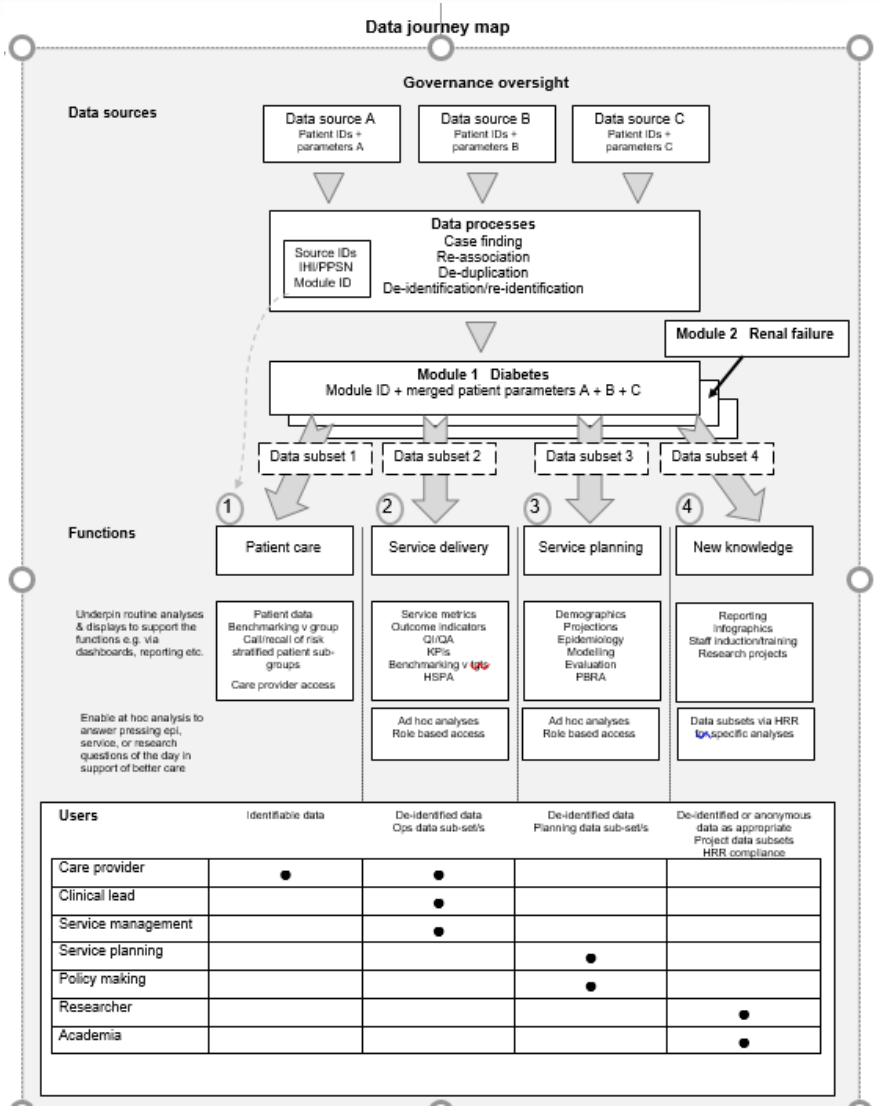
1) Prototype – to test components
2) Minimum Viable Product (MVP) - demo
3) Intermediate - user feedback
4) North Star Vision - mature solution

Leveraging Expertise

HSE Integrated Information Service (IIS)

Clinical leadership/expertise

NHIU Analytical skills



The way forwards - governance structure

- Establishment of **appropriate programme governance** is fundamental to the successful implementation and delivery of the diabetes registry solution.

- Data governance and management initiatives have been established in the HSE in recent years e.g. DAIM and development will align with these and national and international leading practice.

- Proposed governance structure will follow a framework of **strategic, tactical, and operational tiers** with the appropriate programme and data governance within each tier.

- Clear definitions of **user roles** are required for good data governance and role based access management is an important constituent of data governance.

- In developing governance structures, **stakeholder engagement** from across the HSE, the wider health system and involving patient representation to ensure the patient voice is heard

Wind in our sails

- Existing **legal basis** & forthcoming Health Information Bill
- **DOH & HSE digital policy & framework** (EU aligned)
- Evolving **EHR**s, **Summary Care Record**, **Shared Care Record**
- Collaboration within the HSE of the **Clinical leadership**, **IIS** + **NHIU** analytical capacity
- Learnings from **existing** health registries, NKDSS
- **Technical solutions** - cloud environment (security, scalability) + HSE standards & protocols
- **Available** relevant diabetes and renal datasets
- **Data re-association** via IHI/PPSN or probabilistic if required as interim (e.g. DASSL approach)
- **Clinical leadership** interest & rationale

- Way forwards - integration of "**real world**" data in a novel way – but "not siloes upon siloes"
- **Single consortium** to evolve **diabetes** and **renal disease** modules on a phased basis.
- Appropriate "**wrap around**" framework conceptualised – deliver on the four functions identified
- Excellent time to build a sustainable multi-morbidity solution on a phased basis (framework currently referred to as the **Health Support System**)