

Cancer registration and cancer control in Japan

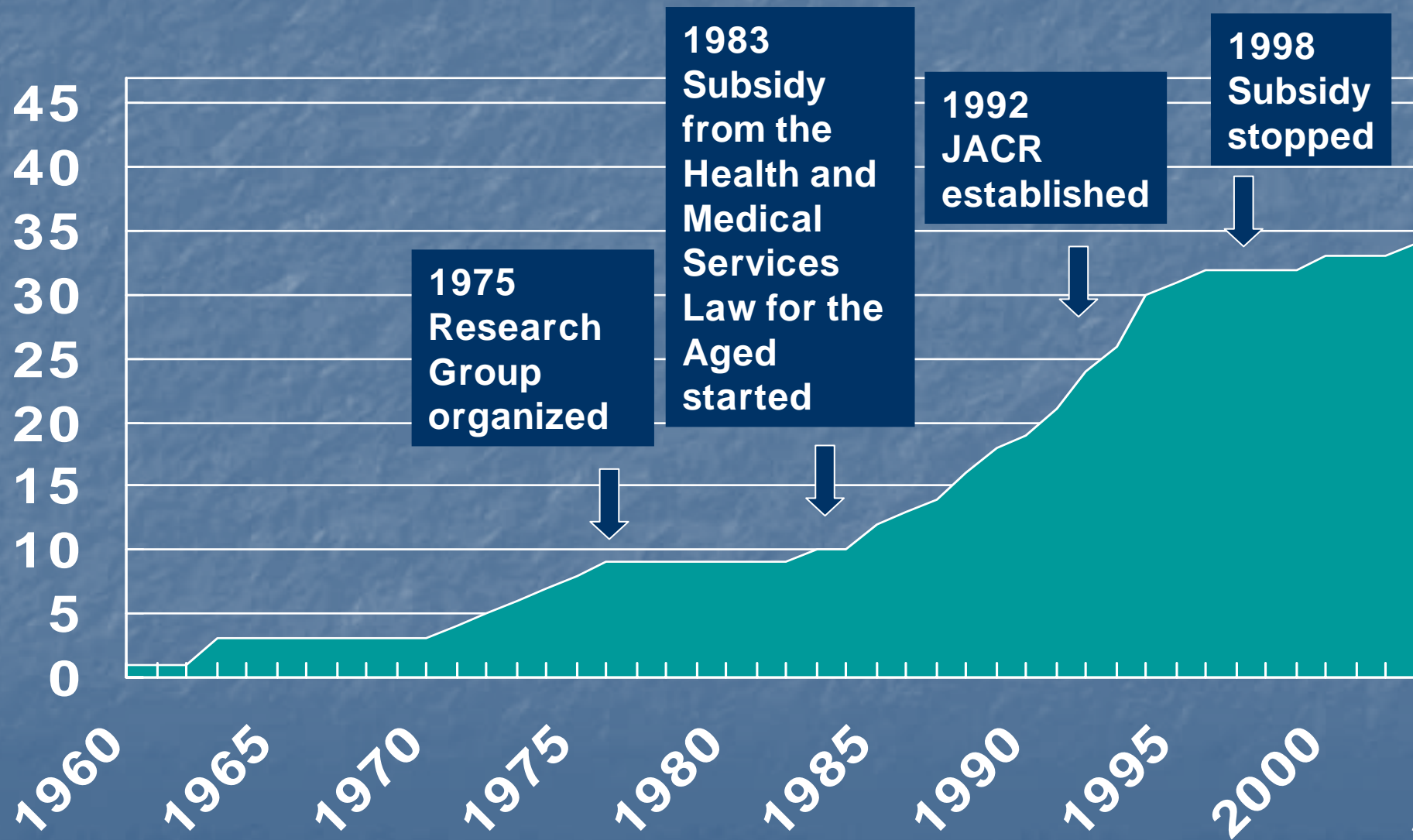
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Brief history of population-based cancer registries in Japan

