

Childhood Cancers - Issues

- Cancer is a **major cause of death to children and AYA generation**. The great variety, and as they are experienced as they go through varied phases from toddler to childhood, adolescent and young adults, **special care is required**.
- The government has designated **15 Designated Hospitals for Childhood Cancers** and **2 National Institutes for Childhood Cancers**, to centralize care while ensuring good access to care through collaborating institutions nationwide.
- Designated Hospitals for Childhood Cancers are also **required to provide services to AYA generation cancer patients**. They support AYA generation cancer patients on treatments, education, finding work and in addressing reproduction issues, **either on-site or at partnering institutions**.
- **Update** of childhood cancer hospital designation **rules** in Aug 2022 added measures towards **centralization of services**, and **long-term follow up service provision**.
- Drug access: limited availability of treatment drugs covered by national insurance, fewer opportunities for participation in clinical trials.

(Basic Plan to Promote Cancer Control Program – 4th term)

Childhood Cancer Control in Japan - timeline

May-Jun 2012	Committee on Childhood Cancer Treatments and Support (3 sessions)		
Jun 2012	Cabinet approves Basic Plan to Promote Cancer Control Programs (2 nd term)		
Sep 2012	Committee on Childhood Cancer Treatments and Support issues report		
Feb 2013	15 Designated Hospitals for Childhood Cancer commissioned		
Feb 2014	2 National Institutes for Childhood Cancers commissioned		
Dec 2015	Accelerated Cancer Control Plan		
Dec 2017- Apr 2018	Committee on Childhood and AYA Generation Cancer Treatments and Support (3 sessions)		
Mar 2018	Cabinet approves Basic Plan to Promote Cancer Control Programs (3rd term)		
Apr 2018	Report from Committee on Childhood and AYA Generation Cancer Treatment and Support		
Jul 201 8	New guidelines on Designated Hospitals for Childhood Cancer set		
Feb 2019	Committee on Designated Hospitals for Childhood Cancer		
Apr 2019	New guidelines on Designated Hospitals for Childhood Cancer set Children's Cancer Hospital Selection		
Aug 2022	New guidelines on Designated Hospitals for Childhood Cancer set		
Dec 2022	Committee on Designated Hospitals for Childhood Cancer		
Mar 2023	Cabinet approves Basic Plan to Promote Cancer Control Programs (4th term)		
Apr 2023	New guidelines on Designated Hospitals for Childhood Cancer set		

Hospitals for Childhood Cancers

- Designation requirements revision (Aug 2022)

Key points

Division of Responsibilities

- **Designated Hospital for Childhood Cancers** to lead childhood cancer care of the regional medical area
- National Institute for Childhood Cancers to lead capacity building, research and development, and central pathological diagnosis services for the nation

Adjust Cooperative Hospital classification, towards centralization

- Type 1-A: cooperative hospitals seeing 20+ cases/annum
 Type 1-B: others
- Hospital-based Cancer Registry required at cooperative hospitals

Long-term follow-up consultation service

- Develop/deliberate optimum long-term follow-up services through collaboration
- Strengthen consultation services for childhood cancers and AYAs, including reproductive medicine

Designation process

- Invite hospitals to apply for designation, select excelling hospitals
- Cooperative Hospitals to be designated by Designated Cancer Care Hospitals, after deliberations within the regional medical area

Designated Hospitals for Childhood

Cancers (Establishment guidelines, Aug 2022)

Partially revised from documents submitted to Study Group on Designated Cancer Care Hospitals (21 Jul 2022)

- 'National Institute for Childhood Cancers' designated by the Minister of Health, Labour and Welfare following recommendations from the designations review committee
- > 'Designated Hospital for Childhood Cancers' designated by the Minister of Health, Labour and Welfare following recommendations from the designations review committee
- 'Cooperative Hospital for Childhood Cancers' designated by Designated Hospital for Childhood Cancers following opinions of the regional council (categories: 1-A, 1-B, 2, 3)

Liaison Council of Childhood Cancer Institutions

- Discuss medical care/quality improvements
- Comprehend updates from each regional block
- · Establish collaboration across regional blocs

National Institute for Childhood Cancers

Driving childhood cancers care and support in Japan

National Center for Child Health and Development

- Establish consultation service support for childhood/AYA generation cancers
- Disseminate information on childhood/AYA generation cancers
- Support diagnosis (radiological/pathological)
- Establish childhood cancers registry
- Build capacity (doctors, nurses, psychologists)
- Serve as Secretariat of the Liaison Council of Childhood Cancer Institutions

National Cancer Center

- Disseminate information on childhood/AYA generation cancers
- Establish childhood cancers registry, support)
- Build capacity (counselors, hospital-based cancer registry administrators)
- Promote and support R&D and clinical research

Advisory Board (external experts)

Regional Councils for Childhood Cancers

- One each for 7 regions in Japan
- Establish regional network for childhood cancers treatmentz

Designated Hospital for Childhood Cancers

Community focal point for childhood cancers care and support

- Provide multidisciplinary treatment, including refractory/relapsed cases
- Offer consultations for children/AYAs suited to developmental stages
- Build capacity
- Promote Clinical Research

