



ICCI
Indian Childhood
Cancer Initiative

INDIAN CHILDHOOD CANCER INITIATIVE (ICCI)

NEWSLETTER, 2025, Issue 1

**Welcome to Issue 1 of 2025,
ICCI's newsletter. We are excited to share with
you the updates & key work done in the last six months.**

In this newsletter, we are sharing an update
on the ICCI meetings and a summary of the key projects
undertaken by our eleven taskforces.

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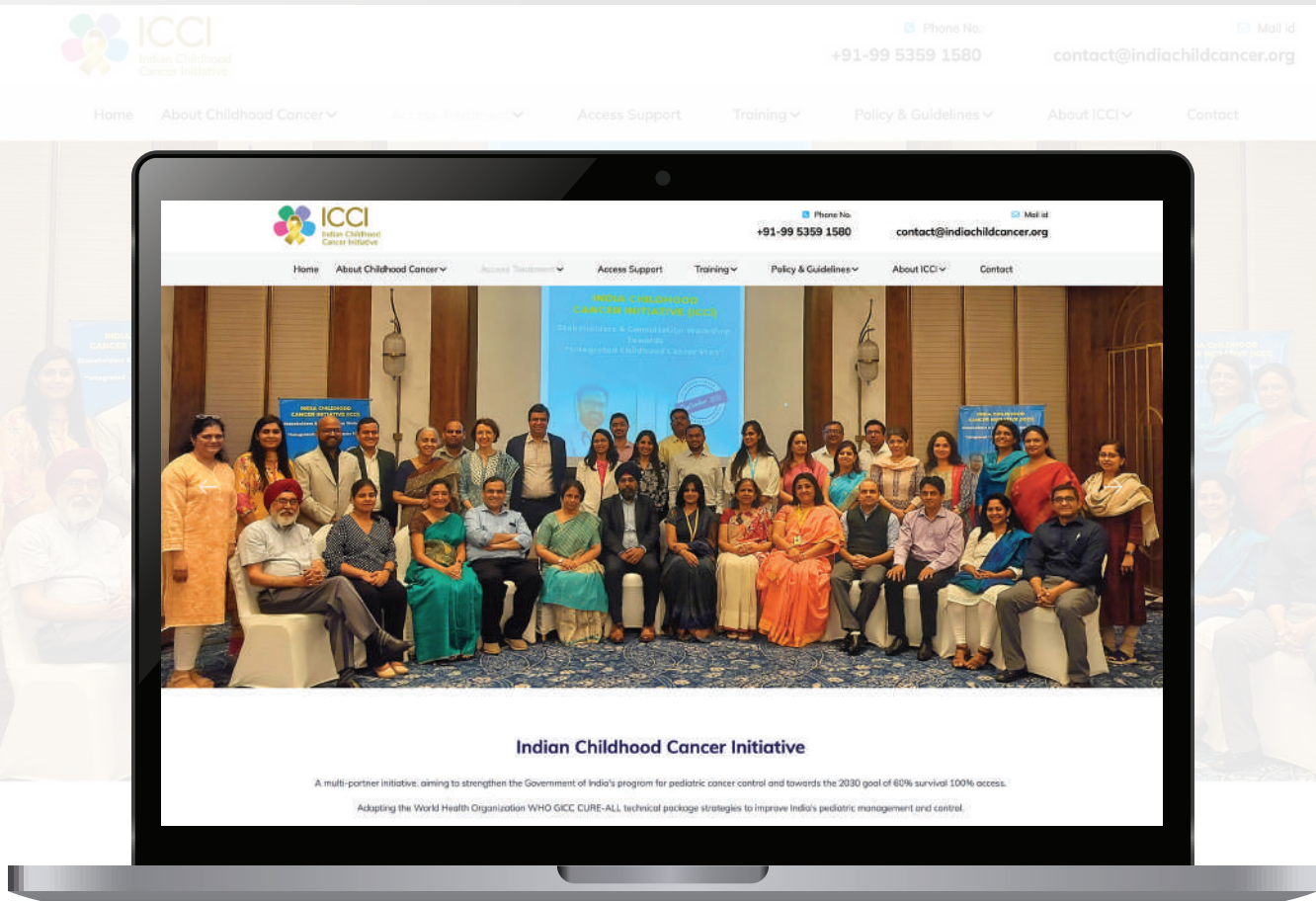
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Creation of Web portal



