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Recognizing and Addressing Fertility Issues among Childhood Cancer Patients and Survivors in India – A Multi Stakeholder Position Statement and Call to Action

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Abstract

Survival rates in childhood and adolescent cancers have improved substantially over the past decades, leading to a growing population of long-term survivors. In India, an estimated 76,000 children and adolescents are diagnosed with cancer annually, and approximately one-quarter receive treatments associated with a high risk of gonadal toxicity. Fertility impairment is therefore an increasingly important survivorship issue. Despite international recommendations advocating fertility counselling and preservation prior to treatment, access to such services in India remains limited. Barriers include low awareness among healthcare providers and families, limited availability of assisted reproductive technology (ART) services in the public sector, high costs, sociocultural factors, and regulatory uncertainties under the Assisted Reproductive Technology Act, 2021. Fertility preservation options are also constrained for prepubertal patients, for whom experimental approaches such as gonadal tissue cryopreservation are not widely available. This viewpoint summarizes the burden of fertility impairment among childhood cancer survivors in India, reviews current standards of care, and highlights key gaps in access and policy. We propose a multi-stakeholder call to action involving

Keywords
- childhood cancer
- fertility preservation
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- oncofertility
- position statement

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clinicians, policymakers, reproductive specialists, and survivor groups to improve counselling, expand services, develop India-specific guidelines, and integrate fertility preservation into pediatric oncology care pathways.

Executive Summary

Childhood cancer survival in India has improved, creating a growing population of survivors with long-term health needs. Approximately 25% of children and adolescents with cancer are exposed to highly gonadotoxic therapies, placing them at risk of infertility. Despite global recommendations for early fertility counselling and preservation, implementation in India remains inconsistent due to limited awareness, high costs, inequitable access to assisted reproductive technology (ART), and regulatory uncertainty.

This policy brief highlights key gaps in oncofertility care and proposes targeted, multilevel actions to integrate fertility preservation into pediatric oncology services in India.

Background and Burden of the Problem

Survival rates in childhood and adolescent cancer (0–19 years of age) have steadily and consistently improved over the last half-century.[1] As the proportion of patients being cured increases, the absolute number of children and adolescent cancer survivors in society is also growing. It is estimated that both USA and Europe have approximately 500,000 survivors of childhood and adolescent cancer who have completed treatment.[2,3] Similar estimates are not available for low- and middle-income countries, where 90% of the childhood cancer burden exists. There is also no published data from India; however, taking into account a larger incident population and a relatively lower survival rate, it is anticipated that there are around 500,000 survivors of childhood and adolescent cancer in India who have completed treatment (Ramandeep Arora, personal communication).

The multimodality treatment offered to these children and adolescents at a young age to achieve high cure rates may lead to adverse health outcomes and premature mortality compared with the general population; these include endocrine disorders, subsequent neoplasms, cardiovascular disease, and reduced fertility among others.[3] The prevalence and severity of these chronic health conditions depend on biological, disease-related, and treatment-related factors and children who are recipients of hematopoietic stem cell transplantation, or are diagnosed with brain tumors and receive cranial irradiation are at the highest risk. Impaired fertility has been reported in both male and female survivors of childhood and adolescent cancer compared with sibling controls.[4,5] This is primarily related to gonadotoxicity, with the highest risk following exposure to alkylating agents and radiation to the gonads.[6–9]

Fertility-related concerns are common among survivors of childhood and adolescent cancer and have a significant impact on their quality of life.[10] Single-institution survivor cohorts from India have also reported impaired fertility as a significant concern.[11–13] A single-center experience from India of 2,631 adult survivors treated between 1971 and 2020 found that 917 (34.9%) are at high-risk of gonadotoxicity. Even amongst children treated after 2000, 27.8% are at high-risk of gonadotoxicity (Prasad et al, manuscript under consideration). There are an estimated 76,000 children and adolescents 0–19 years of age in India who develop cancer every year.[14] Of these, approximately 19,000 (25%) have cancers (including high risk non-Hodgkin lymphoma, brain tumors, sarcomas, and high risk neuroblastoma) where frontline treatment of a newly diagnosed patient will have high (60–80%) or very high (>80%) risk of impact on fertility.[15] In these newly diagnosed patients, the opportunity for fertility preservation prior to the start of treatment is available only to those who are post-pubertal, estimated at approximately 5,000 patients annually. Similarly, if 40% of these 19,000 children and adolescents with cancer achieve long-term cure, they will need counselling and fertility-related services.

