

Data Structure:

One observation per patient containing both raw data values based on the oracle views and derived data values used in the analysis dataset, which will be described in the table below.

Variable Name	Description	Source Form	Derivation	Range (continuous)/Response Options (categorical)
id	De-Identified Subject ID.			1 to 432
Age_at_baseline	Age at baseline (years)	P005 Schedule web page Yreg Form 03A Demographics Ymha1	(yregbacdt – DOB)/(86400*365.25) Yregbacdt: Baseline visit date DOB not provided for patient anonymity	5.1-17.9 years (no missing for 219 subjects for analysis)
age_at_now	Current age (years)	Form 03A Demographics Ymha1	today's_date = '01MAY2012:00:00:00'dt (today's_date - DOB)/(86400*365.25) DOB not provided for patient anonymity	5.3-22.8 years (no missing for 219 subject for analysis)
age_at_kasai	Current age (days)	Form 03 Medical History ymhs1	(ymhs1c1dt - DOB)/86400 ymhs1c1dt: Kasai date DOB not provided for patient anonymity	7.0-125.0 days, or missing
age_at_consent	Age at consent (years)	Form 01 Eligibility yelg	age_at_consent=(yelg.ctxvisdt- DOB)/(86400*365.25) yelg.ctxvisdt: Consent date DOB not provided for patient anonymity	4.3 to 17.9 years (no missing for 219 subject for analysis)
ymhs1c2	Is the research subject listed for liver transplantation?	Form 03 Medical History ymhs1		2=Yes Otherwise missing
ymha1b2	Gender	Form 03A Demographics Ymha1		1=male 2=female

ms_Race	Race	Form 03A Demographics Ymha1	Derived from ymha1b4a - ymha1b4i	Asian Black White Other
cardiac_hx	Congenital heart disease	Form 03 Medical History ymhs1 Form 03C Anomalies yano	Initialize cardiac history as 0 (no cardiac history). But if ymhs1c5 = '2' (yes) or ymhs1c6 = '2' (yes) or if any of the cardiac anomalies (ymhs1c8a- ymhs1c8bb, yanoc08a- yanoc08hh) are non-missing, then cardiac history = 1.	1=has cardio history 0=no
GI_hx	Gastrointestinal malformations	Form 03 Medical History ymhs1 Form 03C Anomalies yano	Initialize GI history as 0 (no GI history). But is if ymhs1c10= . or yanoc10= . (has GI anomaly) and any GI anomalies (ymhs1c10a- ymhs1c10rs, yanoc10- yanoc10usp) are non-missing, then GI history=1	1= has GI history 0=no
yphec2cm	Height (cm)	Form 07 Physical Exam yphe	if missing(yphec2cm) and ^missing(yphec2in) then height = 2.54*yphec2in;	99 to 182 (cm), or missing
yphec1kg	Weight (kg)	Form 07 Physical Exam yphe	if missing(yphec1kg) and ^missing(yphec1lb) then weight = yphec1lb / 2.2;	15 to 109 (kg), or missing
yphec4	Right mid arm circumference (cm)	Form 07 Physical Exam yphe		7.3 to 140 (cm), or missing
yphec5	Right triceps skinfold thickness (mm)	Form 07 Physical Exam yphe		4 to 50.7 (mm), or missing
yphec6	Subscapular skinfold thickness (mm)	Form 07 Physical Exam yphe		3 to 32.2 (mm), or missing
HAZ	Height z-scores	Form 07 Physical Exam yphe	CDC growth chart	-4.44 to 3.37 or missing

WAZ	Weight z-scores	Form 07 Physical Exam yphe	CDC growth chart	-3.58 to 4.32, or missing
zyphec4	Right MAC z-score	Form 07 Physical Exam yphe	if abs(zyphec4) > 6 then zyphec4 = . ; if abs(zyphec5) > 6 then zyphec5 = . ; if abs(zyphec6) > 6 then zyphec6 = . ;	-5.35 to 3.23, or missing
zyphec5	Right triceps z-score	Form 07 Physical Exam yphe		-1.45 to 3.17, or missing
zyphec6	Right subscap z-score	Form 07 Physical Exam yphe		-0.85 to 2.77, or missing
yilbb1mg	Total bilirubin (mg)	Form 08 Initial Lab yilb		0.1 to 16, or missing
yilbb2mg	Indirect bilirubin (mg)	Form 08 Initial Lab yilb		0 to 3.9, or missing
yilbb3mg	Direct bilirubin (mg)	Form 08 Initial Lab yilb		0 to 3.2, or missing
yilbb4mg	Unconjugated bilirubin (mg)	Form 08 Initial Lab yilb		0.1 to 2.7, or missing
yilbb5mg	Conjugated bilirubin (mg)	Form 08 Initial Lab yilb		0 to 4.2 or missing
yilbb6ul	AST (ul)	Form 08 Initial Lab yilb		12 to 331, or missing
yilbb7ul	ALT (ul)	Form 08 Initial Lab yilb		5 to 487, or missing
yilbb9gl	Albumin (gl)	Form 08 Initial Lab yilb		2.6 to 5.5, or missing

yilbb11ul	GGTP (ul)	Form 08 Initial Lab yilb		1.6 to 1027, or missing
yilbb33pl	Platelets	Form 08 Initial Lab yilb		15 to 484, or missing
yilbb13in	INR	Form 08 Initial Lab yilb		0.85 to 1.53, or missing
ymhs1c13a	Polysplenia syndrome	Form 03 Medical History ymhs1		1= has Polysplenia syndrome Otherwise missing
tbili_flag	TB level normal (<= 1.5 mg/dl)	Form 08 Initial Lab yilb	If total bilirubin is missing, then use direct + indirect. If that is missing too, use conjugated + unconjugated Variable used for derivation: yilbb1mg, yilbb2mg, yilbb3mg, yilbb4mg, yilbb5mg If TB level<= 1.5 mg/dl then normal	1=normal 0=not normal Or missing
AST_flag	AST level normal (<=45 IU/L)	Form 08 Initial Lab yilb	If AST level<=45 IU/L then normal Variable used for derivation: yilbb6ul	1=normal 0=not normal Or missing
ALT_flag	ALT level normal (<=40 IU/L)	Form 08 Initial Lab yilb	If ALT level<=40 IU/L then normal Variable used for derivation: yilbb7ul	1=normal 0=not normal Or missing
albumin_flag	Serum Alb level normal (>=40 3.3 g/dl)	Form 08 Initial Lab yilb	If serum Alb level>=40 3.3 g/dl then normal Variable used for derivation: yilbb9gl	1=normal 0=not normal Or missing
GGTP_flag	GGT level normal (<=55 U/L)	Form 08 Initial Lab yilb	If GGT level<=55 U/L then normal Variable used for derivation: yilbb11ul	1=normal 0=not normal Or missing
INR_flag	INR normal (<=1.3)	Form 08 Initial Lab yilb	Variable used for derivation: yilbb13in	1=normal 0=not normal Or missing
platelet_flag	Plate count (>=150*10 ³ /mm ³)	Form 08 Initial Lab yilb	If Plate count >=150*10 ³ /mm ³ then normal Variable used for derivation: yilbb33pl	1=normal 0=not normal Or missing

