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ISN Consolidated Consultation Feedback

WHO Global Strategy on Donation and Transplantation (Draft Version 1, 26 June 2026)

Organization	International Society of Nephrology (ISN)
Contribution	Consolidated feedback received through the ISN consultation process

Consolidated consultation feedback

Section / Heading	Paragraph No.	Line No(s)	Proposed Amendment / Comment	Rationale / Evidence (optional)
Introduction	Paragraph 2	5-8	Clarify distinctions among organs, tissues, and hematopoietic cells; autologous transplantation should not be linked to deceased donation.	
Introduction	Paragraph 3	9-11	Expand the historical overview to include advances in transplant immunology, organ preservation, and precision transplant pathology.	
Introduction	Paragraph 4	13-16	Add regional disparity data and identify LMIC-specific barriers to transplantation access and delivery.	
Introduction	Paragraph 5	17-19	Distinguish organ trafficking, trafficking in persons for organ removal, transplant tourism, and commercialization.	

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Reference to WHO related resolutions and other related documents	Paragraph 9	37-40	Include relevant regional and global transplantation strategies beyond the Americas framework.	
Overview of the Global burden	Paragraph 13	Line 59	Use a recognized disease classification rather than the term “fibro-inflammatory disease,” unless clearly defined.	
Overview of the global situation / a. Burden of diseases and socioeconomic value of transplantation	13	57-60	Despite prevention efforts established by several WHO strategies, the growing global burden of noncommunicable diseases – including metabolic (i.e. diabetes/cardiovascular/kidney), fibro-inflammatory diseases, cancer, and trauma – increasingly leads to complex or end-stage clinical scenarios requiring specialized tertiary care interventions.	Add “kidney” disease to the list of metabolic disease, especially considering that the kidney is the most frequently transplanted organ. Also, adjust the placement of parentheses the in the sentence.
Overview of the Global burden	Paragraph 14	61-63	Broaden the burden discussion beyond chronic kidney disease to include liver disease, heart failure, and corneal blindness.	

Section / Heading	Paragraph No.	Line No(s)	Proposed Amendment / Comment	Rationale / Evidence (optional)
Overview of the global situation / a. Burden of diseases and socioeconomic value of transplantation	15	64-67	**Transplantation provides a substantial survival advantage for organ recipients compared with other treatment modalities. In patients with end-stage kidney disease, kidney transplantation demonstrates a significant survival advantage compared to dialysis.** Five-year adjusted survival probabilities have been reported at approximately 35% for haemodialysis and 41% for peritoneal dialysis, compared with about 73% for kidney transplant recipients.10	Since the paragraph covers considerations on survival for both kidney, liver, and heart – it would be better to begin with the shared key point ("Transplantation provides a substantial survival advantage to organ recipients, compared with other treatment modalities."). This allows to make subsequent sentences about kidney transplantation clearer and avoids unnecessary redundancy.
Overview of the Global burden	Paragraph 16	80-86	Refer to valvular and congenital heart disease and avoid attributing mortality reductions solely to donor skin.	
Overview of the Global burden	Paragraph 17	87-95	Acknowledge transplant-related mortality, graft-versus-host disease, and late complications.	
Access and Coverage of Transplantation	Paragraphs 22-24	118-130	Acknowledge that many patients are never wait-listed, use current data where available, and expand tissue data beyond cornea and skin.	
Transplant Integration within Models of care	Paragraphs 26-27	137-147	Define primary care roles beyond awareness, including multidisciplinary referral and long-term care coordination.	

