Cancer Registry

Cancer Registries

	National Cancer Registry	Hospital-based Cancer Registry	Site-specific Cancer Registry
Legal Basis	Cancer Registry Promotion Act	Cancer Registry Promotion Act (guidelines for hospital-based cancer registry)	-
Purpose	Promoting cancer control	Improving cancer care quality, by evaluating and comparing medical institutions	Investigation for improving cancer stages classification
Responsible entity	National government leads, delegating to prefectural governments	Designated cancer care hospitals, hospitals nominated by prefectures	Academic societies
Registration Subjects	Cancer* patients at all hospitals and designated clinics	Cancer* patients treated at own facility	Each follow own rules
Information Collected	26 Items (Name, date of birth, address, cancer type and stage, circumstance of cancer detection, treatments, date of death)	105 Items (Name, date of birth, cancer type and stage, course of discovery, disease name sharing with patient, TNM classification, treatments, vital status)	Each follow own rules; item numbers large in general
Notes	• Transitioned from prefectural population-based cancer registration in Jan 2016 † continued with approval by prefectural governors • Cases diagnosed since 2016	• Registration required at designated cancer care hospitals from 2006 • Registration forms provided by the National Cancer Center	• By organs e.g. stomach, colon/rectum, lung

* Malignant neoplasms and other diseases designated by government ordinance

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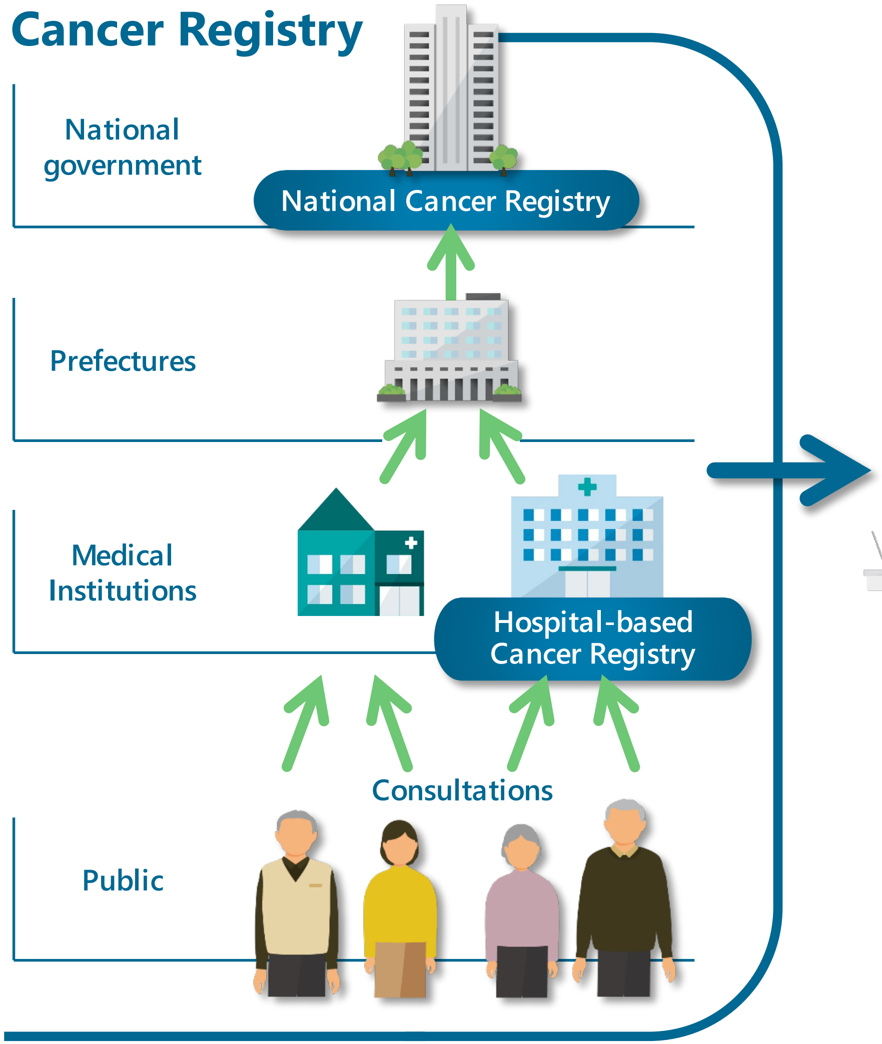
Adapted from Handbook on Population-Based Cancer Registration in Japan, Fifth Series, Apr 2013, incorporating changes Jan 2024