This suggests a high burden of newly diagnosed patients with a potential for gonadotoxicity, including fertility issues, as well as survivors who require evaluation and management for gonadotoxicity and fertility-related concerns. This warrants collective efforts to better define the problem and identify more effective and practical solutions. In this paper, we discuss the current standards of fertility preservation in childhood cancer patients and survivors, the status of services currently available in India for fertility preservation and infertility management, and the gaps and barriers in these services.

Methods

The Indian Childhood Cancer Initiative (ICCI) utilized a multistakeholder consensus process and engaged representatives of major pediatric oncology and reproductive medicine associations in India, non-governmental organizations (NGOs), and survivor advocates beside representatives from psychology, endocrinology, and radiation oncology. The group reviewed evidence, regulations, and practices, incorporated stakeholder input to map gaps in FP services and proposed a call to action to improve oncofertility care of children and adolescents in India.

- Representing the pediatric and adolescent cancer professional societies – Pediatric Hematology Oncology Chapter of the Indian Academy of Pediatrics, Indian Pediatric Hematology Oncology Group (INPHOG), Teenage and Young Adult Cancer Foundation.
- The reproductive medicine professional societies – Indian Fertility Society, Indian Society of Assisted Reproduction, Fertility Preservation Society of India, and

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- The two largest childhood and adolescent cancer survivor communities –KidsCan Konnect from Cankids and Ugam from Indian Cancer Society (ICS).

Current Standards of Care for Reproductive Health and Fertility Preservation for Childhood Cancer Patients and Survivors

Strategies to preserve or reduce the adverse impact of childhood and adolescent cancer treatment and its treatment on fertility and gonadal function are now standard-of-care.[16] The options for fertility and gonadal function preservation depend upon sex, pubertal status, and phase of treatment of the patients, with varying costs and technical expertise.[17–22] While some treatments such as sperm cryopreservation are well established with long-term data on efficacy and outcomes, certain methods are still experimental.[18]

Post-Pubertal Males

Possibly the most successful and commonly adopted fertility preservation strategy in newly diagnosed children and adolescents is sperm cryopreservation/banking in post-pubertal males.[17–19,23] Ideally the sperm sample should be collected prior to the initiation of any cancer-directed treatment, analyzed for quality and then cryopreserved. The sample can then be retrieved when required and used in artificial reproductive therapies (ART).[18] The use of techniques such as intracytoplasmic sperm injection during in-vitro fertilization allows for successful utilization even when the sperm count is low as in survivors with oligospermia. Sperm preservation offers the advantages of being relatively easy, "non-invasive," affordable, and effective.[17,18,23]

Samples are usually collected by masturbation, a process that requires some degree of understanding by the patient and expertise on part of the technician/counsellor to explain process to patient/survivor and caregivers. Samples could also be collected by testicular aspiration or extraction techniques or electroejaculation under sedation.[20,21]

Options for fertility preservation in *post-pubertal females* include oocyte and embryo preservation. While oocyte preservation was considered experimental until a decade ago, it is now considered standard of care.[17,22,24] There is limited data on long-term pregnancy outcomes post oocyte preservation in adolescent girls; however, results are encouraging, with no reported birth defects in children conceived using this technique.[22] The process usually consists of controlled ovarian hyperstimulation for approximately 10 days using subcutaneous gonadotropin hormones, with careful monitoring with blood tests and transvaginal ultrasonography, and involves transvaginal oocyte retrieval under anaesthesia.[18] Oocyte preservation is expensive, invasive and requires considerable technical expertise, with the practical utility limited to older adolescents and adult females. Embryo cryopreservation is generally not an option in adolescent females, as, under the ART law, it can be offered only to married women. While gonadotropin-releasing hormone (GnRH) analogues have been used in adult women with cancer, there are limited data on their use in children.[17,18,24]

Fertility preservation options are limited in *prepubertal children*. Ovarian and testicular tissue cryopreservations involve removing part of the ovary or testes, followed by cryopreservation and autotransplantation. Ovarian tissue cryopreservation appears promising; while over 300 live births have now been reported worldwide from ovarian tissue banked in childhood or adolescence, long-term pregnancy data in prepubertal girls with cancer are limited.[18,22] Testicular tissue cryopreservation and fertility restoration have been reported in animal studies and human case studies under research settings, but are not used in clinical practice and should therefore be considered experimental. Shielding or transposition of the gonads out of the radiation field is a standard procedure in prepubertal children receiving radiation, although radiation scatter is very small in children. Ovarian transposition is more useful in preserving the hormonal function of the ovary but usually may not preserve fertility.[23,24] The use of highly gonadotoxic concurrent chemotherapy in these children may further decrease the utility of gonadal shielding or transposition as fertility preservation strategies.