September is recognized as **Childhood Cancer Awareness Month** and the **ICCI website was launched on 1st September 2024.**

The purpose of the website is to create a one stop platform for all information on childhood cancer. Please see the website at **www.indiachildcancer.org** and give feedback.



A multi-partner initiative, aiming to strengthen the Government of India's program for pediatric cancer control and towards the 2030 goal of 60% survival 100% access.

Adopting the World Health Organization WHO GICC CURE-ALL technical package strategies to improve India's pediatric management and control.

Key focus on ICCI website



Access Support

- ✓ We have mapped government schemes available in 30 states and UTs available for childhood cancer and collated information on N.G.Os helping children suffering from cancer in 31 states and UTs of India.
- ✓ This information is uploaded on the ICCI website, so that it is easily accessible to patients, caregivers and health care providers, under Access Support section.

The screenshot shows the "Access Support" section of the ICCI website. It is divided into two main parts: "Government Schemes" and "N.G.Os".
Government Schemes: This section is titled "Kerala" and includes a breadcrumb trail "Home > Access Support > Kerala". It features two tabs: "Central Government Schemes" (selected) and "State Government Schemes". Below the tabs is a list of schemes with "Read More" links:

- JSSK
- PMNRE
- Rastriya Arogya Nidhi (RAN)
- Dr. Ambedkar Medical Aid scheme
- Health Minister's Discretionary Grants
- Ayushman Bharat

N.G.Os: This section is also titled "Kerala" and includes a breadcrumb trail "Home > Access Support > Kerala". It features a list of N.G.Os with "Read More" links:

- Butterfly Cancer Care Foundation
- PRATYASHA - Cancer Children's Welfare Society
- Leukemia Crusaders
- Cuddles Foundation
- Hope Child Cancer Care Foundation
- Caring for Humanity