Section / Heading	Paragraph No.	Line No(s)	Proposed Amendment / Comment	Rationale / Evidence (optional)
Overview of the global situation / c. Transplantation integration within models of care	Add a new paragraph after the paragraph 27		After organ transplantation, patients continue to receive transplant-specific therapy as well as treatment for other medical conditions. Healthcare professionals in primary care and clinical specialties not directly related to the transplanted organ should be familiar with the general principles of post-transplant follow-up, including potential drug interactions and extra-transplant complications that are relevant to transplant recipients.	Education of healthcare professionals in primary care and clinical specialties not directly related to the transplanted organ is essential for improving long-term outcomes in transplant recipients.
Transplantation within models of care; Strategic Directions 1(d) and 2	27; 61; 33	144–147; 328–332; 182–186	Strengthen the commitment to lifelong post-transplant care: guaranteed uninterrupted access to immunosuppressive medicines; structured long-term graft surveillance; formal pediatric-to-adult transition pathways; and long-term psychosocial support for both recipients and donors.	The strategy is weighted towards achieving transplantation rather than sustaining it. Interruption of immunosuppression supply is a major avoidable cause of graft loss and return to dialysis, and poorly managed transition from pediatric to adult services is a well-documented point of graft failure.
Health System Determinants of Transplantation	Paragraphs 28-34	150-191	Strengthen governance, data, financing, and infrastructure sections by adding accountability, transparency, outcome metrics, financial protection, digital referral systems, logistics, cold-chain capacity, and laboratory quality assurance.	

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Strategic Direction 2 – Health system determinants of transplantation	31	168-173	Consider including competency-based education, certification and periodic re-certification of transplantation professionals, supported by internationally harmonized training standards.	Competency-based education, standardized training and periodic professional assessment contribute to improved quality and safety of transplantation services. Harmonized competency standards also facilitate multidisciplinary collaboration and support consistent implementation of best clinical practices.
Social Determinants and donation of Transplantation	Paragraphs 35-38	Lines 194-221	Expand social engagement and equity measures to include school education, donor registration campaigns, digital outreach, rural and urban access, Indigenous populations, migrants, refugees, disability, conflict, and socioeconomic deprivation. Engage faith leaders in discussions on religion and transplantation. Address commercial determinants and the role of migration, conflict, and statelessness in exploitation risk.	
Social determinants of donation and transplantation	36–37	202–212	Add an expectation that Member States disaggregate donation, referral, waiting-list and transplantation data by ethnicity, sex and socioeconomic status, and report publicly on the inequities identified.	The draft acknowledges ethnic and gender disparities descriptively but places no obligation on Member States to measure them. Disaggregated data is the precondition for targeted action and for assessing whether the strategy's equity objectives are being met.

Section / Heading	Paragraph No.	Line No(s)	Proposed Amendment / Comment	Rationale / Evidence (optional)
International Collaboration	Paragraphs 39-40	223-238	Address regulated bilateral cooperation, regional sharing systems, and safeguards against unethical commercial transplant tourism.	
Innovation and Future Developments	Paragraphs 41-42	Lines 241-253	Balance emerging technologies with practical innovations for LMICs, including affordable preservation, telemedicine, digital donor referral, low-cost HLA typing, and regional tissue banking.	
Vision	Paragraph 43	Lines 256-260	Emphasize equitable access, improved survival, quality of life, and elimination of unethical practices.	
Strategic Directions 1	Paragraphs 45-63	Lines 270-340	Require national planning to assess disease burden, workforce, infrastructure, financing, waiting lists, donor potential, commercialization risks, allocation transparency, living donor protection, and quality assurance metrics.	

Section / Heading	Paragraph No.	Line No(s)	Proposed Amendment / Comment	Rationale / Evidence (optional)
Strategic directions	46	279	This progress should be monitored through the routine collection and reporting of core indicators, including donation rates (per million population), transplant rates disaggregated by organ type, and waitlist mortality, alongside equity indicators capturing disparities by gender, income and geographic region. Data should be derived from robust national information systems, including transplant registries, and contribute to global monitoring platforms such as the Global Observatory on Donation and Transplantation. Standardized reporting at regular intervals should be established to support transparency, benchmarking and accountability.	Change from passive to active (indicators must be implemented and actively suggested by WHO)
National Planning	48	284	Where capacity is evolving, phased system development may be appropriate. Targeted investment can build transplant capacity by moving from fragmented, resource-limited services toward coordinated national systems, combining governance and regulation, infrastructure, training and workforce, and equitable financing and access. This should include the clear institutional separation of roles in brain death determination, organ procurement, and clinical transplantation, as a fundamental safeguard to ensure transparency, accountability, and the prevention of conflicts of interest.	Explicitly add independency of functions to ensure transparency.