Benefits of Cancer Registration

Cancer Registry



For patients and the public

- Leads to clear understanding, and raises public awareness of cancer
- Serves as a point of reference when selecting medical institutions
- (In future) way to learn about treatments and outcomes of patients with similar conditions
- Leads to advanced prevention and treatments through progress in cancer research and treatment* evaluations
  - * Linkage with cancer screening information, site-specific cancer registries and health insurance claim data is necessary for detailed evaluation

For National Government/Prefectures

- Source of accurate and latest data, underpinning data-driven prevention and screening, cancer control measures.
  - Trends in cancer patient numbers
  - Regional differences
  - Data for analysing effect of interventions (prevention, screening, treatments)
  - Clarifies issues

For medical practitioners and researchers

- Quantitative comparisons between medical institutions made possible
- Promotes research on cancer prevention and elucidation of cancer risks

Cancer Registry Legal Basis - Cancer Control Act
(Act No. 98, 2006)

Chapter 3: Basic Policy
Section 2: Promoting Equality in Cancer Treatment
(Improving the collection/provision of cancer treatment information)

Article 17: National and local governments shall improve cancer care information collection and provision schemes and promote counselling and support to cancer patients and their families.

2. **National and local governments shall execute measures to implement cancer registries (comprehend cancer incidence, treatments, vital status of cancer patients, and its analyses) and utilize its data.**

Supplementary Resolution on the Cancer Control Act Draft Bill

(Committee on Health, Welfare and Labour - House of Councillors, 15 Jun 2006)

XVI. **Cancer registration** is **indispensable** to cancer epidemiological research on patient numbers and prevalence of cancer, screening evaluation, and treatment assessments. Following **passage of this law, improvements in hospital-based cancer registry, population-based cancer registration and their accuracy, and procedures for rigorous protection of personal information will be investigated, and necessary measures taken.**