Cooperative Hospital for Childhood Cancers

Facility consolidating childhood cancers care in the region

Type 1

Standard treatment of equitable level as designated hospital offered

- 1-A Facilities treating more cases
- 1-B Facilities treating limited numbers

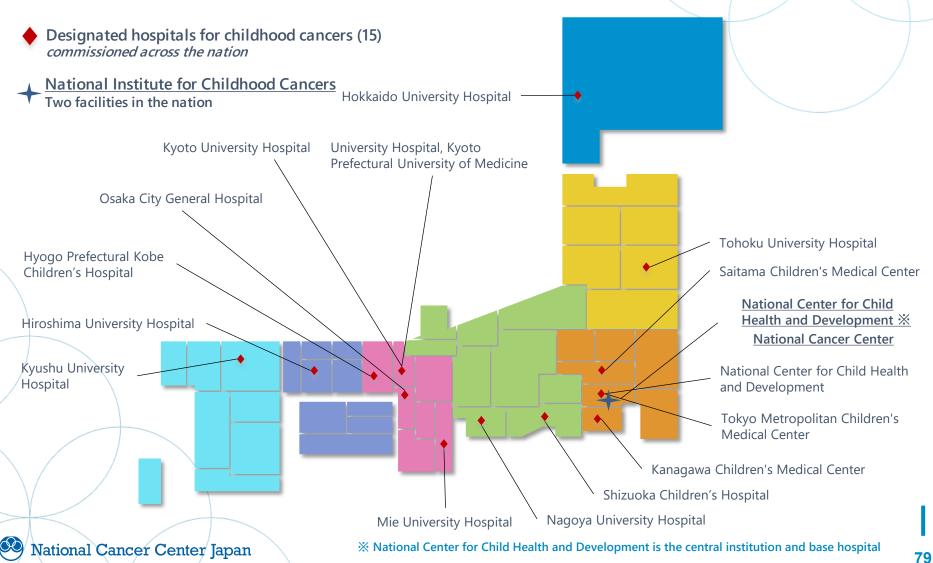
Type 2

Offering treatments of specific cancer types that require centralization, or that can only be performed at a limited number of facilities

Type 3

Offering long-term follow-up services

National Institute for Childhood Cancers and Designated Hospital for Childhood Cancers (As of Apr 2024)



Designated Hospitals for Childhood Cancers

Requirements (Amended, Aug 2022)

Mission

As a central facility providing childhood cancer care and support in the region, the center will play a central role in the regional block council, contribute to improving the quality of cancer care and support for children and cancers of AYA generation in the region as a whole, develop a system for long-term follow-up, and cooperate with regional medical institutions, including designation of Cooperative Hospitals for Childhood Cancers.

Requirements

*Cancer patients in the AYA (Adolescent and Young Adult) generation are defined as cancer patients who developed cancer in the AYA generation and childhood cancer patients who

- 1. Scope of Care (multidisciplinary treatments, multidisciplinary conference, long-term follow-up, AYA generation care, fertility preservation, palliative care teams, collaboration with Cooperative Hospital for Childhood Cancers and the region, second opinion consultations)
- 2. Medical practitioners (radiation therapy physicians, radiological treatment technicians, pharmacists, certified nurses)
- 3. Facilities (radiation treatments, intensive care unit)
- 4. Care record (30 new patients, 10 hematopoietic, 10 solid tumors, annually)
- 5. Third party certification on technical capacity for childhood cancer treatments
- 6. Completion of workshop on long-term follow up for cancers in children/AYA generation by medical staff (physicians/nurses)
- 7. Counselling and support center
- 8. Hospital-based cancer registry
- 9. Clinical research (department specializing in clinical research, CRC staff preferable)
- 10. Supporting, Healing environment (childcarers, learning support, playrooms, long-term accommodation)
- 11. Patient safety framework



Excerpts from the Maintenance Guidelines, Aug 2022

Cooperative Hospitals for Childhood Cancers

Requirements (Aug 2022)

	(1) Cooperative Hospitals for Childhood Cancers - local services	(2) Cooperative Hospitals for Childhood Cancers - specific cancers	(3) Cooperative Hospitals for Childhood Cancers - long-term follow up
Facilities	Care capacity equivalent to Designated Hospitals for Childhood Cancers, for cancers with established standard therapy Type 1-A 20+ new cases/annum Type 1-B others	 (i) capacity of multidisciplinary treatment for specific cancers, and of appropriate treatment suitable to patients' conditions, including standard therapy (ii) Capacity for standard treatments whose provision are limited, such as particle beam therapy 	Capacity for providing long-term follow up for childhood cancer patients, and for appropriate treatment suiting patient conditions, and for referrals to designated hospitals when necessary.
	Third party certification for medical facility for childhood cancers with technical capacity	for (i): Treats the most patients with the specific cancer within the prefecture	-
Staff	medical practitioner requirements for Designated Hos	-	
	-	-	Employs physicians who have attended the Workshop on Long-Term Follow-Up for Cancer in Children and the AYA Generation held by the Japanese Society of Pediatric Hematology/Oncology.
Hospital based Cancer Registry	Staff certified of training at National Cancer Center preferred		-

All must meet the following:

- 1. Partnership network established with hospitals/clinics, as required of Designated Hospitals for Childhood Cancers, with patient safety ensured
- 2. Capacity to provide appropriate care for patients requiring emergency services and/or with complications requiring highly skilled care, in coordination with Designated Hospitals for Childhood Cancers, and Designated Hospitals for Cancer Care
- 3. Counselling and support office, working in coordination with the counseling and support office of Designated Hospital for Childhood Cancers. Staff completing specialist training in childhood cancer counselling preferrable.
- 4. Liaise with other Designated Hospitals for Childhood Cancers within medical area on capacity building
- 5. Update report submitted to partnering Designated Hospitals for Childhood Cancers

Extract from Updated Guidelines, Aug 2022

