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Review Article

Patient advocacy in otorhinolaryngology in the Indian context: clinical integration, ethical imperatives and system-level support

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ABSTRACT

Patient advocacy in otorhinolaryngology is often treated as a peripheral policy interest rather than part of clinical work. This review argues that, for the practising ENT surgeon in India, advocacy is an extension of ordinary clinical duty, functioning simultaneously as an ethical safeguard, a clinical responsibility and an instrument of health equity. Drawing on Indian empirical literature, primary legislation, regulatory instruments and government scheme documentation identified through a structured but non-systematic search of PubMed, Scopus and IndMED (January 2000 to March 2026), supplemented by purposive searching of official portals, we examine four domains. First, clinical-level advocacy, encompassing meaningful informed consent, financial counselling, communication across languages and diagnostic stewardship. Second, the legal framework: Article 21 of the Constitution, the Charter of Patients' Rights and the Rights of Persons with Disabilities Act 2016 create concrete obligations around emergency care, disclosure and disability certification. Third, the financing environment: the Insurance Regulatory and Development Authority of India's 2024 Master Circular reduced pre-existing-disease waiting periods and the moratorium period; the 2019 modern-treatment mandate prevents outright exclusion of balloon sinuplasty and robotic surgery subject to disclosed sub-limits; and the September 2025 removal of GST on individual health policies has materially reduced premiums. Fourth, systemic advocacy through the National Programme for Prevention and Control of Deafness, tele-ENT and the non-governmental referral ecosystem. Indian evidence indicates that most ENT presentations reaching primary care can be managed there given basic facilities and specialist support, reframing district-level advocacy as equipping primary care rather than merely absorbing its referrals.

Keywords: Patient advocacy, Otolaryngology, Health policy, India, Health equity, Delivery of health care

INTRODUCTION

Otorhinolaryngological practice in India sits between two facts that do not sit comfortably together. Techniques and technologies available in Kochi or Delhi are now broadly comparable with those available anywhere; the ability of a patient in a rural block to reach them is not. Hearing loss illustrates the gap plainly. A review of Indian prevalence studies published between 1980 and 2020 found community-based estimates of hearing loss ranging

from 6% to 26.9%, with disabling hearing loss between 4.5% and 18.3%, and consistently higher burdens in rural populations and among the elderly.[1] The same review reported neonatal hearing impairment of 1.59 to 8.8 per 1,000 births in the general population, rising to between 7 and 49 per 1,000 among neonates with identifiable risk factors.[1] Head and neck cancers remain among the commonest malignancies in the subcontinent and continue to present late, for reasons that are largely organisational rather than clinical.[2]

Against this background, we take patient advocacy to mean the work a surgeon does to ensure that a correct diagnosis actually results in treatment the patient can reach, understand and afford. Framed that way, advocacy is not an addition to clinical practice but a description of part of it. The asymmetry of information and authority in many Indian consultations places that obligation squarely on the treating clinician, who is frequently the only person in the encounter able to interpret the system on the patient's behalf.[3]

This review synthesises the clinical, legal, financial, technological and systemic dimensions of that role, and it attempts throughout to distinguish what the Indian evidence shows from what is reasonable inference and what is opinion.

METHODS

This is a narrative review. PubMed, Scopus and IndMED were searched for the period January 2000 to March 2026, using combinations of the terms ("otorhinolaryngology" OR "ENT" OR "head and neck surgery") AND ("patient advocacy" OR "health policy" OR "informed consent" OR "insurance" OR "health equity") AND ("India"). The search was restricted to English-language records, and Google Scholar was used as an informal supplementary check for recent material. Legal, regulatory and programmatic sources-the primary text of the Rights of Persons with Disabilities Act 2016, reported judgments, circulars of the Insurance Regulatory and Development Authority of India (IRDAI), and the portals of the Ministry of Health and Family Welfare, the National Health Mission, the Department of Empowerment of Persons with Disabilities and the Ali Yavar Jung National Institute of Speech and Hearing Disabilities-were identified by direct purposive searching, since such material is not reliably indexed in bibliographic databases.