The use of standard-of-care, least morbid surgical procedures while maintaining oncological efficacy, is an important consideration when fertility may be potentially affected by surgery.

The Pediatric Initiative Network Risk Stratification System places the following at significantly increased or high risk of infertility: cyclophosphamide equivalent dose$\geq$4 g/m^2 in males and $\geq$8 g/m^2 in pubertal females and $\geq$12 g/m^2 in prepubertal females, alkylator therapy $\pm$ total body irradiation; myeloablative and reduced-intensity hematopoietic stem cell transplantation; cisplatin dose $>$500 mg/m^2 in males; testicular radiation $>$0.7 Gy; any ovarian radiation; and hypothalamic radiation $>$30 Gy.[25] The International Guidelines Harmonization group defines the following groups as high risk for hypothalamic-pituitary (HP) dysfunction (which may include secondary gonadal dysfunction): radiotherapy exposing the HP region, CNS tumors or surgery within the HP region, total body irradiation, and hydrocephalus.[26]

Current recommendations for fertility preservation include those given by the PanCareLIFE Consortium, the International Late Effects of Childhood Cancer Guideline Harmonization Group, the American Society of Clinical Oncology, and the position statement of the American Academy of Paediatrics.[23,24,27] ►**Table 1** summarizes the international recommendations for fertility preservation in patients at high risk of infertility.

Current guidelines for post-treatment surveillance and evaluation of gonadotoxicity in males focus on three groups: those at high risk of impaired spermatogenesis, those with testosterone deficiency, and those with physical sexual dysfunction (►**Table 1**). In females, guidelines focus on surveillance and management of premature ovarian insufficiency.

All childhood and adolescent cancer survivors with any exposure which could cause HP dysfunction or primary gonadal dysfunction should be managed by a multidisciplinary team, and referred to a pediatric endocrinologist with relevant expertise.[27–29]

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Table 1 Integrated recommendations for fertility preservation and gonadotoxicity surveillance in childhood cancer patients and survivors

Domain	Patient group	Risk/Indication	Recommended intervention	Strength/Notes
At diagnosis: counselling	All patients (pre- and post-pubertal, both sexes)	Planned exposure to gonadotoxic therapy	Fertility risk counselling and discussion of preservation options	Strongly recommended
Fertility preservation	Male, post-pubertal	Prior to treatment	Sperm cryopreservation	Strongly recommended (standard of care)
Fertility preservation	Male, pre-pubertal	No mature sperm	Testicular tissue cryopreservation	Experimental; consider only in clinical trials
Fertility preservation	Female, post-pubertal	If no delay to cancer treatment	Oocyte or embryo cryopreservation	Strongly recommended
Fertility preservation	Female, any age	Gonadotoxic therapy planned	Ovarian tissue cryopreservation	Moderately recommended
Fertility preservation	Female (radiation exposure)	Pelvic radiation planned	Oophoropexy (ovarian transposition)	Moderately recommended
Fertility preservation	All groups	Concurrent alkylating chemotherapy	Hormonal suppression (GnRH analogues)	Not recommended for fertility preservation
Radiation protection	All patients receiving pelvic RT	Gonadal exposure risk	Gonadal shielding/transposition	Standard supportive strategy
Survivorship: general surveillance	All survivors exposed to gonadotoxic therapy	Long-term follow-up	Growth monitoring + pubertal assessment	Every 6 mo (pre-/peri-pubertal); annually (post-pubertal)
Male survivors – spermatogenesis	Post-pubertal survivors	High-dose alkylators or testicular RT	Semen analysis (on request after counselling)	Not for routine screening
Male survivors – spermatogenesis		Abnormal semen parameters	Referral to andrology/urology	Consider sperm cryopreservation if feasible
Male survivors – hormonal function	Pre-/post-pubertal survivors	Testicular/total body RT $\geq$12 Gy	Early morning testosterone $\pm$ LH	Refer to endocrinology/urology; hormone replacement if needed
Male survivors – sexual function	All survivors	Symptoms or pelvic/spinal treatment	Sexual history assessment	Refer to specialist care
Female survivors – ovarian function	Pre-/post-pubertal survivors	Gonadotoxic therapy exposure	Evaluate for delayed puberty, amenorrhea, menstrual irregularity	Clinical trigger-based evaluation
Female survivors – ovarian function		Clinical suspicion of ovarian insufficiency	FSH, estradiol $\pm$ AMH*	AMH not recommended alone
Female survivors – ovarian function	Pre-pubertal	No puberty by 13 y/no progression	Refer to pediatric endocrinologist	
Female survivors – ovarian function	Post-pubertal	Amenorrhea/irregular cycles	Refer to gynecology/reproductive endocrinology	Hormone replacement as needed

