

Visit Planner

Date of Visit: ____ / ____ / ____

Provider:	Patient: Printa Planner	Gender: Male	Phone:
Visit Provider:	MRN:	DOB: 10/13/2011 (0)	
Conditions: Tyrosinemia Interval	Preferred Language:		
Comorbidities:	First Measure Date:		
Other Allergies:			
Drug Allergies:			
Medications:			

Demographics	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date
Patient has attended an outpatient metabolic visit during the past 12 months?	Yes, No			Yes	356	
Was patient re consented for at age of majority or emancipation	Yes, N/A				Per Visit	
Is patient followed by >1 metabolic center?	Missing/unknown data, yes, no				Per Visit	
If patient is followed by >1 metabolic center note which Metabolic Centers in which States (enter N/A if not applicable)					Per Visit	
If patient is followed by >1 metabolic center, did patient grant permission to share data via IBEM-IS between treating metabolic centers?	Missing/unknown data, N/A, Yes, No				Per Visit	
If deceased, date of death (if N/A enter 01/01/1901)					Per Visit	
Metabolic follow up status	Active, Inactive - Deceased, Inactive - Lost to follow up, Inactive - Moved to another State participating in IBEM-IS, Inactive - Moved to another State not participating in IBEM-IS, Inactive -Refused follow up, Inactive - Treatment deemed not necessary				Per Visit	
Primary Care Provider Name (enter "unknown" if missing information, enter "none" if no primary care provider)					Per Visit	
Primary care status	missing/unknown data, on schedule for preventive care, seen for preventive care but not up to date, does not go to primary care provider				Per Visit	
Immunization status	missing/unknown data, up to date, no immunizations to date, immunization lag due to staging, immunization lag due to other reason (s)				Per Visit	
Socioeconomic Status	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date
Current insurance status	Missing/unknown data, commercial/private insurance, military insurance, none (self-pay), State program (newborn screening funds/special needs program/MCH block grant), State/Federal insurance (Medicaid/Medicare), Other				Per Visit	
Measurements	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date
Weight at this visit (enter 99999 if not measured)	(kg)				Per Visit	
Height at this visit (enter 99999 if not measured)	(cm)				Per Visit	
Head circumference (OFC) at this visit (enter 99999 if not measured)	(cm)				Per Visit	
Past Health History	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date
Date of last outpatient metabolic visit (if unknown enter 01/01/1901)					Per Visit	
Is there evidence of corneal opacity/crystals on ophthalmology exam done since last outpatient visit?	Missing/unknown data, N/A - ophthalmology not done since last outpatient visit, yes, no				Per Visit	
Has patient had general anesthesia since the last outpatient metabolic visit?	Missing/unknown data, yes, no				Per Visit	
Has patient had surgical procedure(s) since the last outpatient metabolic visit?	Missing/unknown data, yes, no				Per Visit	