Sources were selected purposively for relevance to the four domains addressed, rather than through formal systematic screening against pre-specified eligibility criteria. Screening and selection were performed by a single reviewer, without independent duplicate screening or adjudication, and no formal risk-of-bias appraisal was applied to the empirical studies cited. Empirical studies are distinguished in the text and in Table 1 from legal, governmental and organisational sources, which are cited descriptively and carry different evidentiary weight. These features are limitations of the method rather than incidental omissions, and are stated again in the Limitations section.

Table 1: Empirical studies informing the clinical and health-systems claims made in this review.

Sources	Design	Setting	Sample	Key findings
Verma et al, 2021[1]	Systematic literature review (440 identified, 29 analysed)	India	—	Community-based prevalence of hearing loss 6–26.9%; disabling hearing loss 4.5–18.3%; neonatal impairment 1.59–8.8 per 1,000 births, rising to 7–49 per 1,000 in at-risk neonates.
Davey et al, 2018[20]	Retrospective and prospective cohort	Rural Health Training Centre, western Uttar Pradesh	3,840 ear patients	After adoption of Indian Public Health Standards within NPPCD, patient satisfaction reached 81% and receipt of curative ear treatment rose from 17.8% to 68.1% (OR 9.8, p<0.00001).
John M et al, 2016[22]	Retrospective chart review	Family Medicine unit for the urban poor, tertiary teaching hospital, India	12 months of attendances	12.89% of attendances were ENT-related; 23.9% referred to the visiting ENT specialist; 88.30% managed within the unit with basic facilities; only 11.70% required onward tertiary referral.
Emerson et al, 2013[23]	Prospective service evaluation, 3 years	Secondary hospital and tribal camps, Vellore district, Tamil Nadu	2,600 patients	Community volunteers trained to identify and refer ENT conditions; combined community identification, audiology and specialist surgical input improved access in a population of ~430,000.

Continued.

Sources	Design	Setting	Sample	Key findings
Nandimath OV, 2009[3]	Legal and ethical analysis	India	—	Sets out the legal basis of informed consent in India and liability arising from treatment without valid consent.
Jeevitha G, 2025[21]	Qualitative documentary analysis	India (Lok Sabha and Rajya Sabha)	1,016 parliamentary questions	Health-workforce questions concentrated on recruitment and distribution; rural, tribal and specialist-shortage sub-themes were comparatively under-represented.
Sood et al, 2025[24]	Programmatic service-utilisation analysis	India (national)	Nov 2019 – Sep 2023	Over 163 million teleconsultations across 28 states and 8 union territories; the provider-assisted Ayushman Bharat model accounted for more than 93% of use.
Müskens et al, 2022[7]	Systematic review	International	118 assessments from 35 studies	Substantial overuse of diagnostic testing across settings, with wide variation; preoperative testing among the most frequently identified low-value tests.
Lukama et al, 2023[8]	Retrospective cross-sectional	Tertiary hospital, Zambia	1,543 patients	High rates of diagnostic error and inappropriate referral by non-ENT clinicians. Cited here only as evidence that such audits, where performed in comparable settings, find substantial error; not as an Indian figure.

NPPCD: National Programme for Prevention and Control of Deafness; OR: odds ratio.

DISCUSSION

Clinical-level advocacy in daily practice

Informed consent as dialogue rather than signature

The right to autonomy in medical decision-making is well established in Indian jurisprudence, and treatment without valid consent may attract civil or criminal liability. Implied consent suffices for routine examination; procedures such as mastoidectomy or thyroidectomy require express written consent.[3] In practice, however, consent is too often reduced to a signature on a form written in a language the patient reads imperfectly, obtained by the most junior member of the team, at a moment when refusal is not a realistic option. Advocacy at this point means something quite specific: explanation in the patient's own language, in terms that survive translation; an unprompted account of the alternatives, including no operation; and an explicit statement that a second opinion may be sought without penalty or delay.