Cancer Registry Promotion Act - Overview 1

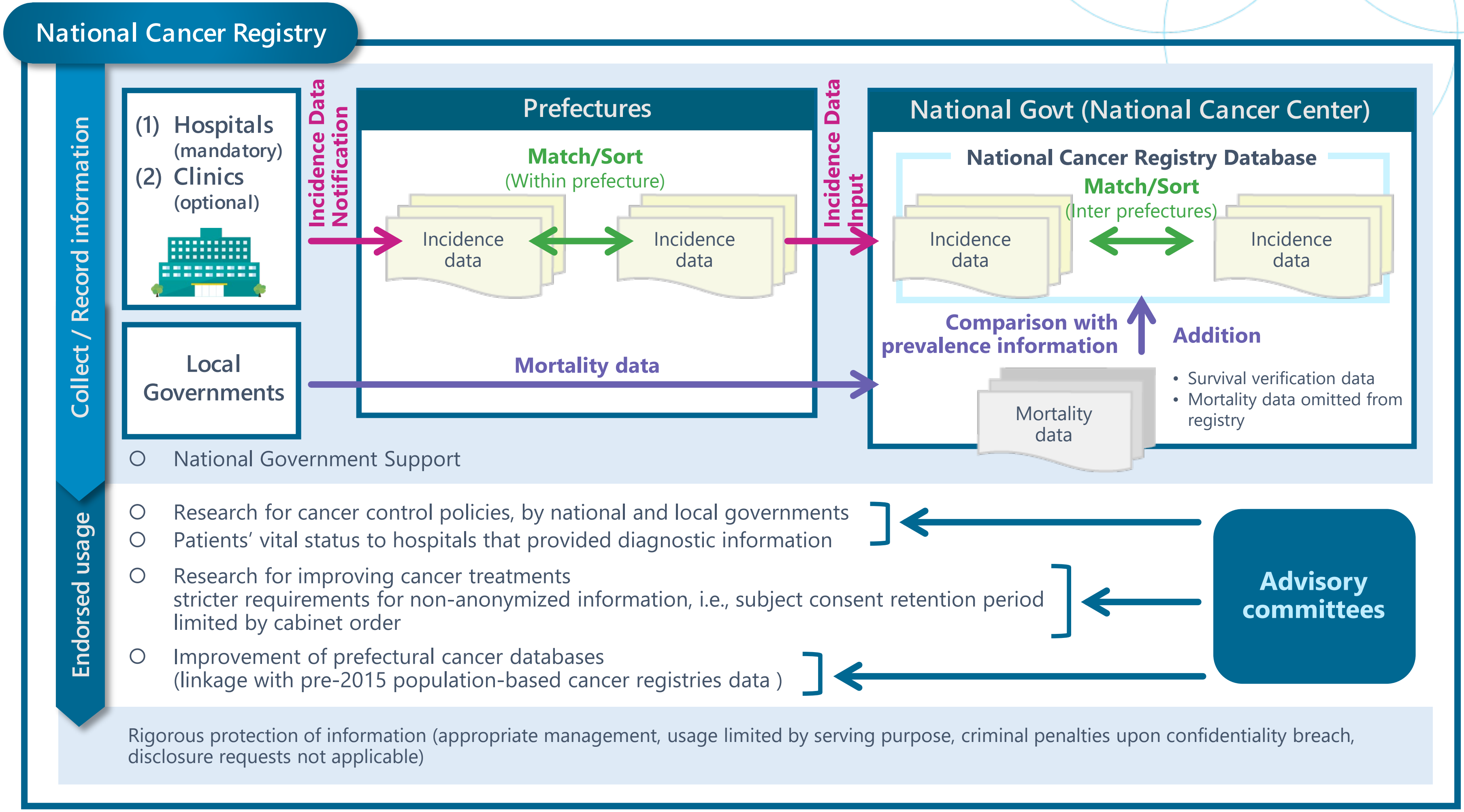
(Passed, Dec 2013; promulgated, Jan 2016)

- National Cancer Registry: nationwide cancer information on incidence, treatments and survival registered and stored in a database, by the national government.
- Hospital-based Cancer Registry: complex cancer data on prevalence, treatments and outcomes at respective hospitals, registered and stored, to evaluate cancer care within the hospital.

Fundamental Principles

1. National Cancer Registry: incidence, treatments and survival accurately comprehended, by collecting a wide range of information.
2. Hospital-based Cancer Registries: promulgated and scaled up, flow of essential information to national cancer registry to be secured.
3. Detailed information on cancer care collected, towards more effective cancer control.
4. To be utilized in cancer research, including at industries, to benefit the public.
5. Rigorous protection for personal information.

Cancer Registry Promotion Act - Overview 2



National Cancer Registry

Collect / Record information

(1) **Hospitals** (mandatory)
(2) **Clinics** (optional)

Incidence Data Notification

Prefectures

Match/Sort
(Within prefecture)

Incidence data ⟷ Incidence data

Incidence Data Input

National Govt (National Cancer Center)

National Cancer Registry Database

Match/Sort
(Inter prefectures)