Visit Planner

Date of Visit: ____ / ____ / ____

Provider:	Patient: Printa Planner	Gender: Male	Phone:			
Visit Provider:	MRN:	DOB: 10/13/2011 (0)				
Past Health History	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date
What type of surgical procedure(s) were done since the last outpatient metabolic visit? If not applicable enter N/A					Per Visit	
Complications associated with surgical procedure(s) done since the last outpatient metabolic visit? If not applicable enter N/A					Per Visit	
List specific comorbidities (enter N/A if not applicable, enter unknown if missing information)					Per Visit	
Emergency Management	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date
Patient/primary caregiver knows how to reach the 24 hour on-call contact information for a metabolic provider	Missing/unknown data, yes, no				Per Visit	
Patient/primary caregiver currently has a written emergency letter for this disorder?	Missing/unknown data, yes, no				888	
Patient/primary caregiver currently has a sick day plan specific to this disorder?	Missing/unknown data, yes, no				Per Visit	
Patient was enrolled in a web-based emergency alert program?	Missing/unknown data, yes - MEMSCIS, yes - other web-based program, no				Per Visit	
Number of ER visits since last metabolic visit	Missing/unknown data, 0,1,2,3,4,5,6,7,8,9,10, >10				Per Visit	
Number of ER visits METABOLIC RELATED since last outpatient metabolic visit	Missing/unknown data, 0,1,2,3,4,5,6,7,8,9,10, >10				Per Visit	
Total number of ER visits with NO metabolic decompensation since last outpatient metabolic visit	Missing/unknown data, 0,1,2,3,4,5,6,7,8,9,10, >10				Per Visit	
Number of hospital admissions (total) since last metabolic visit	Missing/unknown data, 0,1,2,3,4,5,6,7,8,9,10, >10				Per Visit	
Total number of hospital admissions with NO metabolic decompensation since last outpatient metabolic visit	Missing/unknown data, 0,1,2,3,4,5,6,7,8,9,10, >10				Per Visit	
Total number of hospital (inpatient) days METABOLIC RELATED since last outpatient metabolic visit	Missing/unknown data, 0,1,2,3,4,5,6,7,8,9,10,11-20,21-30,31-40, 41-50, 51-60,>60				Per Visit	
Care Coordination	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date
Other health services received currently	Missing/unknown data, None, Audiology, Behavioral/developmental Pediatrics, Cardiology, Dermatology, Endocrinology, Hematology/oncology, Home health care, Nephrology, Neurology, Neuropsychology, Occupational therapy, Ophthalmology, Orthopedics, Otolaryngology, Physical therapy, Psychiatry, Psychology, Public health nursing, Pulmonology, Respiratory therapy, Speech-language therapy, Transplant evaluation - kidney, Transplant evaluation-heart, Transplant evaluation - liver, Transplant received - kidney(complete Transplant survey now if not previously done), Transplant received - heart(complete Transplant survey now if not previously done), Transplant received-liver(complete Transplant survey now if not previously done), Other				Per Visit	
Community resources received currently	Missing/unknown data, none, daycare, family support group related to this IBEM, family support - other, Medical Home, nutritional services (WIC/MAC), personal care attendant (PCA), preschool, Head Start, respite care, social services - county, social services - medical, social services - developmental disability, waived services (CAC/CADI waiver /other waivers), other				Per Visit	
Providers seen at this metabolic visit	Dietitian, genetic counselor, neuropsychologist, nurse, nurse practitioner, physician, physician assistant, psychologist, social worker, other (go to next question and				Per Visit	

Visit Planner

Date of Visit: ____ / ____ / ____

Provider:	Patient: Printa Planner	Gender: Male	Phone:			
Visit Provider:	MRN:	DOB: 10/13/2011 (0)				
Care Coordination	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date
Other providers seen at this metabolic visit(enter N/A if not applicable)	explain)				Per Visit	
Developmental Assessment	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date
Developmental screening occurred at this visit?	Missing/unknown data, yes, no				Per Visit	
Developmental screening tool used at this visit (if screening was done)	Missing/unknown data, N/A - no developmental screening occurred at this visit, Ages and Stages Questionnaire, Ages and Stages - Social/Emotional Questionnaire, Denver (DDST-II), PEDS Questionnaire, provider history, other standardized screening tool				Per Visit	
Developmental milestones achieved at this time?	Missing/unknown data, N/A - no developmental screening occurred at this visit, yes, no				Per Visit	
If developmental milestone(s) not achieved, which one(s) were not achieved?	Missing/unknown data, N/A - developmental screening occurred at this visit and all developmental milestones were achieved, N/A - no developmental screening occurred at this visit, Cognitive, Fine motor, Gross motor, Social-emotional, Speech-language				Per Visit	
If developmental milestones were not achieved, was patient referred for further developmental evaluation?	Missing/unknown data, N/A - all milestones achieved, N/A - no developmental screening occurred at this visit, yes, no				Per Visit	
Was neuropsychological evaluation done since last outpatient metabolic visit? (If yes, complete Neuropsych Survey)	Missing/unknown data, Yes, No				Per Visit	
Overall neuropsychological testing impression (from most recent neuropsych evaluation)	Missing/unknown data, N/A - no neuropsych evaluation has been done on this patient, above average, average, below average				Per Visit	
Are behavioral concerns suspected at this time?	Missing/unknown data, Yes (go to next question and explain), No				Per Visit	
If behavioral concerns are suspected at this time, explain (enter N/A if no behavioral concerns suspected)					Per Visit	
If behavioral concerns are suspected at this time, was patient referred for further evaluation?	Missing/unknown data, N/A - no behavioral concerns suspected, Yes - to behavioral pediatrics, Yes - to neuropsychologist, Yes - to psychiatrist, Yes - to psychologist, Yes - to therapist/counselor, Yes - to other, No				Per Visit	
Education	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date
Was patient referred for Special Education evaluation at this time?	Missing/unknown data, yes, no				Per Visit	
Are Special Educational services received by this patient currently?	Missing/unknown data, yes - IEP/IFSP, yes - 504 plan, yes - other, no				Per Visit	
Reason Special Educational services are received currently?	Missing/unknown data, N/A (no Special Ed services are currently received), cognitive disability, developmental delay, fine motor disability, gross motor disability, learning disability, social-emotional disability, speech-language disability, other health impaired (OHI), other				Per Visit	
If Special Educational services were received prior to enrollment: age (in years) child qualified for services?	Missing/unknown data, N/A - no Special Ed services were received, N/A - patient is >21 years old, <1, >1-2, >2-3, >3-4, >4-5, 6-10, 11-17, 18+				Per Visit	
Laboratory Studies	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date
Molecular testing: Common or targeted mutation panel done at this visit(enter specific mutation(s) on Intake Survey)?	Missing/unknown data, no, yes - abnormal: compound heterozygote, yes - abnormal: homozygote, yes - abnormal: simple heterozygote, yes - alteration(s) of unknown significance detected, yes but no mutations were detected				Per Visit	
Molecular testing: Full sequencing done at this visit(enter specific mutation(s) on Intake Survey)?	Missing/unknown data, no, yes - abnormal: compound heterozygote, yes - Presumed compound heterozygote - 2nd mutation not				Per Visit	

