Which patients are best served with liver transplant?

Fontan procedure for congenital single ventricle heart disease

- Nearly 100% prevalence in adulthood
- Unknown prognosis:
  - May develop HCC
  - May require heart-liver transplant

Dataset barriers in FALD epidemiology

- Limited identification of FALD patients in existing datasets
- Lack of diagnostic code
- Cardiac datasets lack liver data
- "Age out" of pediatric datasets
- Incomplete patient trajectories
- Administrative, not clinical
- Limited crosslinking of deidentified data

Ideal data registry

- Post-Fontan identifiable by diagnostic code
- Multi-center population
- Granular clinical data
- Longitudinal from childhood to adulthood
- Linkage to transplant data source

Kim et al. *Transplantation*. 2021

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