haz_flag	Age-adjusted height z-score > -2	Form 07 Physical Exam yphe	HAZ > -2	1=Yes 0=No Or missing
waz_flag	Age-adjusted weight z-score > -2	Form 07 Physical Exam yphe	WAZ > -2	1=Yes 0=No Or missing
ascites_flag	ascites	Form 03 Medical History ymhs2 Form 07 Physical Exam yphe	If the overall med history flag is 'no' (ymhs2n = '1'), or the ascites flag is set to 'DID NOT OCCUR' (ymhs2adn = '88'), or ascites not present (yphed6 not equal '2'), then ascites_flag = 1 (GOOD). But if the age onset is not missing for ascites (ymhs2ayy, ymhs2amm, ymhs2adt), or if current status is persistent (ymhs2acs =2) or if current treatment is 'yes' (ymhs2act =2), or if ascites is present (yphed6='2'), then ascites_flag=0.	1=good 0=no or missing
hps_flag	Hepatoplumony syndrome	Form 03 Medical History ymhs2	If the overall med history flag is 'no' (ymhs2n=1), or the hps flag is set to 'DID NOT OCCUR' (ymhs2bdn=88), then hps_flag = 1 (GOOD). But if the age onset for hps is not missing (ymhs2byy, ymhs2bmm, ymhs2bdt), or if current status is persistent (ymhs2bcs=2) or if current treatment is 'yes' (ymhs2bct=2), or intervention is not missing (ymhs2bin) then hps_flag = 0	1=good 0=no or missing
evbleed_flag	Variceal bleeding	Form 03 Medical History ymhs2	If the overall med history flag is 'no' (ymhs2n = 1), or the number of lifetime events is 0 (ymhs2eln), then evbleed_flag = 1 (GOOD). But if the number of lifetime events for variceal bleeding is not zero (ymhs2eln in ('1','2','3')), or if the age of onset is NOT missing (ymhs2eyy, ymhs2emm, ymhs2edt), or if the number of episodes in the last 12 months is not missing and not 0 (ymhs2ede). Or if	1=good 0=no or missing

			interventions in the last 12 months (ymhs2ein) is not missing, then evbleed_flag=0.	
Cholangitis_flag	Cholangitis	Form 03 Medical History ymhs2	<p>If the overall med history flag is 'no' (ymhs2n = 1), or the number of lifetime events is 0 (ymhs2eln), then Cholangitis_flag= 1 (GOOD).</p> <p>But if the number of lifetime events for cholangitis is not zero (ymhs2dln in ('1','2','3')), or if the age of onset is NOT missing (ymhs2dyy, ymhs2dmm, ymhs2ddt), or if the number of episodes in the last 12 months is not missing and not 0 (ymhs2dde). Or if interventions in the last 12 months (ymhs2din) is not missing, THEN Cholangitis_flag =0.</p>	1=good 0=no or missing
fracture_flag	Fractures	Form 03 Medical History ymhs2	<p>If the overall med history flag is NO (ymhs2n = 1), or the number of lifetime events is 0 (ymhs2eln), then fracture_flag = 1 (GOOD).</p> <p>But if the number of lifetime events for fractures is not zero (ymhs2iln in ('1','2','3')), or if the age of onset is NOT missing (ymhs2iyy, ymhs2imm, ymhs2idt), or if the number of episodes in the last 12 months is not missing and not 0 (ymhs2ide). Or if interventions in the last 12 months (ymhs2iin) is not missing, then fracture_flag =0.</p>	1=good 0=no or missing
fracture_flag_12	Fractures within the past 12 months	Form 03 Medical History ymhs2	<p>If the number of episodes for fractures in the last 12 months is not missing and not 0 (ymhs2ide). Or if interventions in the last 12 months (ymhs2iin) is not missing, then fracture_flag_12 =0.</p> <p>If the number of episodes in the last 12 months is not missing and equals 0 (ymhs2ide), or interventions in the last 12 months (ymhs2iin) is missing then fracture_flag_12 = 1;</p>	1=good 0=no or missing