Financial counselling as part of surgical planning

Cost determines adherence in India more often than clinicians acknowledge. Frameworks developed for measuring financial hardship after surgery treat material hardship, psychological distress and cost-related non-adherence as distinct and separately measurable domains,[4] and that separation is clinically useful: a patient may accept an operation and then quietly forgo the follow-up audiogram or the second-stage procedure. Out-of-pocket expenditure in India remains high despite expanding insurance penetration.[5] Practical advocacy here consists of an itemised written estimate covering surgeon's fees, implants and consumables before the decision is made; an explicit conversation about what is not covered; and active navigation towards Pradhan Mantri Jan Arogya Yojana, charitable funds or institutional concessions where indicated.

Communication across languages

Language is a determinant of outcome, not merely of satisfaction. Multilingual language models adapted for Indian languages have shown early promise in simplifying clinical documents into readable regional-language text, and there is a reasonable institutional case for adopting such tools for discharge instructions and consent forms, provided the output is verified by a clinician who speaks the language.[6] Older courtesies remain part of the same obligation -among them ensuring a female attendant is present when a male clinician examines a female patient.

Diagnostic stewardship

Defensive practice drives imaging that neither changes management nor reassures anyone for long. A systematic review of diagnostic overuse across health systems found substantial and highly variable low-value testing, with preoperative investigation prominent among the categories identified.[7] Protecting a patient from an

unnecessary contrast study is advocacy in the same sense that arranging their cochlear implant is, and it is considerably more common an opportunity. Where formal audits of diagnostic accuracy have been conducted in comparable resource-limited settings, error and inappropriate-referral rates have been found to be high,[8] though no equivalent Indian study appears to have been published, and the figures from such audits should not be transposed to Indian practice.

LEGAL AND ETHICAL FOUNDATIONS

A working knowledge of four instruments covers most of what an ENT surgeon needs. These are summarised in Table 2.

Table 2: Indian legal and regulatory instruments relevant to ENT practice.

Instrument	Focus	Practical implication for ENT practice	Ref
Constitution, Article 21 (Parmanand Katara, 1989)	Right to life; emergency care	Immediate care for airway and trauma presentations irrespective of payment or formality; auditable triage policy and 24-hour availability of functioning airway equipment.	9, 10
Charter of Patients' Rights (MoHFW)	Patient autonomy and information	Explanation of diagnosis in accessible language; itemised and transparent billing. Consolidates existing rights; not itself binding legislation.	11
Rights of Persons with Disabilities Act, 2016	Disability rights and certification	ENT surgeons certify hearing and speech disability for UDID; accuracy determines access to ADIP, reservations and educational support.	12
Consumer Protection Act and tort law	Medical liability	Legal basis for the requirement of valid informed consent; express written consent for major procedures.	3, 13, 14, 15

UDID: Unique Disability Identity card; ADIP: Assistance to Disabled Persons scheme; MoHFW: Ministry of Health and Family Welfare.

Emergency care under Article 21

The Supreme Court has read the right to life in Article 21 as encompassing a right to emergency medical care. In Parmanand Katara v Union of India (1989), the Court held that a doctor's professional obligation to preserve life is not suspended by legal formality or by the patient's ability to pay.[9] For ENT practice this is not abstract. It applies directly to the child with an inhaled foreign body and the patient with laryngeal trauma, and it translates into institutional obligations that are auditable: a written triage policy, and laryngoscopes, tracheostomy sets and suction that are checked and functioning at three in the morning.[9,10]

The charter of patients' rights

The Charter circulated by the Ministry of Health and Family Welfare consolidates existing entitlements-to safety, to information, to itemised billing-into a single document.[11] It is not itself binding legislation, and should not be described as though it were, but it states clearly what patients are entitled to expect and provides a reference point for departmental practice.

The rights of persons with disabilities act 2016

The Act is the most directly operational statute in ENT practice, because ENT surgeons are certifying authorities for hearing and speech disability under the Unique Disability ID process.[12] A certificate determines access to reservations, concessions, assistive-device schemes and educational provision. Careless certificationin either direction-has immediate consequences for the patient, and accurate assessment of severity is therefore an advocacy act with unusually direct effect.

Consumer protection act and tort law

Since 1995, medical services rendered for consideration have fallen squarely within consumer jurisdiction. In Indian Medical Association v. V.P. Shantha, the Supreme Court held that a patient who pays for treatment is a "consumer" and a doctor or hospital a provider of "service", so that a deficiency in that service is justiciable before the consumer fora rather than only in the civil courts.[13] The position survived a recent challenge: a reference questioning the ruling was made in May 2024 but disposed of as unnecessary later that year, and the principle now operates under the Consumer Protection Act 2019, which replaced the 1986 statute from 20 July 2020.[14] For the ENT surgeon this matters in two directions. It gives the patient an accessible and inexpensive route to redress, which is itself a form of accountability the specialty should welcome rather than resent. But it also shapes conduct at the bedside, since the commonest heads of claim-operating on inadequate consent, failure to disclose a material risk, or a departure from the standard a reasonable practitioner would observe-are the same lapses that good advocacy prevents.[15] The prudent response is neither defensive over-investigation nor complacency, but contemporaneous documentation: a consent process that records the alternatives discussed, and case notes made at the time rather than reconstructed afterwards. Understood this way, liability law is less a threat to be managed than

the legal expression of the same duties this review has argued are clinical.

THE FINANCING ENVIRONMENT

Three separate regulatory and fiscal changes have altered what an Indian ENT surgeon can realistically promise a patient.

The first is IRDAI's Master Circular on Health Insurance Business of 29 May 2024, effective from 1 April 2024, which capped the pre-existing-disease waiting period at 36 months (previously up to 48), reduced the moratorium after which a claim may not be repudiated for non-disclosure from eight years to five, and removed age as a permissible ground for refusing cover.[16]

For otosclerosis, chronic rhinosinusitis and age-related hearing loss this is a material shortening of the interval between diagnosis and affordable surgery.

The second is IRDAI's 2019 guidelines on modern treatment methods listed twelve procedures- balloon sinuplasty and robotic surgery among them- that insurers may not exclude outright; the 2024 Master Circular consolidated rather than created this position.[17] The qualification is important and is regularly lost in summary: insurers remain entitled to apply disclosed sub-limits, so a policy may legitimately cap a robotic procedure at a fraction of the sum insured.[17] The practical counselling point is therefore not that these procedures are covered, but that they cannot be refused as experimental, and that the extent of cover must be read off the individual policy schedule and confirmed by pre-authorisation before the operating list is fixed.

The third change is fiscal rather than regulatory and is the largest in immediate effect. Following the 56th GST Council meeting, the goods and services tax on individual life and health insurance policies was reduced from 18% to zero with effect from 22 September 2025, covering all individual health policies including family floater plans.[18] Group and employer-sponsored policies continue to attract 18%.[18] The asymmetry deserves attention in a specialty whose patients are disproportionately drawn from the informal sector: the exemption benefits precisely those buying cover for themselves, and not those covered through formal employment. (Table 3)

Table 3: Insurance and fiscal changes affecting ENT surgical planning, by instrument and date.

Provision	Instrument	Change	Implication and caveat for ENT practice	Ref
Pre-existing disease waiting period	IRDAI Master Circular, 29 May 2024 (eff. 1 Apr 2024)	Up to 48 months → capped at 36 months	Earlier access to surgery for chronic rhinosinusitis, otosclerosis and age-related hearing loss.	16
Moratorium period	IRDAI Master Circular, 2024	8 years → 5 continuous years	After 5 years, claims may not be repudiated for non-disclosure except on proof of fraud.	16
Age at entry	IRDAI Master Circular, 2024	Entry often restricted beyond 65 → no refusal on age alone	Improves access to geriatric ENT care, including implantation and oncological surgery.	16
Modern treatment methods	IRDAI guidelines, 2019; consolidated 2024	12 listed treatments, including balloon sinuplasty and robotic surgery, may not be excluded outright	Cannot be denied as experimental. However, disclosed sub-limits remain permissible and may cap payment well below the sum insured; verify the policy schedule and obtain pre-authorisation before scheduling.	17
GST on premiums	56th GST Council; notification 16/2025-Central Tax (Rate), eff. 22 Sep 2025	18% → 0% on individual policies	Substantial reduction in the cost of individual and family floater cover. Group and employer-sponsored policies continue to attract 18%.	18

IRDAI: Insurance Regulatory and Development Authority of India; GST: goods and services tax. Insurance regulation is revised frequently; parameters should be reconfirmed against the live circular at the time of counselling.

