Data Sharing Discussion

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What We Can Touch, Keep, and Share

• Who is “we”?
  – Researchers at dialysis provider organizations
  – Researchers at academic centers
What We Can Touch

- Eligibility criteria: age, start date of dialysis, “competency”
- Opt-out status
- Age (grouped if >90), sex, race/ethnicity
- Provider organization, site
- Comorbidities
- Dialysis session data: e.g., duration, bp (pre and post), weight (pre and post), vascular access type
- Specified laboratory measurements
- QOL responses
- Dates of hospitalizations
- Dates of death or transfer to another renal replacement modality
What We Can Keep

- **Eligibility criteria:** only for eligible participants
- **Opt-out status:** aggregated only
- Age (grouped if >90), sex, race/ethnicity
- Provider organization, **site (identity coded)**
- Comorbidities
- Dialysis session data: e.g., duration, bp (pre and post), weight (pre and post), vascular access type
- Specified laboratory measurements
- **QOL responses** (domain scores only)
- Dates of hospitalizations
- Dates of death or transfer to another renal replacement modality
What We Can Share

• Eligibility criteria: remove dates
• Opt-out status
• Age (grouped if >90), sex, race/ethnicity
• Provider organization, site
• Comorbidities
• Dialysis session data: remove dates
• Specified laboratory measurements
• QOL responses (domain scores only)
• Dates of hospitalizations
• Dates of death or transfer to another renal replacement modality
What We Will Share

• **Eligibility criteria:** remove dates
• **Opt-out status**
• Age (grouped if >90), sex, race/ethnicity
• **Provider organization, site**
• Comorbidities
• Dialysis session data: **remove dates**
• Specified laboratory measurements
• **QOL responses** (domain scores only)
• Dates of hospitalizations
• Dates of death or transfer to another renal replacement modality

TiME
What We Will Share

• Participant identity needs to be protected
  – Remove all dates
  – Categorize age as >90 years
  – Remove facility identifier

• Dialysis provider organization needs to be protected
  – Remove facility identifier
  – Aggregate facility characteristics
Data Sharing Obstacles

• Acceptability to dialysis provider organizations
• Within-study group sharing
  – Should provider organizations receive data from DCC?