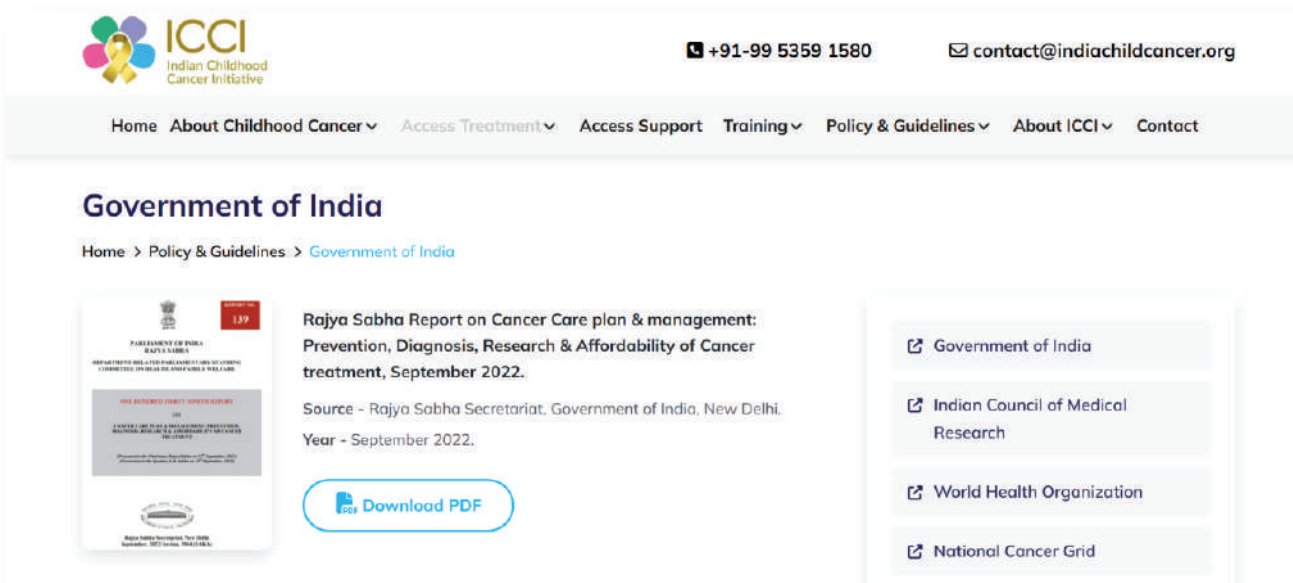
Key focus on ICCI website



Policy and Guidelines on Childhood Cancer

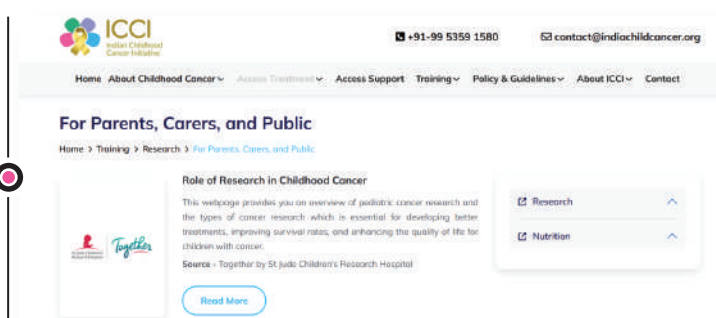
We have uploaded information on policy and guidelines available for childhood cancer from sources like Government of India, ICMR, WHO, PHO IAP, NCG etc.

More information will be added under this section soon.



Training

An important section on the ICCI website is on training. We will be uploading training material available under seven categories listed below. The training section will have information on courses, workshops, you tube videos available for parents/care givers and health care professionals.



- ✓ **Data and Registry** (Uploaded)
- ✓ **Nutrition** (Uploaded)
- ✓ **Research** (Uploaded)
- ✓ **Psycho social** (Uploaded)
- ✓ **Palliative Care** (Work in progress)
- ✓ **PHO Fellowship** (Work in progress)
- ✓ **Nursing** (Work in progress)

Comprehensive standards & guidelines for pediatric psycho-oncology services



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Develop comprehensive standards and guidelines for pediatric psycho-oncology services.

A key focus area of the psychosocial taskforce is to develop comprehensive standards and guidelines for pediatric psychosocial services. To achieve this we brought together key stakeholders, including experts in pediatric oncology, psychologists, social workers, and representatives from relevant organizations, to collaboratively develop the same.

A two day meeting was held on the 5th & 6th September 2024, at Radisson New Delhi. The meeting was attended by 50 participants. The two days of the meeting were focused on group discussions and breakout sessions on key areas of psychosocial oncology services. Six focus areas were identified, namely:

- 🗨️ Evaluation/triage/referral
- 🗨️ Interventions
- 🗨️ Manpower and Training
- 🗨️ Survivorship/reintegration
- 🗨️ End of life/palliative care
- 🗨️ Sibling and caregiver support

Next Steps:

- ✅ The first three areas will be prioritised after which the next three will be targeted. Regular meeting will be planned with the groups for updates
- ✅ A task list for each of the working groups will be created to ensure standard formats for all verticals of the guidelines

Comprehensive standards & guidelines for pediatric psycho-oncology services



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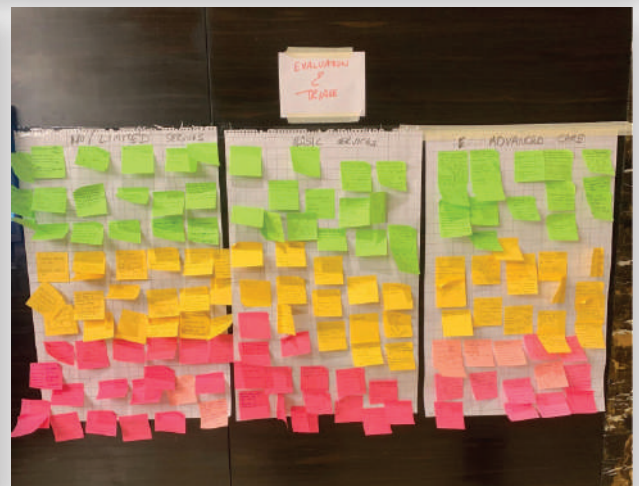


