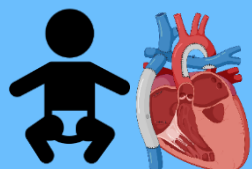


# Big data in transplantation practice- the devil is in the detail- Fontan Associated Liver Disease

## Which patients are best served with liver transplant?

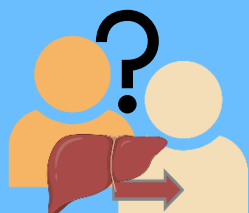


Fontan procedure for congenital single ventricle heart disease

FALD



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

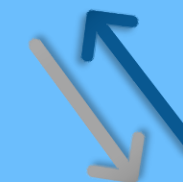


Administrative, not clinical

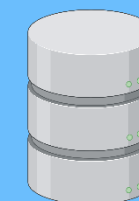


Limited crosslinking of deidentified data

## 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

@TransplantJrnl

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