Section / Heading	Paragraph No.	Line No(s)	Proposed Amendment / Comment	Rationale / Evidence (optional)
Strategic Direction 1(b) – Legislation and policies	51	297–299	Amend to extend cooperation beyond the national level. Suggested revision: "…including cooperation between designated health and law enforcement authorities, relevant ministries, border agencies and other stakeholders, and participation in international information-sharing and cooperation mechanisms."	Organ trafficking is inherently transnational, yet the provision as drafted confines cooperation to domestic entities.
Strategic Direction 1 - Transplantation governance	55	309-310	Consider including a recommendation for Member States to establish a national monitoring and evaluation framework with standardized performance indicators for organ donation and transplantation programs.	Regular monitoring of standardized indicators enables evidence-based decision-making, identifies system gaps and supports continuous quality improvement of transplantation services.
Strategic Direction 1(c) – Oversight	56–57	311–317	Add an explicit expectation that Member States establish mandatory reporting and surveillance of patients who receive transplants abroad, using a defined minimum dataset (country of transplantation, organ, donor type where known, and clinical outcome) reported to the competent national authority.	Without systematic case ascertainment, transplant tourism remains invisible to regulators and cannot be quantified or acted upon. The UK model – Human Tissue Authority oversight combined with professional expectations on clinicians to report patients returning after overseas transplantation – is an implementable example that could inform WHO guidance.
Financial equity	61	328	Financing policies should consider full coverage of costs of donation	Active language regarding full coverage of transplantation costs, including long term immunosuppression and monitoring.

Section / Heading	Paragraph No.	Line No(s)	Proposed Amendment / Comment	Rationale / Evidence (optional)
Strategic Direction 1(d) – Financing policies	62	333–336	Address the timing of reimbursement. Suggested addition: "Systems should minimise financial barriers to donation, including provision for advance payment or direct reimbursement of expenses where appropriate."	Reimbursement in arrears is a barrier to donation. Donors who cannot absorb upfront travel, accommodation and lost-income costs, or who must wait months for repayment, are disproportionately those on lower incomes. A reimbursement-only model therefore entrenches inequity in who is practically able to donate.
Strategic Direction 1(d) – Financing policies	62	333–336	Broaden donor protection beyond direct expenses to include employment protection during assessment and recovery, income protection, and safeguards against adverse consequences for life, health, travel and mortgage-related insurance.	Financial disadvantage arising from donation extends beyond reimbursable expenses. Employment insecurity and insurance penalties are recognized deterrents to living donation in the UK and elsewhere, and are not captured by the current wording.
Strategic Direction 2: Access to transplantation / a. Organisation and Infrastructure for transplantation	67	352-354	Transplantation and related services may be implemented progressively. Regional collaboration and referral networks may support countries with limited capacity while national programmes are strengthened. **All opportunities to reduce organ conservation time (i.e., the interval between organ procurement from the donor and transplantation into the recipient) should be considered. These include improvements in transport infrastructure, state-funded priority transport for donor organs, and state-funded support for the travel of potential organ recipients to the transplant center.**	Pre-transplant cold and warm ischemia times have a substantial impact on post-transplant outcomes. Therefore, all organizational and logistical measures to reduce organ preservation time (i.e., the interval between organ procurement from the donor and transplantation into the recipient) should be implemented.

Section / Heading	Paragraph No.	Line No(s)	Proposed Amendment / Comment	Rationale / Evidence (optional)
Strategic Direction 2: Access to transplantation / b. Professional capacity in transplantation	Add new paragraph after the paragraph 68		Specialized university and continuing medical education programs should be established to train healthcare professionals in primary care and clinical specialties not directly related to the transplanted organ. These programs should focus on the general principles of post-transplant follow-up, potential drug interactions, and extra-transplant complications relevant to transplant recipients.	Training healthcare professionals in primary care and clinical specialties not directly related to the transplanted organ is essential for improving overall long-term outcomes in transplant recipients.
Strategic Directions 2(b) and 3(b) – Professional capacity	68; 84	357–362; 418–419	Add a WHO-facilitated learning-network commitment. Suggested wording: “WHO should facilitate structured learning networks between countries with mature transplantation systems and those developing services, including mentorship programs, fellowships and transplant center partnerships.”	Workforce provisions are currently framed as national responsibilities at a high level. Country-to-country learning has in practice been the most effective mechanism for system development – the international diffusion of the Spanish donation coordination model being the clearest example – and established programs, including in the UK, are regularly approached for equivalent exchange without any structure to support it.
Strategic Directions 3 National Donation Programs	Paragraphs 69-89	Pages 365-434	Address variation in infrastructure, legal requirements, DCD adoption, long-term donor care, lifelong surveillance, financial and employment protection, and regional paired exchange programmes.	