Group photo of all the participants for the psycho social meeting

Breakout sessions



Discussion on the topic assigned to the group



Display of the notes discussed at the breakout sessions

Position statement



Position Statement:

Delivering psychological and social support to children with cancer in India and their families

As a first step to advocating psycho-social care in pediatric oncology, the ICCI Psychological and Social Support Taskforce proposes a position statement emphasising the need for a comprehensive approach beyond medical treatment, advocating for a robust interdisciplinary support system for young cancer patients and their families in India.

Policy:

Delivering psychological and social support to children with cancer in India and their families: a position statement from the social and psychological taskforce of the Indian childhood cancer initiative

5 Dec 2024, ecancer

Rhea Daruvala, Ruchira Misra, Bindu Nair, Hiba Siddiqui, Usha Banerji, Valerie M Crabtree and Ramandeep Singh Arora

You can read the article at

<https://doi.org/10.3332/ecancer.2024.1812>

Position statement



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The taskforce identified eight priority areas essential for addressing the psychosocial needs of pediatric oncology patients & their families.

Every child with cancer should have holistic care

Every child with cancer should have early assessment and intervention of their psycho-social needs

Promotion of interdisciplinary collaboration is essential for delivery of social and psychological care to these children

Encouraging community outreach and education to raise awareness at the community level about pediatric oncology and psychological and social aspects associated with childhood cancers

Advocate for policy to include psychological and social support services in pediatric oncology

Encourage research and innovation in psycho social aspects of pediatric oncology that are culturally sensitive and relevant

All children with cancer should have access to psychological and social support services

There should be standards for psychological and social support in pediatric oncology centers

Nursing Core Group Meeting, TMH, Mumbai



- ✓ At the National Pediatric Haematology Oncology Nursing Conference held on 19th-20th February, 2024, It was also decided that there's a need for the formation of a professional organization for pediatric hemato-oncology nurses in India that serves as a platform to empower nurses to define, advocate, promote and practice the highest standards of nursing care for children and youth suffering from cancer and blood disorders.
- ✓ A closed group meeting of 15 participants was held in TMH, Mumbai, 2nd September 2024, to take the work forward.
- ✓ Discussion was held on proposed constitution of the group, feedback from the last national conference, planning for the next national conference, assessment of baseline standards for PHO Nursing care in India, work on proposed nursing training module and content for ICCI website.
- ✓ The formation of a separate nursing body was proposed with it's name, vision, mission and Objectives.

Proposed name of the nursing body:

IPHONA

(Indian Pediatric Hematology Oncology Nursing Association)

Proposed Vision

To build a future where all children with cancer and blood disorders receive highest standard of nursing care

Nursing Core Group Meeting, TMH, Mumbai



Proposed Vision

To create a forum of professional nurses in India to train, empower, support, advocate, provide evidence-based care & opportunities to undertake research in order to optimize outcomes for children with cancers and blood disorders and their families throughout the continuum of care.

Proposed Objectives:

- 🌀 To create a network of professional nurses who are competent to provide holistic care to children with cancer and blood disorders in India
- 🌀 To develop and implement nurse led research programs to improve outcome for children with cancer and blood disorders
To develop nursing quality indicators and implement quality improvement projects to ensure quality and safe nursing care
- 🌀 To collaborate and build partnerships with other healthcare professionals, organizations and communities
- 🌀 To develop structured training programs for nurses to improve knowledge and enhance skills
- 🌀 To empower nurses to educate and advocate for patients and their families.
- 🌀 To facilitate self-care and psychological support to nursing colleagues

Nursing Core Group Meeting, TMH, Mumbai



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Group photo of the participants at the meeting



Discussion at the meeting

Delphi Consensus for guidelines on survivors of child leukemia



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A round 1 Survey on “Delphi Consensus For Guidelines on Survivors Of Childhood Leukemia in India” was conducted with the efforts to adapt the COG guidelines for childhood cancer survivorship care to India through a Delphi consensus.