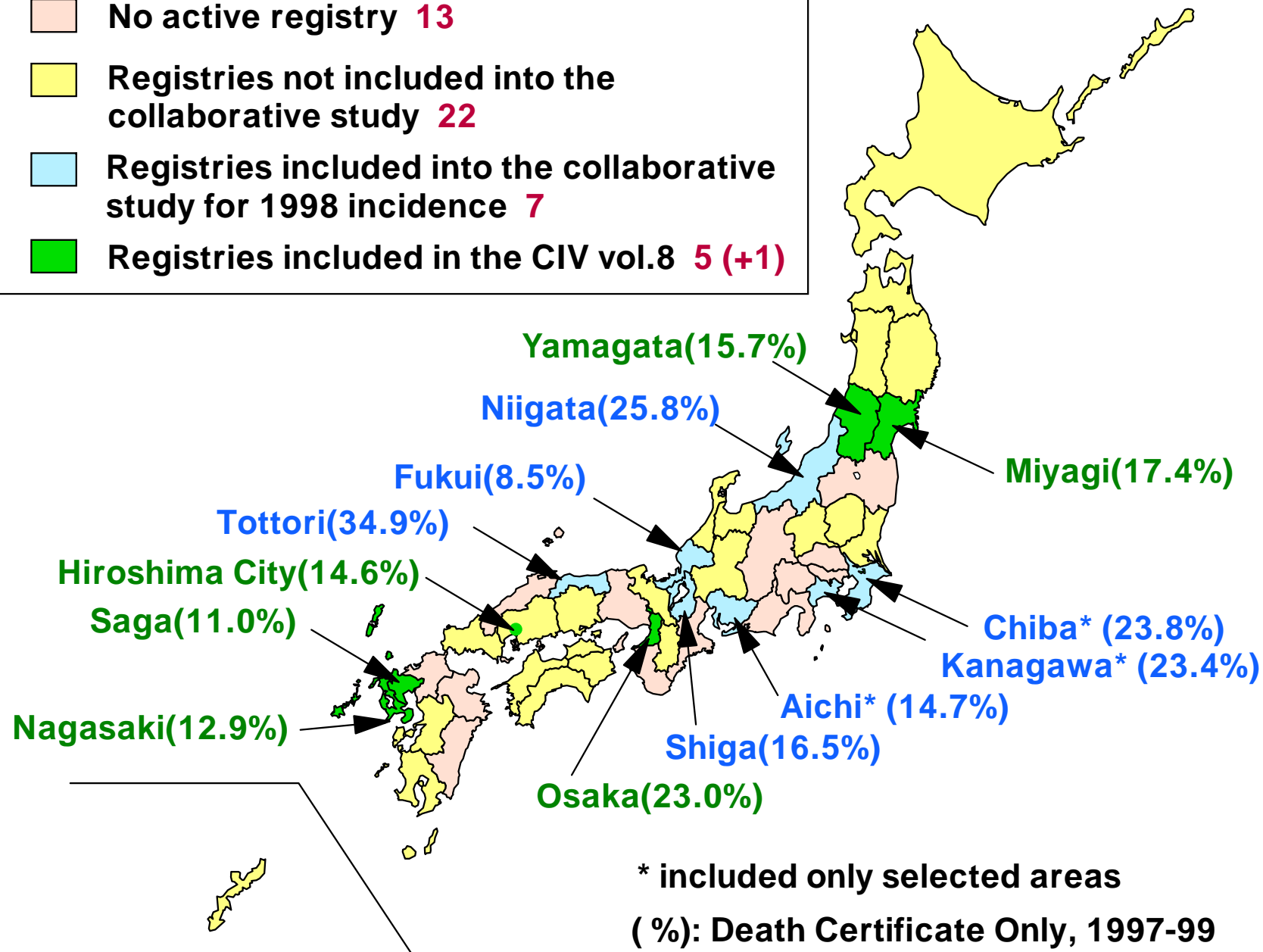
- 1957-58 Cancer registries was first established in Hiroshima and Nagasaki city
- 1959-62 Prefecture-wide cancer Registries in Miyagi, Aichi and Osaka Prefecture was started
- 1975 Research Group for population-based cancer registries with support from Ministry of Health, Labour and Welfare was organized
 - Pls: I. Fujimoto, S. Fukuma, A. Hanai, A. Oshima and H. Tsukuma
- 1992 Japanese Association of Cancer Registries was established