SYSTEMIC AND PUBLIC HEALTH ADVOCACY

The National programme for prevention and control of deafness

NPPCD gives district ENT surgeons a defined role in early detection, surgical treatment of chronic suppurative otitis media, and training of primary-level workers.[19] There is direct Indian evidence that adherence to the programme's standards changes outcomes rather than merely documentation. In a cohort of 3,840 ear patients attending a rural health training centre in western Uttar Pradesh, adoption of Indian Public Health Standards for ear care was followed by a rise in patient satisfaction to 81% and an increase in receipt of curative treatment from 17.8% to 68.1% (odds ratio 9.8, $p<0.00001$).[20] The design is a single-centre before-and-after comparison and does not establish causation, but the magnitude of the difference is difficult to attribute wholly to secular trend, and it identifies standards adherence as a concrete target for departmental advocacy.

Newborn hearing screening

The problem in India is generally not initial screening coverage but completion of the diagnostic pathway within the window in which intervention alters language outcome. Given a neonatal impairment rate of 1.59 to 8.8 per 1,000 births, rising to 7 to 49 per 1,000 in at-risk neonates,[1] the yield of a functioning tracking system is considerable. Advocacy here is unglamorous and administrative: a database that follows the infant rather than the appointment, and audiology records integrated with maternity and paediatric services so that a referred baby is not simply lost.

What district-level advocacy should actually ask for

Specialist maldistribution is the binding constraint, and parliamentary attention to it has been uneven; a documentary analysis of 1,016 questions on health workforce found that rural, tribal and specialist-shortage themes were comparatively under-represented relative to recruitment and distribution generally.[21] The Indian service-delivery evidence, however, points away from the assumption that the answer is simply more specialists absorbing more referrals. In a family medicine unit serving the urban poor, 12.89% of attendances were ENT-related; of those referred to a visiting ENT specialist, 88.30% were managed within the unit using basic ENT facilities, and only 11.70% required onward referral to the tertiary hospital-about half of those for audiometric or imaging access rather than for diagnostic difficulty.[22] A three-year programme in Vellore district reached a population of roughly 430,000, including a tribal population of 30,000, by training community volunteers to identify and refer ENT conditions to periodic camps supported by an ENT specialist and audiologist.[23]

Read together, these suggest that the most productive object of district-level advocacy is the equipping and support of primary care-an otoscope, a functioning audiometer, a trained community worker and a reachable specialist-rather than the expansion of tertiary referral volume. That framing also resolves an apparent tension in the advocacy literature between task-sharing and specialist provision: the two are complementary, provided the specialist input is directed at supporting first-contact care rather than replacing it.

Tele-ENT

eSanjeevani has achieved genuine scale. Between its national rollout in November 2019 and September 2023 it supported over 163 million teleconsultations across all 28 states and 8 union territories, with the provider-assisted Ayushman Bharat model accounting for more than 93% of use.[24] That architecture-a health worker at the spoke, a doctor at the hub-is well suited to ENT triage and follow-up, and to supporting primary-level identification of ear disease. Evaluations from Odisha and Kerala report broadly favourable patient acceptability alongside persistent barriers of connectivity and digital literacy.[25,26] Tele-ENT extends specialist reach; it does not create operating capacity, and it should not be offered to policymakers as though it did.

Table 4: Examples of non-governmental organisations with ENT-relevant referral activity.

