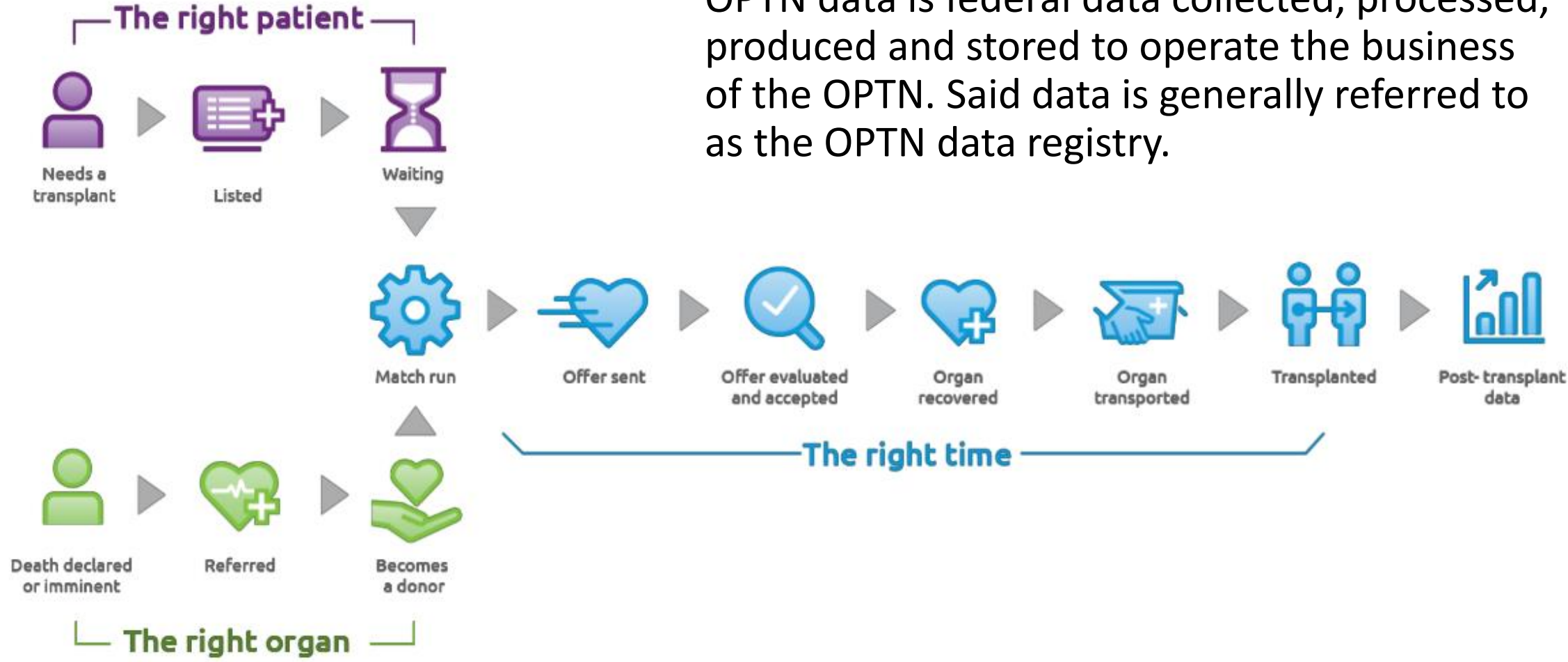# OPTN Data Advisory Committee Report to the Board

Jesse Schold, Chair

Data Advisory Committee (DAC)

Data Is Managed Across Transplant Lifecycle

OPTN data is federal data collected, processed, produced and stored to operate the business of the OPTN. Said data is generally referred to as the OPTN data registry.

