

# Value of Better Health Data in Cancer

**For cancer care**

**For cancer trials & research**

**For patient insights**

**For service planning**

**For value for money  
& sustainable budgets**

Good quality health data is vital for health professionals to provide safe and effective care. Health systems need to learn from our collective data to improve the quality, integration and safety of care. Health research needs to be accelerated so we can better prevent disease, improve care pathways and develop new forms of care delivery and treatment more quickly.

By comparison with our peers, Ireland fares poorly in the collection of quality data on cancer care and treatment.

The accompanying report *'Uncovering the Value of Real World Data for Blood Cancer'* captures

***"Better data is needed to get a more complete picture of the care needs of everyone in Ireland living with or after a cancer diagnosis."***

recommendations from key stakeholders and experts on how to improve availability and use of better cancer data for multiple objectives including policy making and service planning, clinical decision making and patient care, for clinical trials and research and for measuring cost effectiveness and value for money in cancer care.

## Diagnosis of issues in Ireland's cancer data environment

- **Ireland is behind other European countries in terms of the availability and quality of health data due to deficits in the health information system, which make it inefficient to capture useable data for both hospital databases and population registries.**
- **Lack of cancer data collection and usage also reduces Ireland's attractiveness as a location for cancer trials and research as well as the ability to measure cost effectiveness and ensure value for money for health interventions and treatments.**
- **Cancer data sources include registries, hospital and patient records, claims data, health, demographic and socio-economic databases but these remain fragmented. Most current cancer data sources in Ireland lack scale, robustness and detail to support decision-making for policy and planning.**

# How to create a Better Data Environment for Cancer in Ireland

 **Invest** in Ireland's health information infrastructure

 **Don't wait for perfect** to make better use of data that exists

 **Provide** clarity on trust and patient consent with new data policy and legislation informed by patients and data users

 **Educate** patients on link between their data, research and a better health service

 **Communicate to healthcare professionals** the uses and benefits of data they collect

 **Link up and integrate** existing data collections and registries with bottom up tech solutions and standardisation

 **Aim to Lead** in the use of artificial intelligence and new digital technologies in health service for better patient care and health service outcomes

## Key outcomes from the report include:

### 1. Patient experience and quality of life data are essential to the future of cancer treatment and care in Ireland

The centrality of patient experience data to the treatment of cancer needs to be recognised in health policy and plans.

### 2. A new data policy is required around both patient consent and the secondary use of data

Enhanced access to data depends on the confidence of patients to securely share their sensitive data, but also on increased interoperability and data standardisation.

Trust and consent are seen as key issues that require clarity and a more robust legislative foundation.

However, a shift in culture is also required and must be informed by deliberation with patients.