Organisation	Primary focus	Referral opportunity	Ref
Society to Aid the Hearing Impaired (SAHI)	Rural hearing care	Donor-funded implant sponsorship; village-level screening camps.	29
VAANI Deaf Children's Foundation	Deaf children and families	Early identification, parent training, school integration support.	30
National Association of the Deaf	Deaf rights	Indian Sign Language interpretation in clinical and legal settings.	31
Cancer Patients Aid Association	Cancer support	Financial aid, subsidised medicines and care navigation for marginalised patients.	32
Dr S. R. Chandrasekhar Institute of Speech and Hearing	Voice disorders	Interdisciplinary rehabilitation for laryngeal pathology and professional voice users.	33

Technology access and the ADIP scheme

The Assistance to Disabled Persons scheme funds hearing aids and cochlear implants for children from low-income families, with the Ali Yavar Jung National Institute of Speech and Hearing Disabilities acting as nodal agency and empanelling surgical centres.[27,28] The surgeon's role runs well beyond the operation: identifying candidates with severe-to-profound sensorineural loss who derive insufficient benefit from amplification, supporting the application and UDID documentation, and -most consequentially-setting realistic family

expectations about the years of mapping and auditory-verbal therapy that determine whether the implant achieves anything. Where families fall outside the income or age criteria, non-governmental programmes provide an alternative route.[29]

The non-governmental referral ecosystem

Non-governmental organisations supply what the public system largely does not: long-term rehabilitation, family support and navigation. Table 4 lists organisations with established ENT-relevant activity. The list is illustrative rather than exhaustive, and reflects organisational self-description rather than independent evaluation of service quality.

Key Takeaways

The argument of this review is that advocacy is best understood as clinical work performed at the points where the health system fails to transmit a correct decision into an actual treatment. Those points are identifiable and, for the most part, addressable at departmental level.

At institutional level, the achievable asks are modest and specific: itemised billing, a functioning patient-support desk, and audit of emergency equipment availability against the Article 21 obligation rather than against convenience.[10,11] At the level of health financing, persistently high out-of-pocket expenditure argues for routine direction of patients towards Jan Aushadhi generics and day-care surgical models where clinically appropriate.[8] The head and neck cancer community has a reasonable case for arguing that these tumours warrant systematic registration and resource planning proportionate to their burden; we present that as a considered recommendation rather than as a finding, since we identified no Indian policy proposal to that effect.

Three gaps recur. The rural specialist shortfall remains the principal constraint, and tele-ENT supplements it without resolving it.[24,25,26] Condition-specific standard operating procedures that a non-specialist can actually follow at first contact remain scarce, despite evidence that structured standards change outcomes when adopted.[20] And the conversion of informed consent from signature to dialogue remains unfinished across much of Indian practice-a change that requires no legislation, no funding and no new technology, only the decision to do it.

Limitations

The evidence base is heterogeneous, spanning peer-reviewed studies, primary legislation, regulatory circulars and organisational self-reports. These are not of equivalent evidentiary weight, and the text distinguishes them, but they are nonetheless discussed within a single synthesis. No Indian study of diagnostic concordance between non-specialist clinicians and ENT specialists could be identified. The single non-Indian audit cited is presented as evidence that such error exists where measured, not as an estimate applicable to India. This is a genuine gap in the Indian literature and a reasonable target for primary research. The search was restricted to English-language sources, which may have excluded relevant regional-language material, including state government guidance.

CONCLUSION

Patient advocacy in otorhinolaryngology is not an administrative addendum to surgical practice but part of what determines whether surgical practice works. It operates on three levels: as clinical responsibility, through accurate diagnosis and restraint in investigation; as ethical safeguard, through consent that is genuinely informed and emergency care that is genuinely available; and as an instrument of equity, through informed use of the insurance and fiscal environment, of NPPCD and ADIP, and of the non-governmental sector.

The Indian evidence reviewed here points to a specific conclusion about where effort is best directed at district level. Most ENT presentations reaching primary care can be managed there when basic equipment and specialist backing are available. The task is therefore less to expand tertiary referral than to make first contact competent — which is, in the end, a claim that the surgeon's advocacy is most valuable when exercised on behalf of patients they will never personally see. That argument deserves to rest on evidence held to the same standard the surgeon applies at the bedside.

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