Trends for number of prefecture-wide population-based cancer registries in Japan



Population-based Cancer Registries in Japan

- No active registry **13**
- Registries not included into the collaborative study **22**
- Registries included into the collaborative study for 1998 incidence **7**
- Registries included in the CIV vol.8 **5 (+1)**



Current status and issues for population-based cancer registries in Japan

- Registration is on a voluntary basis.
- Registries are run by prefectural government.
 - Little support from national government
- Data completeness and timeliness is not good.
 - DCO% > 20% in 22 out of 30 registries
 - DCN% > 30% in 15 out of 22 registries
 - I/M ratio < 1.5 in 12 out of 31 registries
 - Incidence can be reported 3-4 years later
- Standardization is not fully considered.
 - Each registry managed locally
 - No central organization to promote standardization

Current status of nationwide cancer statistics in Japan

● **Cancer mortality**

- Though well-established vital statistics, all cancer deaths are measured.
- Rough statistics is reported 0.5 year later and fixed statistics is reported 1.5 year later.

Aug 2003 (fixed stat. for 2002) 304,568 for all sites

Jul 2004 (rough stat. for 2003) 309,465 for all sites

● **Cancer Incidence**

- No nation-wide population-based cancer registry.
- Based on 9-13 prefecture-wide population-based cancer registries, nationwide incidence is estimated since 1975.
- Estimated statistics is reported 4.5 years later.