Section / Heading	Paragraph No.	Line No(s)	Proposed Amendment / Comment	Rationale / Evidence (optional)
Strategic Direction 3 – National donation programmes	72	381-384	Consider expanding this provision by recommending that Member States establish donor coordinators as a formally recognized professional role with defined competencies, standardized training, certification and sustainable financing.	Countries with well-established transplantation systems have demonstrated that trained donor coordinators significantly increase donor identification, consent rates and overall transplantation activity. Formal recognition of this role contributes to the sustainability and effectiveness of national donation programs.
Strategic Direction 3(a) – Organisation and infrastructure for donation; Strategic Direction 5	76; 100–101	394–398; 487–495	Add provision for ethical cross-border living donation. Suggested wording: "WHO should explore guidance on ethical cross-border living donation pathways, including donor assessment, independent verification of voluntariness, follow-up arrangements, reimbursement and information sharing between jurisdictions."	Population mobility – migrant families, international students, workers living abroad and families dispersed across several countries – means donor and recipient are increasingly resident in different jurisdictions. There is currently no framework governing where assessment takes place, who holds safeguarding responsibility, or how long-term follow-up is delivered. Legitimate pathways would also make it easier to distinguish genuine related donation from brokered arrangements.
Strategic Direction 3(a) – Living donation	76	394–398	Remove the qualifier "where appropriate" from long-term follow-up of living donors and specify a minimum follow-up dataset (organ-specific function, blood pressure, cardiovascular risk and psychosocial outcome) at defined intervals.	Long-term follow-up is the principal evidence base both for donor safety and for the informed consent of future donors. A discretionary approach risks follow-up becoming the first element omitted where resources are constrained.

Section / Heading	Paragraph No.	Line No(s)	Proposed Amendment / Comment	Rationale / Evidence (optional)
Strategic Direction 3(a) – Organisation and infrastructure for donation	77-79	405–406	Replace the current sentence (79) with: "National programs should monitor organ utilization rates and develop strategies to reduce avoidable organ discard, including equitable deployment of emerging preservation and assessment technologies."	In many established programs the largest near-term gains lie in utilization rather than in additional consent. DCD optimization and improved retrieval has increased the safe use of marginal organs.
Strategic Direction 3(c) – Public awareness	85–87	422–430	Strengthen from encouragement to expectation. Suggested wording: "The strategy should place greater emphasis on culturally tailored approaches, co-designed with communities and faith groups, particularly in minority populations where access and donation rates may differ."	UK experience of implementing opt-out (deemed consent) legislation demonstrated that legislative change alone does not shift family consent rates; sustained, co-produced community and faith engagement proved to be the determining factor, particularly among minority ethnic communities with the greatest unmet need.
Strategic Direction 3(c) – Public awareness	86	425–428	Expand the list of practical approaches to include behavioral science–informed interventions, trusted-messenger and peer models, community co-production, and active identification and management of misinformation, including on social media platforms.	Communication is currently framed around media training and school curricula. This omits the substantial evidence base on behavioral approaches, and does not address online misinformation, which is now a fast-moving threat to public trust in donation systems.
Strategic Directions 5 International Access to transplantation	Paragraphs 98-104	Pages 480-503	Consider government financing, insurance systems, bilateral agreements, international partnerships, and safeguards against systematic organ use from resource-poor countries for recipients in the Global North.	