Incidence data ⟷ Incidence data

Comparison with prevalence information

Addition

- Survival verification data
- Mortality data omitted from registry

Mortality data

Local Governments

Mortality data

○ National Government Support

Endorsed usage

○ Research for cancer control policies, by national and local governments
○ Patients' vital status to hospitals that provided diagnostic information
○ Research for improving cancer treatments
stricter requirements for non-anonymized information, i.e., subject consent retention period limited by cabinet order
○ Improvement of prefectural cancer databases
(linkage with pre-2015 population-based cancer registries data)

Advisory committees

Rigorous protection of information (appropriate management, usage limited by serving purpose, criminal penalties upon confidentiality breach, disclosure requests not applicable)

Cancer Registry Promotion Act - Overview 3

Furtherance of Hospital-based Cancer Registry

Strengthening hospital-based cancer registry schemes, towards improving efficient cancer treatment information collection by the national government

Capacity Building - Personnel

Training professionals to ensure the day-to-day operations of national cancer registry

Utilization of Cancer Registration Information

○ National Government/Prefectures

→ improve cancer control, provide vital status to medical institutions of diagnosis, publish statistics, support counselling for patients

○ Medical Institutions

→ provide information to patients, analyze/evaluate and compare cancer treatments, thereby advancing cancer treatments

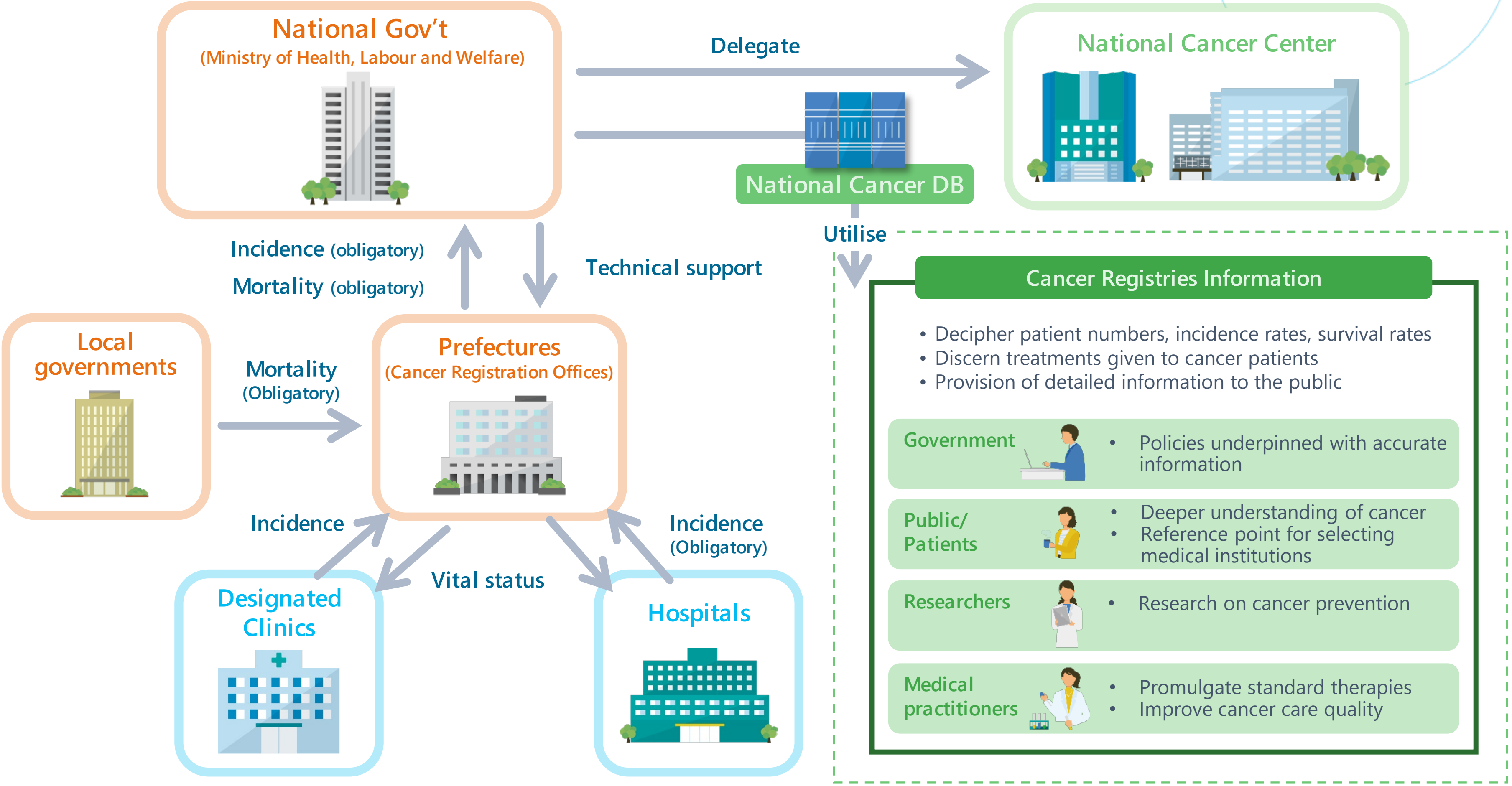
○ Researchers

→ improves quality of cancer care

Greater information provided to the public, cancer care quality improved, cancer control policies underpinned by scientific evidence

National Cancer Registry

Nationwide cases diagnosed 2016 onwards are registered under uniform data standards, allowing the nation to comprehend cancer incidence, care, and outcomes in Japan; aggregated information on cancer and its treatments are provided to the public. Personal information at cancer registries are scrupulously guarded.



National Gov't
(Ministry of Health, Labour and Welfare)

Delegate

National Cancer Center

National Cancer DB

Utilise

Incidence (obligatory)
Mortality (obligatory)

Technical support

Local governments

Mortality
(Obligatory)

Prefectures
(Cancer Registration Offices)

Incidence

Vital status

Incidence
(Obligatory)

Designated Clinics

Hospitals

Cancer Registries Information

- Decipher patient numbers, incidence rates, survival rates
- Discern treatments given to cancer patients
- Provision of detailed information to the public

Government	• Policies underpinned with accurate information
Public/ Patients	• Deeper understanding of cancer • Reference point for selecting medical institutions
Researchers	• Research on cancer prevention
Medical practitioners	• Promulgate standard therapies • Improve cancer care quality

Cancer Registries - International Comparison

	Legal basis (Year passed)	Hospital reporting to registries	Report non-compliance consequences	Patient explanation requirements	Patient consent requirements	Patient names in registries	Disclosure requests by patients	Vital status to medical institutions
United States (States)	National Cancer Act (1971)	Compulsory	License revocation/fines	None (required in 1-2 states)	None (Religious right of refusal in 1 state)	Included	Accepted in 2-3 states	Yes
Canada (Provinces)	Statistics Act (1918)	Compulsory	Imposed (English-speaking provinces)	None	None	Included	Accepted in 1 province	Various provided through registration
UK	-	(Mandated to registries)	(Bound by NHS contracts)	None (Trial with briefing sheets in progress)	None; Refusal accepted	Included, NHS No.	Accepted	Yes
Australia (States)	Public Health Act - New South Wales (1991)	Compulsory	Fines in many states	None (Recommended in 1-2 states)	None	Included	Accepted in 2-3 states	No
Korea	Cancer Control Act (2003)	Compulsory	-	-	None	Included	-	-
Japan	Cancer Registry Promotion Act (2013)	Compulsory	Publication of offense	None	None	Included	Not accepted	Yes

Revised extract from research on legal/ethical framework for population-based cancer registries, 2007, lead by Eiji Maruyama, a Health and Labour Sciences Research Grant project
** Japanese information from the Cancer Registry Promotion Act prepared by Cancer and Disease Control Division, Health Service Bureau MHLW*