Jul 2004 (estimated stat. for 1999) 529,523 for all sites

Recent events related to cancer registry in Japan

Legislative aspects

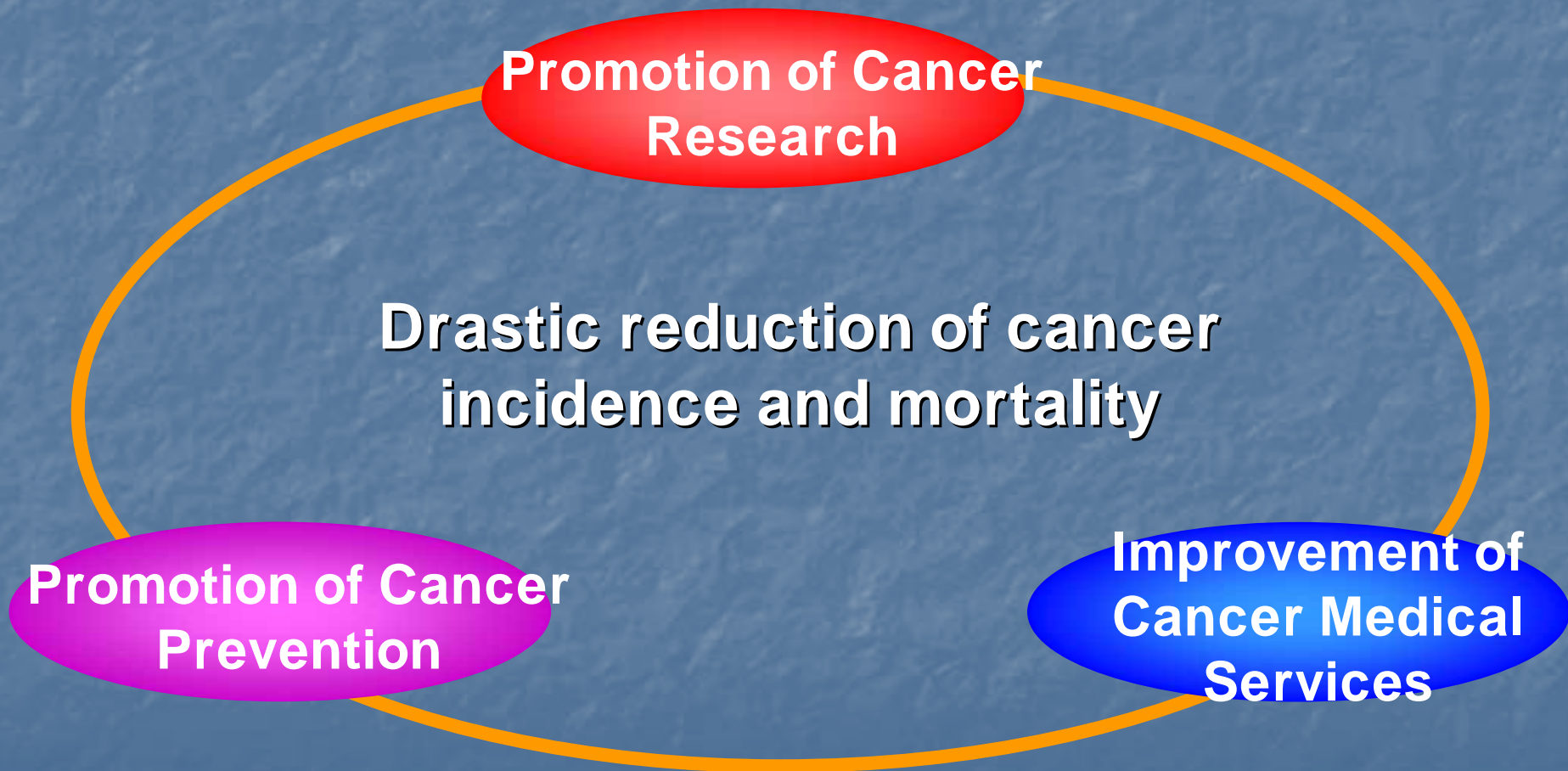
- In May 2003 : **Health Promotion Law** was enforced and legislative basis for population-based cancer registry was established.
 - article #16: National and local governments have to make effort to collect incidence data on life-style related diseases.
- In Jan 2004: Official statement from Health Service Bureau of MHLW indicated that population-based cancer registry is **exemption** from the general rule of the **Privacy Protection Law**.
 - Providing clinical data with individual identifier from hospitals to population-based cancer registry is not illegal even if informed consent from the patients is not obtained.

Recent events related to cancer registry in Japan

Structural aspects

- In Aug 2001: Hospital-based cancer registry was included in the prerequisites for '**Designated Regional Cancer Hospitals.**'
 - In Dec 2003: Standardized data content and format were fixed and authorized.
- In 2004: **The 3rd Term Comprehensive 10-Year Strategy for Cancer Control (2004-2014)** started.
 - Slogan "Aiming at drastic reduction of cancer incidence and mortality"
 - Research group (PI: T. Sobue) started to promote standardization and improve data quality, especially completeness and timeliness.

The 3rd Term Comprehensive 10-Year Strategy for Cancer Control, 2004-2014



Objectives and standards for population-based cancer registries in 10-year project periods

1. Official approval from the privacy protection council
2. Standardized data content and format
3. Data completeness
 - Use of death certificates
 - Above the certain level of I/M ratio, DCO%, DCN% and registration rate
 - Follow-back for DCO cases
4. Data timeliness
 - Incidence data can be fixed within the certain period
 - Incidence above the expected number
5. Data quality
 - Below the certain level of missing data
 - Error check program
 - Assign tumor registrars
6. Follow-up for survival
7. Annual report
8. Data use for cancer research

National Cancer Center

- Administration Office

- Hospital (Central, East)

- Research Institute



- **Research Center for Cancer Prevention and Screening**

- Cancer Screening Division

- Cancer Screening Technology Division

- Epidemiology and Prevention Division

- **Statistics and Cancer Control Division**