Abbreviations: AMH, anti-Müllerian hormone; FSH, follicle-stimulating hormone; GnRH, gonadotropin-releasing hormone; LH, luteinizing hormone; RT, radiotherapy.

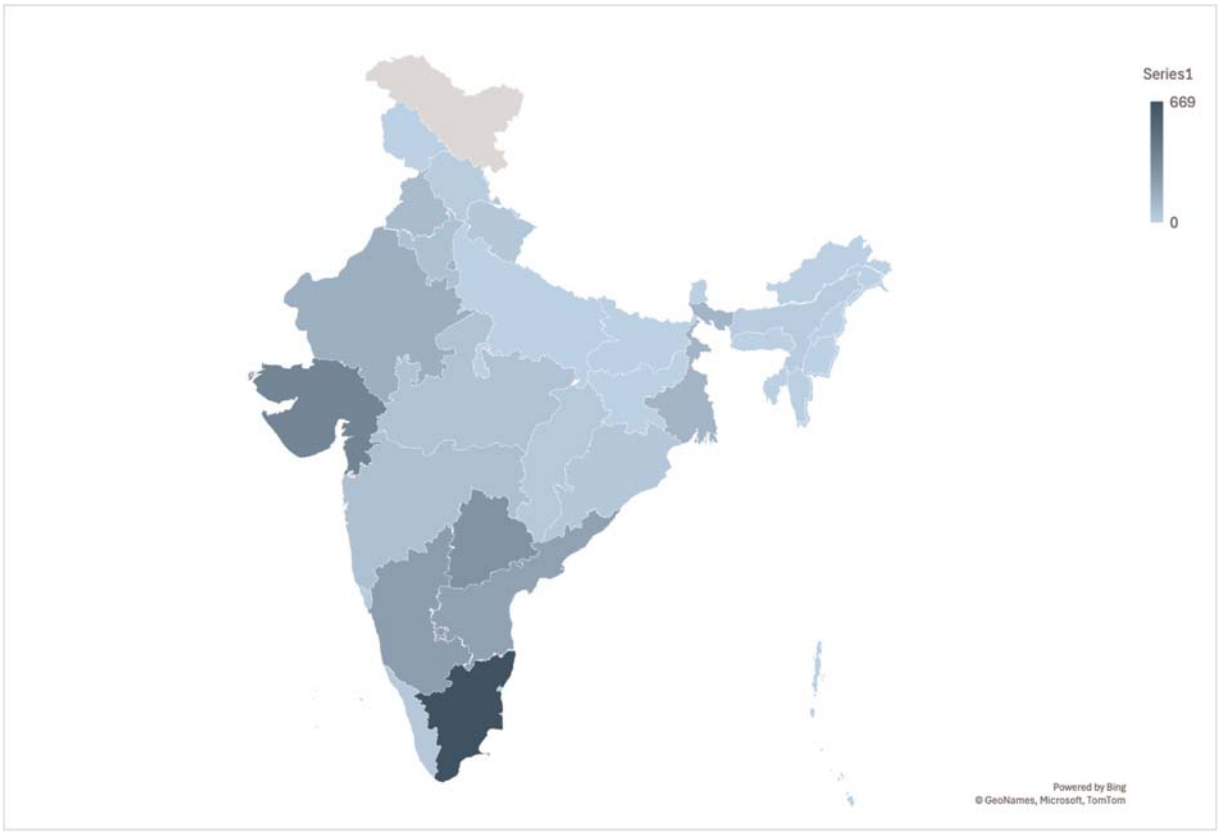


Fig. 1 Distribution of ART clinics in India by state as of December 2025. ART, artificial reproductive therapies.