cholangitis_flag_12	Cholangitis within the past 12 months	Form 03 Medical History ymhs2	If the number of episodes for cholangitis in the last 12 months is not missing and not 0 (ymhs2dde). Or if interventions in the last 12 months (ymhs2din) is not missing, then cholangitis_flag_12 =0. If the number of episodes in the last 12 months is not missing and equals 0 (ymhs2de), or interventions in the last 12 months (ymhs2din) is missing then cholangitis_flag_12 = 1.	1=good 0=no or missing
nspleensize	Spleen size (cm)	Form 07 Physical Exam yphe	If spleen location is not applicable (yphe5a = '4') then nspleensize = 0. If spleen size is not applicable (yphe5b = 'NP') then nspleensize = 0. If spleen size (yphe5b = '1-2') then nspleensize = 1.5	0 to 20.5 (cm), or missing
YMHS2DDE	Past 12 month Cholangitis Events	Form 03 Medical History ymhs2		0 to 11, or missing
ymhs1e1h	Receive prophylactic antibiotics for cholangitis	Form 03 Medical History Ymhs1		1=yes Otherwise missing
ymhs1e1b	Receive Vitamin D	Form 03 Medical History Ymhs1		1=yes Otherwise missing
vitamin	Receive any vitamin supplementation	Form 03 Medical History Ymhs1	If vitamin A (Ymhs1e1a=1) or Vitamin D (Ymhs1e1b=1) or Vitamin E (Ymhs1e1c=1) or Vitamin K (Ymhs1e1d=1) or ADEK (Ymhs1e1e=1) or Other multivitamin (Ymhs1e1f=1) is taken then vitamin=1	1=yes Otherwise missing
ymhs1e1g	Receive ursodeoxycholic acid	Form 03 Medical History Ymhs1		1=yes Otherwise missing

diuretics	Receive diuretics	Form 03 Medical History Ymhs1	if Furosemide (ymhs1e1m=1) or Spironolactone (ymhs1e1n=1) is taken then diuretics=1	1=yes Otherwise missing
ymhs1e1l	Receive non-selective beta blockers	Form 03 Medical History Ymhs1		1=yes Otherwise missing
yanoc10a	Gastrointestinal malformations: Abdominal heterotaxia	Form 03C Anomalies		1=yes Otherwise missing
yanoc10b	Gastrointestinal malformations: Abnormal pancreatic structure	Form 03C Anomalies		1=yes Otherwise missing
yanoc10c	Gastrointestinal malformations: Absent hepatic artery	Form 03C Anomalies		1=yes Otherwise missing
yanoc10d	Gastrointestinal malformations: Absent portal vein	Form 03C Anomalies		1=yes Otherwise missing
yanoc10e	Gastrointestinal malformations: Annular pancreas	Form 03C Anomalies		1=yes Otherwise missing
yanoc10f	Gastrointestinal malformations: Anomalous hepatic artery	Form 03C Anomalies		1=yes Otherwise missing
yanoc10g	Gastrointestinal malformations: Anomalous portal vein	Form 03C Anomalies		1=yes Otherwise missing
yanoc10h	Gastrointestinal malformations:	Form 03C Anomalies		1=yes Otherwise missing

	Duodenal/Jejunal atresia			
yanoc10i	Gastrointestinal malformations: Esophageal atresia	Form 03C Anomalies		1=yes Otherwise missing
yanoc10j	Gastrointestinal malformations: Gastroschisis	Form 03C Anomalies		1=yes Otherwise missing
yanoc10k	Gastrointestinal malformations: Imperforated anus	Form 03C Anomalies		1=yes Otherwise missing
yanoc10l	Gastrointestinal malformations: Intestinal malrotation	Form 03C Anomalies		1=yes Otherwise missing
yanoc10m	Gastrointestinal malformations: Micrognathia/Agnathia	Form 03C Anomalies		1=yes Otherwise missing
yanoc10n	Gastrointestinal malformations: Midline liver	Form 03C Anomalies		1=yes Otherwise missing
yanoc10o	Gastrointestinal malformations: Omphalocele	Form 03C Anomalies		1=yes Otherwise missing
yanoc10p	Gastrointestinal malformations: Pancreatic cyst	Form 03C Anomalies		1=yes Otherwise missing
yanoc10q	Gastrointestinal malformations: Preduodenal portal vein	Form 03C Anomalies		1=yes Otherwise missing
yanoc10r	Gastrointestinal malformations: Right-sided stomach	Form 03C Anomalies		1=yes Otherwise missing
yanoc10s	Gastrointestinal malformations:	Form 03C Anomalies		1=yes Otherwise missing

	Tracheoesophageal Fistula (TEF)			
yanoc10t	Gastrointestinal malformations: Transverse (left-sided) liver	Form 03C Anomalies		1=yes Otherwise missing
yanoc10u	Gastrointestinal malformations: Other	Form 03C Anomalies		1=yes Otherwise missing
YMHS2IIS	Bone Fracture Site	Form 03B Medical History		Text
PedsQL	PedsQL Total Score >= 69.7 (normal)	PedsQl Pediatric Quality of Life forms Yql2p Yql5c Yql5p Yql8c Yql8p Yql13c Yql13p Yql13p Yql19	Steps for derivation: 1. Reverse PedsQL scores: e.g. reversed yql2p1=-25* yql2p1+ 100; (yql2pl in [0=never, 1=almost never, 2=sometimes, 3=often, 4=almost always]) 2. Sum up all reversed PedsQL scores (total #23) in one form. 3. If less than 13 scores are missing, then mean_score=sum/#not missing scores 4. For each year's response of each subject: if mean_score for Children's form exists then mean_score=children's mean score; otherwise mean_score=parent's mean score. 5. Only include records that age at taking PedsQL between 5 to 18 years old, and days from enrolled > 183 days. 6. Take the earliest record of each subjects if multiple years of record for one subject exists. 7. If mean_score >=69.7 then PedsQl=1; If mean_score <69.7 then PedsQl=0;	1=yes 0=no or missing

choly_prophy_flag	Absence of Need for Cholangitis Prophylaxis	Form 03 Medical History Ymhs1	If not missing prophylactic antibiotics for cholangitis (ymhs1e1h) then choly_prophy_flag = 0 ; Else choly_prophy_flag=1 (good)	1=yes 0=no No missing for 219 analysis subject
all_labs	Total # Subjects with ALL above Lab Indices Normal	Form 08 Initial Lab yilb	If all flags of labs (TB, AST, ALT, GGT, INR, Serum Alb, and Platelet) are Yes then all_labs=1; If any lab flag is No then all_labs=0; else missing	1=Yes 0=No Or missing
all_complications	Absence of Known Complications of Chronic Liver Disease	Form 03 Medical History ymhs2 Form 07 Physical Exam yphe	If all flags of complications (Ascites, Hepatpulmonary syndrome, Variceal bleeding, Fractures, adjusted weight z-score, adjusted height z-score) are 1, then all_complications=1; if any complication flag is 0, then all_complications=0; else missing	1=Yes 0=No Or missing
ideal_survivor	>5-year native liver survivor with ideal outcomes		Qualified ideal survivor should have all 4 criteria: 1. Normal liver biochemical tests (all_labs=1) 2. Absence of complications of chronic liver disease (all_complications=1) 3. Not receiving medications for liver disease (choly_prophy_flag=1) and 4. Normal HRQOL (PedsQL=1)	1=Yes 0=No Or missing
chocolate	King's College ideal survivor		If TB level < 1.2 (TB level: If total bilirubin is missing, then use direct + indirect. If that is missing too, use conjugated + unconjugated Variable used for derivation: yilbb1mg, yilbb2mg, yilbb3mg, yilbb4mg, yilbb5mg) and AST (yilbb6ul) less than 50 ul and Albumin (yilbb9gl) more than 3.5gl and GGTP (yilbb11ul) less than 55 ul and INR (yilbb13in) < 1.2 and Platelets (yilbb33pl) greater than 150 then chocolate=1	1=Yes 0=No Or missing