Visit Planner

Date of Visit: ____ / ____ / ____

Provider:		Patient: Printa Planner		Gender: Male		Phone:	
Visit Provider:		MRN:		DOB: 10/13/2011 (0)			
Laboratory Studies	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date	
	identified, yes - abnormal: homozygote, yes - abnormal: simple heterozygote, yes - alteration (s) of unknown significance detected, yes but no mutations were detected						
Lab tests chemistry collected at this visit	Missing/unknown data, none, ABG-WNL, ABG-Abn, Anion Gap-WNL, Ammonia - WNL, Ammonia - Abn, Anion Gap-Abn, Ca+++WNL, Ca+++Abn, Cl-WNL, Cl-Abn, CO2-WNL, CO2-Abn, Gluc-WNL, Gluc-Abn, K+-WNL, K+-Abn, LDH - WNL, LDH - Abn, Magnesium - WNL, Magnesium - Abn, Na+-WNL, Na+-Abn, Phosphorus - WNL, Phosphorus - Abn, Total Cholesterol(fasting) - WNL, Total Cholesterol (fasting) - Abn, Total Cholesterol(random) - WNL, Total Cholesterol(random) - Abn, Uric Acid - WNL, Uric Acid - Abn, Other				Per Visit		
Lab tests hematology collected at this visit	Missing/unknown data, none, Fibrinogen - WNL, Fibrinogen - Abn, Hct-WNL, Hct-Abn, Hgb-WNL, Hgb-Abn, INR-PTT - WNL, INR-PTT - Abn, Peripheral blood smear - WNL, Peripheral blood smear - Abn, Plat-WNL, Plt-Abn, RBC-WNL, RBC-Abn, WBC-WNL, WBC-Abn, Other				Per Visit		
Lab tests liver function collected at this visit	Missing/unknown data, none, Albumin-WNL, Albumin-Abn, AlkPhos-WNL, AlkPhos-Abn, ALT-WNL, ALT-Abn, AST-WNL, AST-Abn, direct bili-WNL, direct bili-Abn, GGT - WNL, GGT - Abn, Globulin - WNL, Globulin - Abn, prealbumin-WNL, prealbumin-Abn, total bili-WNL, total bili-Abn, Total Protein - WNL, Total Protein - Abn, Other				Per Visit		
Lab tests renal function collected at this visit	Missing/unknown data, none, BUN-WNL, BUN-Abn, Cr-WNL, Cr-Abn, 24-hour creatinine clearance-WNL, 24-hour creatinine clearance-Abn, Nuclear Medicine GFR-WNL, Nuclear Medicine GFR-Abn, Other				Per Visit		
Lab tests miscellaneous collected at this visit	Missing/unknown data, none, BNP-WNL, BNP-Abn, CK-WNL, CK-Abn, CRP-WNL, CRP-Abn, ESR-WNL, ESR-Abn, ferritin-WNL, ferritin-Abn, transferrin-WNL, transferrin-Abn, TSH-WNL, TSH-Abn, T4 (free)-WNL, T4 (free)-Abn, T4(total)-WNL, T4(total)-Abn, UA-WNL, UA-Abn, Zinc-WNL, Zinc-Abn, Other (go to next question and explain)				Per Visit		
Lab tests other general (indicate type and if WNL or Abn) collected at this visit, enter N/A if not applicable					Per Visit		
Has patient required blood/blood product transfusion since last outpatient metabolic visit?	missing/unknown data, yes(related to poor treatment compliance), yes(unrelated to tyrosinemia treatment compliance), no				Per Visit		
Has patient undergone liver transplant since the last outpatient metabolic visit?	Missing/unknown data, yes (complete Transplant Survey now), no				Per Visit		
Biochemical testing specific to this IBEM collected at this visit	Missing/unknown data, not done, alpha-fetoprotein - Abn high, alpha-fetoprotein -WNL, plasma tyrosine -Abn high, plasma tyrosine-WNL, plasma phenylalanine-Abn high, plasma phenylalanine-WNL, plasma methionine-Abn high, plasma methionine-WNL, filter paper succinylacetone -detected, filter paper succinylacetone-not detected, urine succinylacetone-detected, urine succinylacetone- not detected, urine organic acids-Abn, urine organic acids-WNL, Total 25-hydroxyvitamin D -WNL, Total 25-hydroxyvitamin D -Abn low, other (go to next question and explain)				Per Visit		
Other biochemical testing specific to this IBEM (indicate type and if WNL or Abn) collected at this visit, enter N/A if not applicable					Per Visit		
Imaging Studies	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date	

