

Data Sharing Discussion

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Steering Committee Meeting
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TIME

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

TIME

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

TIME

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

TIME

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?