To review the round 1 survey results a two-day meeting was held at AIIMS, New Delhi, on August 3-4, 2024, along with the INPHOG late effects sub committee and PHO. The agenda included discussions on proposals for Phase II and other studies on cancer survivorship and late effects, as well as Delphi-based guidelines for long-term follow-up on ALL, AML, and CML—key projects of the survivorship taskforce.



Survivorship & Late Effects Meeting – AIIMS, New Delhi, 3rd August 2024

Delphi Consensus for guidelines on survivors of child leukemia



Subsequently, a round 2 Survey on “Delphi Consensus For Guidelines On Survivors Of Childhood Leukemia In India” has been conducted in October 2024, included revised questions based on the first round's analysis.

Experts received aggregated responses from Round 1 and were asked to reconsider their ratings after reviewing feedback and discussions. This final round aimed to achieve consensus on adapted childhood cancer survivorship guidelines for India.

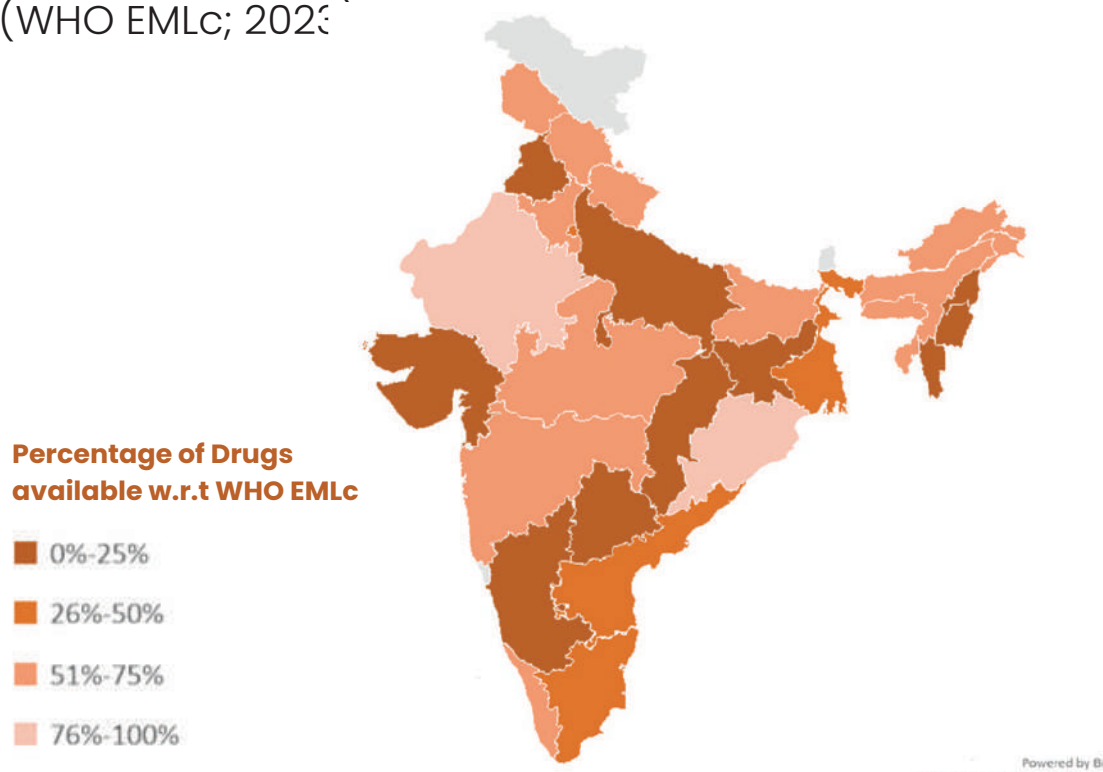


Survivorship & Late Effects Meeting – AIIMS, New Delhi, 4th August 2024

National Essential Medicine List



One of the key focus area of Drugs and Diagnostics taskforce is to determine potential gaps of anticancer drugs for childhood cancer listed in India's National List of Essential Medicines (NLEM; 2022) as well as EMLs for states and union territories in comparison with the World Health Organization's Essential Medicines List for Children (WHO EMLc; 2023).