These guidelines were developed in the European and American contexts. Ongoing work in India aims to adapt them to the Indian context (Gargi Das, personal communication). Existing guidelines in India are not specific to childhood and adolescent cancer patients and survivors.[30]

Current Status of ART and Oncofertility in India

The number of clinics offering fertility preservation and ART in India is rapidly increasing.[31] According to the National ART & Surrogacy Registry, as of December 2025, there are 2,616 ART clinics registered in India.[32]

However, these services are not distributed uniformly, with just six states in South and West India (Tamil Nadu, Gujarat, Telangana, Karnataka, Andhra Pradesh, and Rajasthan) accounting for 71% of all registered ART clinics (►**Fig. 1**), highlighting the paucity of services in many other large demographic areas. Further, these services are almost entirely restricted to urban areas and the private sector, further skewing access.[33–36] Direct medical costs paid by patients for infertility treatment are significantly higher than the annual average income and GDP per capita.[37] This when coupled with the absence of insurance cover for such treatment, points to unaffordability and the risk of catastrophic expenditure for those in need.[33,34,38] Furthermore, lack of awareness and these limitations in access and affordability result in a substantial proportion of those seeking fertility care receiving alternative and traditional treatments.[39]

►**Supplementary Table S1** (available in the online version only) summarizes the cost and availability of oncofertility and ART services in India.

Oncofertility is the intersection of oncology and reproductive medicine, with a focus on fertility preservation at the time of cancer diagnosis as well as after completion of treatment.[40] Delivering effective oncofertility services requires awareness of the need of such services, identification of cancer patients or survivors who will benefit from this, counselling of the patient or caregiver, communication with the ART specialist, availability of a center equipped to provide a service, and appropriate legal and regulatory framework. Another complexity in children with cancer is their prepubertal status, which presents unique challenges in the delivery of care.

In India, knowledge and awareness among healthcare providers, patients, and families about the impact of childhood cancer treatment on future fertility and hormonal function remains limited.[11,41,42] Many patients and families do not receive information about how cancer treatments can affect future fertility.[11] As mentioned above, there are an increasing number of ART clinics in India, with underrepresentation in rural areas, the public sector, and certain geographical regions such as Uttar Pradesh and Bihar. The 2022 report from ICMR on the Situational Analysis of Childhood Cancer Services in India showed that fertility preservation services were available in 18% of tertiary centers treating childhood cancer in the public sector, 34% in the private sector, and 16% in the charitable trust sector.[43]

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Even where ART clinics exist, fertility preservation services are mostly limited to embryo, oocyte, and semen preservation, with very few centers offering gonadal tissue freezing.[33] There is very little published information from India on testicular and ovarian tissue freezing. A 26-year-old female patient with Hodgkin lymphoma underwent freezing of the ovarian cortex at the start of treatment, and after end of treatment, she underwent heterotopic autologous ovarian transplantation, which was not successful.[44] More recently, the Centre for Fertility Preservation at the Manipal Academy of Higher Education has conducted and published animal studies on prepubertal testis in mice, and its first human study on prepubertal testes from boys with cancer found that the spermatogonial quantity in immature testicular tissue did not vary significantly between hematological and non-hematological cancers.[45–47]

Other factors that affect availability and accessibility include cultural, operational, and legal issues. Societal attitudes may discourage open discussion about fertility and the use of ART, making it harder for families to consider or accept