Section / Heading	Paragraph No.	Line No(s)	Proposed Amendment / Comment	Rationale / Evidence (optional)
Strategic Direction 5: International access to transplantation	Add new paragraph before the paragraph 98, rename section to "Strategic Direction 5: Regional and international access to transplantation"		**Limitations in access to transplantation services across different regions of the same country should be evaluated, and organizational and logistical improvements should be implemented to ensure equitable access to transplantation for all citizens, regardless of the distance between their place of residence and the transplant center.**	Currently, the section "Strategic Direction 5: International Access to Transplantation" focuses only on international access to transplantation for countries that lack transplantation programs. However, regional disparities in access to transplantation within the same country, resulting from long travel times from patient residence to the nearest transplant center, may substantially limit or even prohibit access to transplantation for a significant proportion of the population.
Strategic Area 6 Investing in technological advancements, research and innovation	Paragraphs 105-108	Lines 506-525	Strengthen LMIC research capacity and avoid overemphasizing technologies that remain inaccessible to most countries.	
Strategic Direction 6 – Technological advancement, research and innovation	105; 108	505–525	Add an equity safeguard: innovation policy should include mechanisms for technology transfer, pooled or joint procurement and tiered pricing, so that preservation, perfusion and assessment technologies are not confined to high-income countries.	The draft implicitly assumes that the benefits of innovation will diffuse. Perfusion and related technologies are capital-intensive and risk widening both between-country and within-country inequity in access to transplantation, creating a new disparity alongside those the strategy already identifies.

Section / Heading	Paragraph No.	Line No(s)	Proposed Amendment / Comment	Rationale / Evidence (optional)
Roles and responsibilities – Member States; communities and civil society	110 -116	533–566	Add: “National transplantation programs should include donor and recipient representatives within governance and policy development structures.”	Patient and donor involvement is currently framed as consultation, awareness-raising and advocacy rather than participation in governance. Formal representation within program governance is now standard practice in many UK transplantation structures and improves the legitimacy of policy decisions.
World Health Organization accountability	111	539 to 542	The WHO Secretariat will proactively develop and advance robust implementation guidance and practical tools, grounded firmly in existing evidence and global best practices, while ensuring deliberate flexibility for adaptation to national and regional contexts. In parallel, a comprehensive monitoring framework will be established to rigorously track progress, strengthen accountability, and actively support Member States in achieving and sustaining their targets.	Change from passive to active voice (monitoring “must” be developed and implemented). Enforce the need for dashboard implementation.
Roles and responsibilities – WHO; Vision	111; 43	539–542; 256–260	Replace the permissive formulation that a monitoring framework “may be developed” with a commitment that WHO will develop, within a defined period, a core indicator set with baseline values and measurable 2035 targets against which Member State progress is reported.	The Vision is time-bound to 2035 but contains no measurable targets, and the monitoring framework is discretionary. Without agreed indicators and baselines, progress against this strategy cannot be assessed and its accountability provisions remain largely declaratory.

Section / Heading	Paragraph No.	Line No(s)	Proposed Amendment / Comment	Rationale / Evidence (optional)
Roles and responsibilities – World Health Organization	112	543–546	Specify an operational WHO role: designation of reference or collaborating transplantation centres; development of global core training curricula and competency frameworks; coordination of fellowship and twinning arrangements; and hosting of communities of practice.	As drafted, the WHO role is facilitative and non-specific. These are concrete, comparatively low-cost mechanisms that WHO is uniquely placed to convene, and they would give the strategy practical traction in countries developing services.

General Comments

Overall, the draft WHO Global Strategy provides a comprehensive and well-structured framework for strengthening donation and transplantation systems. The proposed amendments are intended to further enhance implementation, governance and quality of transplantation services across Member States.

The draft is comprehensive and ethically grounded, but it would be stronger with clearer balance across transplantation domains, more globally representative evidence, and sharper implementation guidance.

- Balance and scope: Reduce nephrology-centric emphasis and more fully address liver, heart, lung, pancreas, intestinal, vascularized composite, and tissue transplantation.
- Global applicability: Use evidence beyond high-income settings and avoid relying predominantly on U.S. cost and outcome data.
- Implementation focus: Add measurable indicators for governance, financing, infrastructure, donor and recipient outcomes, equity, digital systems, and financial protection.
- Patient perspective: Include shared decision-making, patient-reported outcomes, survivorship, self-management, and long-term quality of life.
- Relevant innovation: Balance advanced biomedical technologies with practical, scalable health-system and implementation innovations for Member States.

This is high-income focused, but there are opportunities for learning across countries: UK Organ Utilisation Group Report: Honouring the gift of donation: utilising organs for transplant - summary report of the Organ Utilisation Group - GOV.UK