The right patient

Needs a transplant → Listed → Waiting

Match run → Offer sent → Offer evaluated and accepted → Organ recovered → Organ transported → Transplanted → Post-transplant data

The right time

Death declared or imminent → Referred → Becomes a donor

The right organ

DAC's Annual Data Review Highlights

- Endorsed ten OPTN proposals to modify data collection, which will result in 96 changes

- Reviewed two-year monitoring reports for DAC sponsored projects – Refusal Codes and Modify Data Submission policy (Data Lock)

- Endorsed six updates to data definitions and form instructions

- Provided feedback on the Secretary of the U.S. Department of Health and Human Services (HHS) directive to expand OPTN data collection
  - Reviewed referral and evaluation information about potential transplant candidates (DAC Pre-Waitlist Workgroup)
  - Reviewed ventilated patient referrals for donation (MPSC OPO Performance Monitoring and Enhancement Workgroup)

Full report available on SharePoint.

Objective: Increased Alignment Between Board, HRSA, and DAC

- DAC seeks to increase alignment with the Board and HRSA on the following:

  - Need for identifying a data champion role on Board

  - Continue to leverage DAC's advisory skillset

  - Need roadmap to improve and incrementally invest in OPTN data registry

OPTN Recognizes Need To Increase Data Availability

- OPTN Strategic Plan identifies the objective to "Enhance OPTN data collection: To increase availability of actionable data"; OPTN Goal to enhance OPTN efficiency.

  - DAC supports partnership with Board and HRSA to make substantial investment and improvement in the OPTN data registry to achieve and expedite this objective
  - While modernizing OPTN Computer System is important, it is equally important to expand and improve understanding of the OPTN data registry

DAC Recognizes Need To Be More Nimble

- DAC recognizes challenges which hamper the OPTN data registry's relevance and value to the community. Examples:

  - Currency with clinical practice (e.g., machine perfusion data); recommend developing an OPTN fast-track process to identify new data collection (e.g., COVID response demonstrates OPTN's agility to adapt)

  - Timely implementation of OPTN data changes is impacted by annual Office of Management and Budget (OMB) review and approval; recommend adjusting frequency of OMB submissions to align with Board approval cycles

  - OPTN data changes may fall under OMB's substantive definition; recommend HRSA explore options for flexibility in making minor changes (e.g., removal of obsolete data collection)

DAC and Board Engagement

- Strengthen partnership between the Board, DAC and HRSA to be intentional about improving the OPTN registry

- Board and HRSA's Data and Analytics Team work with DAC to plan, prioritize and manage data initiatives

  - Define OPTN's data strategy

  - Strengthen data governance

  - Invest in interoperability

  - Adjust stakeholder engagement

OPTN Initiative: Define OPTN's Data Strategy

- Improve data collection and architecture as part of OPTN modernization initiative

- Accelerate the use of available government and public data

- Develop a transplant data standard with the federal Office of the National Coordinator (ONC) for Health Information Technology

OPTN Initiative: Strengthen Data Governance

- Establish best practices and set expectations in OPTN policy:

  - Identify ownership and stewardship for OPTN data

  - Document OPTN's intent for collecting data and improve definitions

  - Identify critical data and measure quality

  - Audit the most critical data

  - Lock editing of critical data (data lock 2.0)

  - Re-evaluate transplant follow-up data collection and adjust to reduce burden

- Provide public with a searchable OPTN data dictionary

OPTN Initiative: Invest in Interoperability

- Adopt clinical data standards to align with the healthcare community

- Collaborate with OPOs to standardize their data collection and processes

- Streamline data collection and exchange methods; align with Network Operations Oversight Committee (NOOC) on plans and investment

OPTN Initiative: Adjust Stakeholder Engagement

- Identify feasibility of engaging and involving government, healthcare members, academic institutions, and electronic medical record (EMR) and electronic donor record (EDR) vendors in the data management processes

- Examine issues and challenges involved in expanding the definition of OPTN data to include other supplemental public and government data for use by members and community

  - This initiative has the potential of reducing member data burden

- Supplemental and government data includes but is not limited to pharmacy data, claims data, and government special studies data

Does Board Support DAC's Recommendations?

- Identify data champion on the Board

  - Codify Board role in OPTN Bylaws, require data expertise

- Develop plan to support data efficiency objective in the OPTN Strategic Plan and improvements to OPTN data registry

Next Steps

- Identify Board data champion

- DAC Chairs to schedule planning session in FY25 Q2

Questions?