



# Bioethical Underpinnings of a Fair, Equitable, & Transparent Deceased Donor Organ Procurement, Allocation & Distribution System

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# Ethical principles for OT I

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- **Respect for persons**

- Especially for their *autonomous choices* (e.g., in deceased organ donation, acceptance of organ transplant)

- **Utility**

- Maximizing good consequences, such as increasing number of transplants, saving lives or life years, etc.
- Balancing benefits & harms & costs



# Ethical principles II

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- **Justice** [often explicated by fairness and increasingly by equity, e.g., health equity]
  - Focuses on the pattern of distribution of benefits and burdens
    - Who gets what under what conditions?
  - Formal criterion of justice: treat similar cases similarly, dissimilar ones dissimilarly
  - Material criteria of justice: identify relevant similarities & differences (e.g., urgency)

[On principles of allocation, see, e.g., OPTN White Paper, updated 2015]



# Ethical principles III

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- Broadly embedded in laws, regulations, & policies re organ transplantation
  - Relevant to OPTN/UNOS policy process
  - But need to be
    - Specified (e.g., for allocation)
    - Balanced (in case of conflicts)
- Meeting these principles required for fair, equitable OT system/processes (necessary, though not sufficient)



# Public & professional trust

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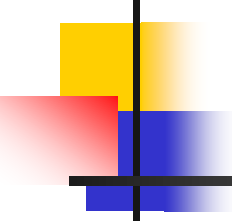
- SoT: calls for recommendations “to maximize public and professional trust” in entire organ transplant process
  - Task: boost trustworthiness by highlighting & employing ethical principles in system & processes
  - Trustworthy system/processes can elicit & sustain professional & public trust
    - whether building, rebuilding, or enhancing public & professional trust to make it as robust as possible



# Trust in connection b/t organ donation & allocation

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- Importance of fair, equitable organ allocation for public's decisions to donate organs
  - Studies: if organ allocation is deemed fair, equitable, & trustworthy, public more willing to donate organs (Boulware, et al., 2007; HRSA, 2013, etc.)
  - Trust in fair, equitable organ allocation: a precondition for increasing organ donation



# Ways to achieve fairer, more equitable system

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- Monitor & review claims & evidence of disparities in access, allocation, etc.
  - Disparities often indicative of inequities, which justice/equity require addressing
    - E.g., evidence of disparities & inequities over time regarding African Americans' access to organ transplants
    - Corrective measures in name of justice/equity



# Two major fairness/equity topics in Final Rule

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- Distinguish:
  - Access to donated organs (121.8)
  - Access to transplant services (121.4 (a)(3))
- The first receives close ethical & policy attention; the second less so & in piecemeal fashion.
  - For a fairer, more equitable system, the second also needs more systematic attention perhaps in another venue





# Final Rule (121.8): equitable allocation

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- 121.8: OTPN shall develop policies for “equitable allocation of cadaveric organs among potential recipients”
  - “sound medical judgment”
  - “the best use of donated organs”
  - avoid wastage & futile transplants, promote patient access & efficient management
  - Not use “geography” unless for above



# Final Rule (121.4): inequities re socioeconomic status

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- 121.4.(a)(3): OPTN responsible to develop policies that “reduce inequities resulting from socioeconomic status,” including
  - Ensuring registration fee not a barrier
  - Procedures for transplant hospitals to make reasonable efforts to obtain financial resources for those unable to pay
  - Recommendation for private & public payers to improve coverage for OT & follow up
  - “Reform of allocation policies based on assessment of their cumulative effect on socioeconomic inequities”



# Waiting list access: disparities

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- Disparities in health care, guidance, referral, financial resources, etc.
  - “Primary barrier” for poor people in access to transplantation is “gaining access to waiting list” [IOM, 1999]
  - Patient distrust of system also a factor
- Transplant center discretion
- “Many uninsured Americans give organs, but they rarely receive them.”  
[Herring, et al., (2008)]



# Donated organs as public resources

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- Task Force on Organ Transplantation: donated organs as scarce public, national resources
- Several implications:
  - Organ procurement & transplant teams: *trustees & stewards* of donated organs
  - Importance of fair, public participation in setting allocation criteria



# Fair, transparent, public deliberative process

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- Combines transparency & fairness
  - Transparency: open, public communication
  - Procedural fairness: engagement of all stakeholders
  - Deliberative process presupposes (at least thin) trust & can help engender & sustain more robust trust



# Fair, transparent, public deliberative process

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- SoT: policy change “in an open, transparent, fair, and equitable manner”
  - Technical expertise, modeling, simulation, etc. —indispensable
  - Professional & public participation—crucial
  - Transplant community—broadly conceived
  - Concerns re recent acrimonious conflicts, etc.



# References

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- Health Resources & Services Administration (HRSA), *2012 National Survey of Organ Donation Attitudes and Behaviors* (2013).
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