

Dialysis Survey

Question to add to all Enrollment surveys for urea cycle defects, MSUD, OA only:

Has patient received dialysis prior to enrollment in the IBEM-IS? (pick list) Missing/unknown data, yes, no
(if yes, complete Dialysis survey)

Question to add to all Interval surveys for urea cycle defects, MSUD, OA only:

Has patient received dialysis since the last outpatient metabolic visit? (pick list) Missing/unknown data, yes, no
(if yes, complete Dialysis survey)

Dialysis Survey

Number of different episodes during which dialysis (any type) was used prior to enrollment in IBEM-IS (pick list)
Missing/unknown data,
0,1,2,3,4,5,6,7,8,9,10,>10

Number of different episodes during which dialysis (any type) was used since the last outpatient metabolic visit (pick list)
Missing/unknown data,
0,1,2,3,4,5,6,7,8,9,10,>10

Type(s) of dialysis received (1st dialysis treatment) (check boxes/check all that apply)
Missing/unknown data,
APD/CCPD, ECMO, CAPD, CVVH,
CVVD, CVVDHF, hemodialysis, peritoneal dialysis

Reason for dialysis (1st dialysis treatment) (pick list)
Missing/unknown data, hyperammonemia,
MSUD, organ failure, sepsis, other

Date of start of 1st dialysis treatment (enter 01/01/1901 if unknown) Date field

Duration (in days of 1st dialysis treatment) (enter 999999 if unknown) (integer) (units = days)

Type(s) of dialysis received (2nd dialysis treatment) (check boxes/check all that apply)
Missing/unknown data,

APD/CCPD, ECMO, CAPD, CVVH,
CVVD, CVVDHF, hemodialysis, peritoneal
dialysis

Reason for dialysis
(2nd dialysis treatment)

(pick list)
Missing/unknown data, N/A,
hyperammonemia,
MSUD, organ failure, sepsis, other

Date of start of 2nd dialysis treatment
(enter 01/01/1901 if unknown or N/A)

Date field

Duration (in days of 2nd dialysis treatment) (integer) (units = days)
(enter 999999 if unknown or N/A)

Type(s) of dialysis received
(3rd dialysis treatment)

(check boxes/check all that apply)
Missing/unknown data,
APD/CCPD, ECMO, CAPD, CVVH,
CVVD, CVVDHF, hemodialysis, peritoneal
dialysis

Reason for dialysis
(3rd dialysis treatment)

(pick list)
Missing/unknown data, N/A,
hyperammonemia,
MSUD, organ failure, sepsis, other

Date of start of 3rd dialysis treatment
(enter 01/01/1901 if unknown or N/A)

Date field

Duration (in days of 3rd dialysis treatment) (integer) (units = days)
(enter 999999 if unknown or N/A)

If more than 3 dialysis treatments have
been received, enter start date of each
treatment followed by duration in days for
each treatment, separating episodes with a
comma. Enter 99999 if N/A.

Free text

Example: 01/01/2009 (2 days), 07/12/09 (1 day)