Visit Planner

Date of Visit: ____ / ____ / ____

Provider:	Patient: Printa Planner	Gender: Male	Phone:			
Visit Provider:	MRN:	DOB: 10/13/2011 (0)				
	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date
Abdominal imaging done since last outpatient metabolic visit?	Missing/unknown data, no, yes-abdominal CT-WNL, yes-abdominal CT-Abn, yes-abdominal MRI-WNL, yes-abdominal MRI-Abn, yes-abdominal ultrasound-WNL, yes-abdominal ultrasound-Abn, Yes-Abdominal x-ray-WNL, Yes-Abdominal x-ray-abn				Per Visit	
Is there evidence of hepatocellular carcinoma on imaging done since last outpatient visit?	Missing/unknown data, no, yes, N/A - imaging not done				Per Visit	
Cardiac imaging done since last outpatient metabolic visit?	Missing/unknown data, no, yes-chest x-ray-WNL, yes-chest x-ray-Abn, yes-echocardiogram-WNL, yes-echocardiogram-Abn, yes-EKG-WNL, yes-EKG-Abn, yes-stress test-WNL, yes-stress test-Abn				Per Visit	
Musculoskeletal imaging done since last outpatient metabolic visit?	Missing/unknown data, No, Yes-bone x-rays-WNL, Yes-bone x-rays-Abn, Yes-EMG-WNL, Yes-EMG-Abn				Per Visit	
Dexa scan since last outpatient metabolic visit (z-score >-2), specify site	Missing/unknown data, N/A, hip, heel, pelvis, spine, total body, wrist, other				Per Visit	
If abnormal dexa scan since last outpatient metabolic visit (z-score = -3 to -2), specify site	Missing/unknown data, N/A, hip, heel, pelvis, spine, total body, wrist, other				Per Visit	
If abnormal dexa scan since last outpatient metabolic visit (z-score = -4 to -3), specify site	Missing/unknown data, N/A, hip, heel, pelvis, spine, total body, wrist, other				Per Visit	
If abnormal dexa scan since last outpatient metabolic visit (z-score <= -4), specify site	Missing/unknown data, N/A, hip, heel, pelvis, spine, total body, wrist, other				Per Visit	
Neurological imaging done since last outpatient metabolic visit?	Missing/unknown data, no, yes-cranial ultrasound-WNL, yes-cranial ultrasound-Abn, yes-EEG-WNL, yes-EEG-Abn, yes-head CT-WNL, yes-head CT-Abn, yes-head MRI-WNL, yes-head MRI-Abn				Per Visit	
Renal/pelvic/genital imaging done since last outpatient metabolic visit?	Missing/unknown data, no, yes-genitogram-WNL, yes-genitogram-Abn, yes-nuclear medicine DMSA renogram-WNL, yes-nuclear medicine DMSA renogram-Abn, yes-pelvic ultrasound-WNL, yes-pelvic ultrasound-Abn, yes-renal ultrasound-WNL, yes-renal ultrasound-Abn, yes-testicular ultrasound-WNL, yes-testicular ultrasound-Abn, yes-VCUG-WNL, yes-VCUG-Abn				Per Visit	
Other imaging (indicate type of imaging and if WNL or Abn) done since last outpatient metabolic visit?, enter N/A if not applicable					Per Visit	
Pharmacotherapy	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date
Is oral nitisinone prescribed?	Missing/unknown data, yes, no				Per Visit	
If on nitisinone, dose prescribed (enter 99999 if N/A)	(mg/day)				Per Visit	
If on nitisinone, frequency prescribed?	Missing/unknown data, N/A - not prescribed, once/day, twice/day, three time/day, other				Per Visit	
Patient/primary caregiver reports nitisinone is taken as prescribed?	Missing/unknown data, N/A - not prescribed, yes - 4-7 days/week, yes - 1-3 days/week, no (0 days/week)				Per Visit	
If nitisinone is not taken as prescribed, reason given (enter N/A if not applicable)?					Per Visit	
Method of payment for nitisinone, if prescribed	Missing/unknown data, N/A - not prescribed, Commercial/Private insurance, Military insurance, None - can't afford to fill medication, Self-pay, State program(newborn screening funds/special needs program/MC block grant), State/Federal insurance (Medicaid/Medicare), Other				Per Visit	