Of the 44 medicines in WHO EMLc, the availability in NLEM was 67%, and 5–82% (median 49%) across state/UT EMLs with availability 7% in Mizoram and Nagaland, while Rajasthan and Odisha listed more medicines than NLEM. 13/44 medicines on the WHO EMLc list were mentioned in less than 10% (Realgar-Indigo naturalis, tioguanine, pegasparagase, rasburicase, nilotinib, procarbazine, all-trans retinoic acid, arsenic trioxide, dasitinib, pegylated doxorubicin, everolimus, peg-filgrastim, vinorelbine) while 3/44 medicines (dexamethasone, prednisolone, hydrocortisone) were mentioned in more than 90% of the state/UT EMLs.

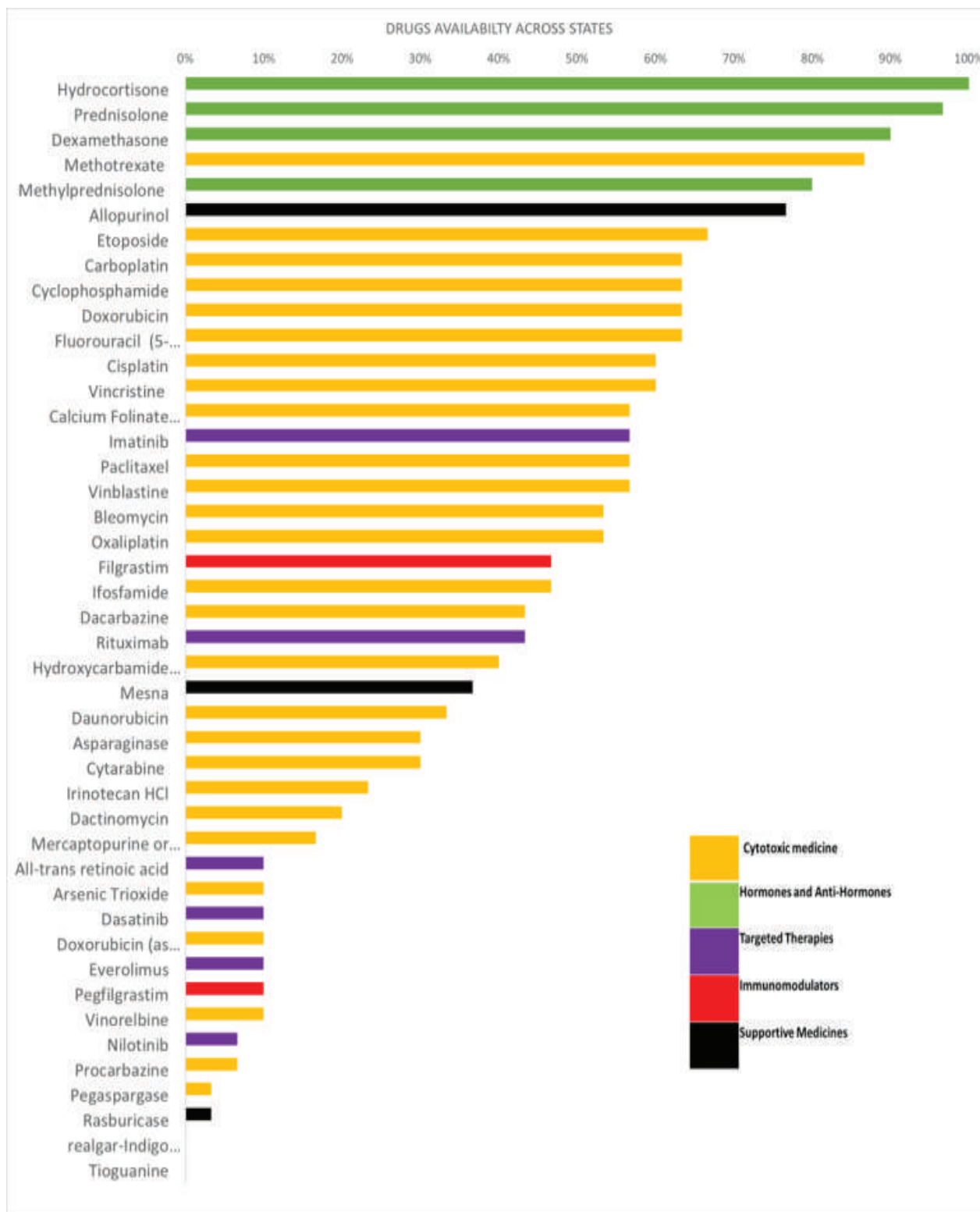
National Essential Medicine List



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Of the 26 WHO GICC tracer cancer medicines, availability was 88% in the NLEM (pegasparagase, rasburicase, peg-filgrastim absent) and it ranged from 8–100% (median 83%) across state/UT EMLs.



ICCI at PHOCON 2024



At the 27th annual PHOCON (Paediatric Haematology Oncology Conference) & 8th PHOSSCON (Pediatric Hematology Oncology Support Services Conference) held in Jammu on 22nd-23rd November. ICCI presented the work done by its taskforces and how to engage with ICCI.



Presentation by Information and Awareness Taskforce



Presentation by Survivorship & Reintegration taskforce

ICCI at PHOCON 2024



We are happy to share that many **ICCI stakeholders** presented at the PHOCON-PHOSSCON 2024 as faculty and conducted various sessions according to their expertise.

Sripriya Mahesh (Nutrition)

Rhea Daruvala, Hiba Siddiqui, Ruchira Misra, Michelle Normen (Psychosocial)

Rasmi Palassery, Shilpi Chauhan (Information & Awareness)

Vasudeva Bhat, Shivani Chauhan (Financing and Policy)

Maharshi Trivedi, Haresh Gupta (Drugs and Diagnostics)

Maya Prasad (Supportive Care)

Shruti Kakkar (Access to care)

Vandana Dhamankar, Chandan Kumar (Survivorship & reintegration)

Sindhu Nair, Surya Sukumaran, Puja Srivastava (Nursing)

ICCI Taskforces and Taskforce Chairs



In the last six months, **ICCI welcomed few new taskforce chairs** as the existing ones stepped down from their role. We now have 11 task forces as we have divided the Continuity of Care taskforce into Palliative Care and Survivorship and Reintegration separately.



Dr. Vasudev Bhat
(Pediatric oncologist)

at Kasturba Medical College, Manipal, stepped as the new chair for Finance and Policy taskforce



Dr. Maharshri Trivedi
(Pediatric oncologist)

at The Gujarat Cancer and Research Hospital, Ahmedabad, is the new chair for Drugs & Diagnostics taskforce



Dr. Archana Iyengar
(Pediatric Palliative Care Consultant)

Pain relief & Palliative Care Society, Hyderabad, is the new chair for Palliative care taskforce



Dr. Vandana Dhamankar
(MD, Deputy Director General, Medical Affairs)

Director Survivorship and Rehabilitation, Indian Cancer Society is the new chair for Survivorship and Reintegration taskforce

ICCI Taskforces and Taskforce Chairs



S. no.	Taskforce	Chair	Email
1	Financing and Policy	Vasudev Bhat Shalini Jatia	vasudev.bhat@manipal.edu shalinijatia@hotmail.com
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4	Survivorship and Reintegration	Vandana Dhamankar Chandan Kumar	vandana@indiancancersociety.org chandan.kumar@resonancehealth.org
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