Table 2 Call to action

Clinical Practice
Target – Pediatric oncologists, hematologists, reproductive specialists, and cancer care teams.
- Standardize assessment and management of fertility risk across all pediatric oncology centers. - Formulate India-specific fertility preservation guidelines for children and adolescents with cancer. - Use standard-of-care treatment protocols that minimize gonadotoxicity. - Ensure consistent counseling and referral practices for fertility preservation in cancer care. - Develop decision-aid tools to help families make informed fertility preservation choices.
Care pathways
Target - Oncology care teams, survivorship clinics, and healthcare administrators.
- Incorporate fertility preservation discussions at diagnosis: adopt a multidisciplinary approach with early referral to reproductive specialists. - Include fertility assessment and counseling in survivorship care plans for follow-up. - Clearly document fertility discussions and interventions in patient records for continuity. - Include Oncofertility Navigator who can assist the ART providers and ensure better communication between oncologist and patients. - Provide ongoing psycho-oncology and mental health support to patients, survivors, and families through treatment. - Embed fertility preservation checkpoints at key treatment milestones (e.g. diagnosis, pre-treatment, end of treatment, survivorship transition).
Access and Infrastructure
Target - Health policymakers, hospital administrators, ART providers, and NGOs.
- Develop a network of oncofertility centers (national, regional, institutional) equipped for children and adolescents. - Establish clear referral pathways or hub-and-spoke models linking pediatric cancer centers to ART/oncofertility hubs. - Expand fertility preservation services to underserved regional and rural healthcare facilities. - Introduce government or NGO financial support schemes to subsidize fertility preservation costs for eligible families. - Create public–private partnership models (with civil society support) to bridge gaps in the public sector.
Education and Awareness
Target - Medical educators, oncology and nursing trainees, patient advocacy groups, and public health communicators.
- Integrate oncofertility into oncology and obstetrics/gynecology training curricula (case-based, practical focus). - Develop culturally appropriate patient and caregiver education materials on fertility risks and options. - Implement training programs to improve providers' communication skills for discussing fertility preservation. - Increase awareness of fertility issues and solutions among patients, caregivers, and healthcare providers. - Counsel survivors facing infertility on third-party reproduction (e.g. donor gametes) and adoption, and refer them to accredited services.
Policy and Advocacy
Target - Policymakers, legal and regulatory bodies, professional societies, and NGOs.
- Clarify fertility preservation provisions in India's ART Act for children and adolescents with cancer. - Form an alliance of oncology and reproductive medicine providers with patients, carers, and civil society. - Establish peer support groups for survivors to share experiences and address fertility concerns together.
Research
Target - Academic researchers, government and philanthropic funders, and technology developers
- Conduct research to quantify fertility preservation needs, optimize low-gonadotoxic cancer therapies, and identify access barriers. - Focus on fertility preservation solutions for prepubertal patients (an underserved area). - Develop and evaluate low-cost fertility preservation models tailored to India's context.

Abbreviation: ART, assisted reproductive technology.

these options.[33,34] The high cost and additional time required for fertility preservation mean that fewer families of female patients opt for these services. Some oncologists may also be less inclined to prioritize fertility discussions with their patients, depending on the clinical situation. One commonly reported barrier is the anticipated delay in starting definitive treatment in aggressive tumors due to fertility preservation procedures. Over the past decade, initiatives such as the Late Effects Subcommittee of the INPHOG, the ICCI, and other NGO-led programs have enabled more holistic care.[48] After Completion of Therapy (ACT) Clinics for childhood cancer survivors under the ICS PICASSO (Partnership in Cancer Survivorship Optimization) project provide "Late Effects Funding" to support fertility-related evaluation and treatment for adult survivors of childhood cancer.[48] However, so far, only a miniscule proportion of survivors benefits from such initiatives.

Finally, while the 2021 ART Act has made several positive changes in supervision, regulation, licensing, and ensuring good ethical practices in assisted reproduction including surrogacy, it has been conspicuously silent on gonadal tissue freezing as well as any fertility interventions in individuals younger than 21 years of age, leading to uncertainty among healthcare providers regarding the extent of services they can provide to children and adolescents with cancer.[49]

Call to Action

►**Table 2** summarizes the priority areas and action items to improve fertility outcomes in Children and Adolescents with Cancer in India.

Conclusion

This position statement highlights that fertility preservation services in India differ greatly between pre-pubertal and post-pubertal patients and between the diagnostic and survivorship phases of care. Significant gaps in awareness, accessibility, affordability, acceptability, and quality must be addressed to improve fertility outcomes for young cancer patients and survivors. Addressing fertility preservation among childhood and adolescent cancer patients and survivors in India requires a comprehensive approach involving enhanced communication, education, and systemic changes to healthcare delivery. By implementing these strategies, we can improve the quality of life of survivors, enabling them to make informed reproductive choices in the future.

Patient Consent

Patient consent not applicable.

Authors' Contributions

All authors contributed to the conception, drafting, and critical revision of the manuscript and approved the final version.

Conflict of Interest

None declared.

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