Visit Planner

Date of Visit: ____ / ____ / ____

Provider:	Patient: Printa Planner	Gender: Male	Phone:			
Visit Provider:	MRN:	DOB: 10/13/2011 (0)				
PharmacoTherapy	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date
Other medications (see optional DocSite detailed medication survey also)	Missing/unknown data, none, Ammonul, analgesics, antacids, antianxiety, antibiotics, anticoagulants/thrombolytics, anticonvulsants, antidepressants, antiemetics, antifungals, antivirals, antihistamines, antihypertensives, antiinflammatories, antipsychotics, antipyretics, aromatase inhibitor, biophosphonates, bronchodilators, contraceptives - oral, contraceptives - injections, corticosteroids, diuretics, estrogen, GnRH analog, growth hormone, immunosuppressives, insulin, insulin sensitizers, iron, laxatives, manitol, progesterone, sleeping medications, testosterone, vitamins, other				Per Visit	
Nutrition	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date
What type(s) of milk/formula is patient taking?	Missing/unknown data, None, Baby formula (regular), Baby formula (soy), Breastmilk, Rice milk, Skim milk, 1% milk, 2% milk, Soy milk, Special metabolic formula, Toddler formula (regular), Toddler formula (soy), Whole milk, Other				Per Visit	
Is patient prescribed a protein restricted diet?	Missing/unknown data, yes, no				Per Visit	
If patient is prescribed a protein restricted diet, prescribed protein grams/day from foods - not including metabolic formula (enter 99999 if N/A)	(grams/day)				Per Visit	
If protein restricted diet (from foods, not including metabolic formula) is prescribed and followed 0 or 1-3 days/week, reason given (enter N/A if not applicable)					Per Visit	
Is patient prescribed low protein foods?	Missing/unknown data, yes, no				Per Visit	
Method of payment for low protein foods, if prescribed	Missing/unknown data, N/A - not prescribed, commercial/private insurance, military insurance, none - can't afford to fill medication prescription, self-pay, State program (newborn screening funds/special needs program/MCH block grant), State/Federal insurance (Medicaid/Medicare), Other				Per Visit	
If prescribed metabolic formula, amount of protein prescribed from metabolic formula per day (enter 99999 if N/A):	(grams/day)				Per Visit	
If on special metabolic formula, name(s) of formula(s), enter N/A if not applicable					Per Visit	
Patient/primary caregiver reports metabolic formula is taken as prescribed?	Missing/unknown data, N/A-not prescribed, yes - 4-7 days/week, yes - 1-3 days/week, no (0 days/week)				Per Visit	
If metabolic formula is prescribed and not taken as prescribed, reason given? (enter N/A if not applicable)					Per Visit	
Method of payment for metabolic formula, if prescribed	Missing/unknown data, N/A - not prescribed, commercial/private insurance, military insurance, none - can't afford to fill prescription, self-pay, State program (newborn screening funds/special needs program/MCH block grant), State/Federal insurance (Medicaid/Medicare), WIC, Other				Per Visit	
If on a tyrosine restricted diet, prescribed tyrosine in mg/day from foods (enter 99999 if N/A)	(mg/day)				Per Visit	
If on a phenylalanine restricted diet, prescribed phenylalanine in mg/day from foods (enter 99999 if N/A)	(mg/day)				Per Visit	
Patient uses feeding device (NG tube, G tube, GJ tube)?	Missing/unknown data, yes, no				Per Visit	
If other nutritional supplementation is taken (explain), enter N/A if not					Per Visit	

Visit Planner

Date of Visit: ____ / ____ / _____

Provider:	Patient: Printa Planner	Gender: Male	Phone:			
Visit Provider:	MRN:	DOB: 10/13/2011 (0)				
Nutrition	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date
applicable.						
Additional nutritional comments? (enter N/A if not applicable)					Per Visit	
Other	Today's Action	Last Value	Date Last	Pt. Goal	Int. Days	Due Date
Other Comments					Per Visit	

Last Visit Comment:

Visit Comment: