Netherlands Heart Tissue Bank

Data-dictionary V1.1 (under construction)

Medical History

Medical History- Cardiac

Variable name	Field label	Field type	Options	Field info	Dependency
Incl_type	The included subject is a:	dropdown	1 = Patient with (previous) heart failure/cardiomyopathy; 2 = Person without (previous) heart failure/cardiomyopathy		
Incl_diag_owncentre_d	Date of first diagnosis heart failure or cardiomyopathy:	date			The included subject is a: == 1
Incl_HF_first_pres	Setting of first presentation with heart failure or cardiomyopathy:	dropdown	1 = Hospitalization; 2 = Emergency department (SEH/EHH) without hospitalization; 3 = Cardiology outpatient; 9999 = Unknown		The included subject is a: == 1
Incl_HF_first_loc	Location first diagnosis heart failure/cardiomyopathy	dropdown	10 = 1e lijn (General practitioner); 20 = 2e lijn (General hospital); 30 = 3e lijn (Specialized hospital); 9999 = Unknown		The included subject is a: == 1
Incl_HF_type	What is/are the primary cause/causes of heart failure/cardiomyopathy	checkbox	10 = Ischemic cardiomyopathy; 20 = Hypertensive cardiomyopathy; 30 = Valvular cardiomyopathy; 40 = Metabolic cardiomyopathy; 50 = Arrhythmia / tachycardia; 60 = Hypertrophic cardiomyopathy; 70 = Idiopathic dilated cardiomyopathy; 80 = Infectious (a.o myocarditis); 90 = Restrictive cardiomyopathy; 100 = Peripartum cardiomyopathy; 110 = Genetic/Familial; 120 = Pericardial disease; 130 = Toxic cardiomyopathy by alcohol abuses; 131 = Toxic cardiomyopathy by chemotherapy; 132 = Toxic cardiomyopathy by radiation; 133 = Toxic cardiomyopathy by drugs		The included subject is a: == 1

Variable name	Field label	Field type	Options	Field info	Dependency
			abuses; 134 = Toxic cardiomyopathy by other causes; 5555 = Other reasons; 9999 = Unknown		
Incl_HF_type_other	What is/are the primary cause/causes of heart failure/cardiomyopathy	textarea			What is/are the primary cause/causes of heart failure/cardiomyopathy == 5555
MH_ischemia_det	Cardiac ischemia/coronary stenosis ever assessed?	radio	1 = Yes; 0 = No	by CT-angio, CT-heart, PET, CMR, MIBI, CAG.	
MH_CAD	Coronary artery disease (CAD) ever present?	radio	1 = significant CAD; 2 = non-significant CAD; 3 = no CAD	Noted in medical history. Select the most severe form of CAD that has ever been present in the subject. Significant CAD as noted in medical history, or >70% stenosis on CAG or proven otherwise. Wand onregelmatigheden = no CAD	Cardiac ischemia/coronary stenosis ever assessed? == 1
MH_CADvessel	CAD location	checkbox	1 = Left main; 2 = LAD; 3 = RCX; 4 = RCA; 6 = Graft; 5555 = Other; 9999 = Location unknown	Based on SYNTAX classification	Coronary artery disease (CAD) ever present? == 1
MH_CAD_d	Date of FIRST diagnosis significant CAD	date			Coronary artery disease (CAD) ever present? == 1
MH_ACS	Acute coronary syndrome	radio	1 = Yes; 0 = No	ACS entails STEMI, NSTEMI and unstable angina	

Variable name	Field label	Field type	Options	Field info	Dependency
MH_ACS_type	Acute coronary syndrome type	radio	1 = STEMI; 2 = NSTEMI; 3 = Unstable Angina Pectoris; 9999 = Unknown		Acute coronary syndrome == 1
MH_ACS_d	Date of first diagnosis ACS	date			Acute coronary syndrome == 1
MH_PCI	Percutaneous coronary intervention (PCI)	radio	1 = Yes; 0 = No		
MH_PCI_d	Date of first PCI	date			Percutaneous coronary intervention (PCI) == 1
MH_CABG	Coronary artery bypass graft (CABG)	radio	1 = Yes; 0 = No		
MH_CABG_d	Date of first CABG	date			Coronary artery bypass graft (CABG) == 1
MH_VDR	Cardiac valve replacement / repair	radio	1 = Yes; 0 = No		
MH_VDR_type	Valve replacement/repair type	checkbox	1 = AVR/TAVI; 2 = MVR/Mitraclip/MVP; 5555 = Other		Cardiac valve replacement / repair == 1
MH_VDR_type_other	Other replacement/repair type	textarea			Valve replacement/repair type == 5555
MH_VDR_d	Date of first valvular replacement	date			Cardiac valve replacement / repair == 1
MH_SVT_AF	Atrial fibrillation	radio	1 = Yes; 0 = No		
MH_SVT_AF_type	Atrial fibrillation type	radio	1 = paroxysmal AF; 2 = persistent AF; 3 = permanent AF; 4 = non-specified AF	Choose most severe form that is applicable.	Atrial fibrillation == 1
MH_AF_d	Date first diagnosis AF	date			Atrial fibrillation == 1

Variable name	Field label	Field type	Options	Field info	Dependency
	(regardless of AF type)				
MH_SVT_AFL	Atrial flutter	radio	1 = Yes; 0 = No		
MH_AFl_d	Date first diagnosis Atrial Flutter	date			Atrial flutter == 1
MH_SVT_oth	Atrial tachycardia (other than AF/Aflut)	radio	1 = Yes; 0 = No		
MH_SVT_other_type	Type of SVT	radio	1 = Inappropriate sinustachycardia (IST); 2 = Sinus nodal reentrant tachycardia (SNRT); 3 = Ectopic atrial tachycardia; 4 = Multifocal atrial tachycardia (MAT); 5 = Sinus tachycardia; 6 = Atrioventricular nodal reentrant tachycardia (AVNRT); 7 = Atrioventricular reentrant tachycardia (AVRT); 8 = Junctional ectopic tachycardia (JET); 9 = Nonparoxysmal junctional tachycardia (NPJT); 9999 = Unknown type		Atrial tachycardia (other than AF/Aflut) == 1
MH_AT_d	Date first diagnosis Atrial tachycardia (other than AF/Aflut)	date			Atrial tachycardia (other than AF/Aflut) == 1
MH_SVT_int_abl	SVT intervention: ablation/maze	radio	1 = Yes; 0 = No		Calculation SVT == 1
MH_SVT_int_abl_d	Date first ablation/maze	date			SVT intervention: ablation/maze == 1
MH_SVT_int_ecv	Cardioversion for SVT (ECV/Chemical)	radio	1 = Yes; 0 = No		Calculation SVT == 1
MH_ECV_d	Date first cardioversion	date			Cardioversion for SVT

Variable name	Field label	Field type	Options	Field info	Dependency
					(ECV/Chemical) == 1
MH_Amy	Was cardiac amyloidosis diagnosed?	radio	1 = Yes; 0 = No	As stated in "Diagnosis and treatment of cardiac amyloidosis: a position statement of the ESC Working Group on Myocardialand Pericardial diseases", European Heart Journal 21th of April 2021.	
MH_Amy_d	date first diagnosis amyloidosis	date			Was cardiac amyloidosis diagnosed? == 1
MH_Amy_type	What is the type of amyloidosis?	radio	1 = AL; 2 = ATTRwt; 3 = ATTRv; 4 = AA; 5 = AFib; 6 = AApoAI; 7 = AApoAAII; 8 = AApoAIV; 9 = AB2M; 10 = AGel; 5555 = Other; 9999 = Unknown	As stated in "Diagnosis and treatment of cardiac amyloidosis: a position statement of the ESC Working Group on Myocardialand Pericardial diseases", European Heart Journal 21th of April 2021.	Was cardiac amyloidosis diagnosed? == 1
MH_Amy_type_oth	Specify 'other' type of amyloidosis	string			What is the type of amyloidosis? == 5555
MH_car_remarks	Additional remarks	textarea			

Medical History- Non-Cardiac

Variable name	Field label	Field type	Options	Field info	Dependency
MH_TIA	Transient ischemic attack (TIA)	radio	1 = Yes; 0 = No	A brief episode of neurological dysfunction caused by loss of blood flow (ischemia) in the brain, spinal cord, or retina, without tissue death (infarction). This includes for example amaurosis fugax.	
MH_TIA_d	Date (first) TIA	date			Transient ischemic attack (TIA) == 1
MH_stroke	Stroke	radio	1 = Yes; 0 = No	Permanent neurological dysfunction due to focal ischemia of brain, spine or retina, caused by an acute infraction of neurological tissue due to trombosis, embolus, systemic hypoperfusion or bleeding.	
MH_stroke_d	Date (first) stroke	date			Stroke == 1
MH_PAD	Peripheral artery disease	radio	1 = Yes; 0 = No	Perhipheral artery disease is defined as one of the following: • Claudicatio intermittens • Carotis stenosis of > 50% • Limb amputation due to artery disease • Previous or expected surgical operation of the abdominal aorta, arteries of the limb or carotid artery.	
MH_PAD_d	Date first diagnosis peripheral artery disease	date			Peripheral artery disease == 1
MH_PHT	Pulmonary hypertension	radio	1 = Yes; 0 = No	Noted in medical history. Please ESC guidelines pulmonary hypertension 2015: http://eurheartj.oxfordjournals.org/lookup/doi/10.1093/eurheartj/ehv317. If noted in medical history but not according to guidelines, choose yes and use text box at the end of this form to write down the findings	
MH_PHT_d	First diagnosis of pulmonary	date			Pulmonary

Variable name	Field label	Field type	Options	Field info	Dependency
	hypertension				hypertension == 1
MH_PHT_group	Pulmonary hypertension classification	radio	1 = pulmonary arterial hypertension (group 1); 2 = PH due to left heart disease (group 2); 3 = PH due to pulmonary pathology and/or hypoxia (group 3); 4 = Chronic trombo-embolic PH (CTEPH) (group 4); 5 = Multifactorial/mixed PH (group 5); 9999 = Unknown type	Based on ESC guidelines pulmonary hypertension 2015: http://eurheartj.oxfordjournals.org/lookup/doi/10.1093/eurheartj/ehv317	Pulmonary hypertension == 1
MH_COPD	Chronic obstructive pulmonary disease (COPD)	radio	1 = Yes; 0 = No		
MH_COPD_t	COPD gold classification	radio	1 = COPD gold 1; 2 = COPD gold 2; 3 = COPD gold 3; 4 = COPD gold 4; 9999 = COPD stage unknown		Chronic obstructive pulmonary disease (COPD) == 1
MH_COPD_d	Date first diagnosis of COPD	date			Chronic obstructive pulmonary disease

Variable name	Field label	Field type	Options	Field info	Dependency
					(COPD) == 1
MH_Asthma	Asthma	radio	1 = Yes; 0 = No		
MH_Asthma_d	Date first diagnosis of Asthma	date			Asthma == 1
MH_PD_oth	Other pulmonary disease	radio	1 = Yes; 0 = No		
MH_PD_d	Date first diagnosis of other pulmonary disease	date			Other pulmonary disease == 1
MH_PE	Pulmonary embolus	radio	1 = Yes; 0 = No		
MH_PE_d	Date of first pulmonary embolus	date			Pulmonary embolus == 1
MH_sleepapnea	Sleep apnea / sleep breathing disorder	radio	1 = Yes; 0 = No		
MH_sleepapnea_type	Sleep apnea type	radio	1 = OSAS; 2 = CSAS; 3 = Both OSAS and CSAS; 9999 = Unknown		Sleep apnea / sleep breathing disorder == 1
MH_sleepapnea_d	Date first diagnosis of sleep apnea	date			Sleep apnea / sleep breathing disorder == 1
MH_sleepapnea_int	Sleep apnea intervention	checkbox	0 = none; 1 = CPAP; 2 = mandibular	Select applicable therapy. If patient is prescribed a therapy but has never used it after prescription/refused to use it,	Sleep apnea / sleep breathing

Variable name	Field label	Field type	Options	Field info	Dependency
			reposition device; 3 = sleep position therapy; 4 = surgery; 5 = weight reduction; 5555 = other; 9999 = unknown	please select none.	disorder == 1
MH_sleepapnea_int_other	Specify other sleep intervention device	string			Sleep apnea intervention == 5555
MH_DM	Diabetes Mellitus	radio	1 = Yes; 0 = No		
MH_DM_type	Diabetes Mellitus type	radio	1 = Type 1 DM; 2 = Type 2 DM; 5555 = other Type DM; 9999 = Unknown		Diabetes Mellitus == 1
MH_DM_rx	Diabetes treatment	radio	1 = No treatment; 2 = Diet; 3 = Oral medication; 4 = Insulin; 5555 = Other; 9999 = Treatment unknown	When multiple options are possible. Please select one treatment in the following order: insuline > oral medication > diet	Diabetes Mellitus == 1
MH_DM_d	Date first diagnosis diabetes mellitus	date			Diabetes Mellitus == 1
MH_KD	Kidney disease	radio	1 = Yes; 0 = No	based on medical history or GFR <60 during more than 3 months (at least 2 or more measurements)	
MH_KD_d	Date first diagnosis kidney	date			Kidney disease == 1

Variable name	Field label	Field type	Options	Field info	Dependency
	disease				
MH_KD_dial	Dialysis	radio	1 = Yes; 0 = No		Kidney disease == 1
MH_KD_dial_d	Date first dialysis	date			Dialysis == 1
MH_KD_ntx	Kidney transplantation	radio	1 = Yes; 0 = No		Kidney disease == 1
MH_KD_ntx_d	Date of kidney transplantation	date			Kidney transplantation == 1
MH_Thy	Thyreoid disease	radio	1 = Yes; 0 = No	Noted in medical history. Watch out for use of thyroid medication such as euthyrox. Subclinical hyper/hypothyreoidism should be noted as 'no'. HyperPARAthyreoidism is not a thyreoid disease.	
MH_Thy_type	Type of thyreoid disease	radio	1 = HYPERthyreoidism; 2 = HYPOthyreoidism; 5555 = other; 9999 = unknown	if multiple take first diagnosis	Thyreoid disease == 1
MH_Thy_type_other	type of thyreoid disease	textarea			Type of thyreoid disease == 5555
MH_Thy_d	Date first diagnosis thyreoid disease	date			Thyreoid disease == 1
MH_anaemia	Anaemia	radio	1 = Yes; 0 = No	Anaemia as a consequence of surgery is NOT considered anaemia.	
MH_anaemia_d	Date first diagnosis anaemia	date			Anaemia == 1

Variable name	Field label	Field type	Options	Field info	Dependency
MH_FeD	Iron deficiency	radio	1 = Yes; 0 = No	Iron deficiency as a consequence of surgery is NOT considered Iron deficiency.	
MH_FeD_d	Date first diagnosis iron deficiency	date			Iron deficiency == 1
MH_Can	Cancer (current or previous)	radio	1 = Yes; 0 = No	Any form of cancer except basal cell carcinoma.	
MH_Can_type	Type of cancer	checkbox	1 = Lung; 2 = Breast; 3 = Esophageal; 4 = Colo-rectal; 5 = Hematological; 6 = Prostate; 7 = Uterine/ovary; 8 = Melanoma; 9 = Urinary/Bladder; 10 = Thyroid; 11 = Kidney/Renal; 12 = Oropharynx; 5555 = Other	Only primary cancer, no metastasis.	Cancer (current or previous) == 1
MH_Can_type_other	type of cancer	textarea			Type of cancer == 5555
MH_Can_d	First diagnosis cancer	date			Cancer (current or previous) == 1
MH_Can_CHR	Underwent chest radiation	radio	1 = Yes; 0 = No		Cancer (current or previous) == 1
MH_Can_CHR_d	Date of start chest-radiation	date			Underwent chest radiation == 1
MH_Can_chemo	Received	radio	1 = Yes; 0 = No		Cancer (current or

Variable name	Field label	Field type	Options	Field info	Dependency
	chemotherapy				previous) == 1
MH_Can_Chemo_d	Chemotherapy date	date		Please use the first day the patient received chemotherapy.	Received chemotherapy == 1
MH_HT	Hypertension	radio	1 = Yes; 0 = No		
MH_HT_d	Date of first diagnosis hypertension	date			Hypertension == 1
MH_HC	Hypercholesterolemia	radio	1 = Yes; 0 = No		
MH_HC_d	Date of first diagnosis hypercholesterolemia	date			Hypercholesterolemia == 1
MH_SD_auto	Auto-immune/-inflammatory disease	radio	1 = Yes; 0 = No	(Rheumatoid) arthritis; Gout; Morbus Bechterew; Psoriasis; Crohn's disease; Celiac disease; Systemic lupus erythematodes (SLE); Sjogren's syndrome; Vasculitis; for a complete overview of auto-immune/-inflammatory diseases: https://pubmed.ncbi.nlm.nih.gov/28655210/	
MH_SD_auto_type	Type auto-immune/-inflammatory disease(s)	checkbox	1 = (rheumatoid) arthritis; 2 = Gout; 3 = Bechterew; 4 = Psoriasis; 5 = Crohn; 6 = Celiac disease; 7 = Lupus; 8 = Sjogren's syndrome; 9 = Vasculitis; 5555		Auto-immune/-inflammatory disease == 1

Variable name	Field label	Field type	Options	Field info	Dependency
			= Other		
MH_SD_auto_type_other	Other auto-immune disease(s)	textarea			Type auto-immune/-inflammatory disease(s) == 5555
MH_SD_auto_d	Date first diagnosis auto-immune/-inflammatory disease(s)	date			Auto-immune/-inflammatory disease == 1
Amy_trt_redflag_op	Cardiac and extracardiac amyloidosis red flags present	checkbox	1 = Polyneuropathy; 2 = Dysautonomia; 3 = Family history for amyloidosis; 4 = Bilateral carpal tunnel syndrome; 5 = Ruptured biceps tendon; 6 = Lumbar spinal stenosis; 7 = Deafness; 8 = Cutis laxa; 9 = Macroglossia; 10 = Skin discoloration; 11 = Skin bruising; 12 = Corneal lattice dystrophy; 13 = Vitreous deposits		

Variable name	Field label	Field type	Options	Field info	Dependency
MH_noncar_remarks	Additional remarks	textarea			

Medical History- Family

Variable name	Field label	Field type	Options	Field info	Dependency
FH_Sde	Sudden death (<60y)	radio	1 = Yes; 0 = No; 9999 = Unknown	First or second degree family members	
FH_SCDe	Sudden cardiac death (<60y)	radio	1 = Yes; 0 = No; 9999 = Unknown	First or second degree family members	Sudden death (<60y) == 1
FH_CMP	Cardiomyopathy	radio	1 = Yes; 0 = No; 9999 = Unknown		
FH_HF_type	Etiology of familial cardiomyopathy	checkbox	10 = Ischemic cardiomyopathy; 20 = Hypertensive cardiomyopathy; 30 = Valvular cardiomyopathy; 40 = Metabolic cardiomyopathy; 50 = Arrhythmia / tachycardia; 60 = Hypertrophic cardiomyopathy; 70 = Idiopathic dilated cardiomyopathy; 80 = Infectious (a.o myocarditis); 90 = Restrictive cardiomyopathy; 100 = Peripartum cardiomyopathy; 110 = Genetic/Familial; 120 = Pericardial disease; 130 = Toxic cardiomyopathy by alcohol abuses; 131 = Toxic cardiomyopathy by chemotherapy; 132 = Toxic cardiomyopathy by radiation; 133 = Toxic cardiomyopathy by drugs abuses; 134 = Toxic cardiomyopathy by other causes; 5555 = Other reasons; 9999 = Unknown		Cardiomyopathy == 1
FH_Cor	Coronary interventions or myocardiac infarction (<65y)	radio	1 = Yes; 0 = No; 9999 = Unknown		
FH_other	Other familial diseases	textarea			

Medical History- Intoxications

Variable name	Field label	Field type	Options	Field info	Dependency
Intox_smok	Smoking	dropdown	0 = Non smoker; 1 = Smoker; 2 = Previous smoker	smoker = smoker <6 months before patient died	
Intox_smok_py	Smoking packyears	numeric		1 pack year = 20 cigarettes/day OR 2.5 packs of shaque/week OR 7 sigars/day for 1 year. Calculator available here: https://www.smokingpackyears.com/	Ever smoked == 1
Intox_smok_fd	Year of last smoking	year			Smoking == 1
Intox_alc	Alcohol usage	radio	1 = Yes; 0 = No; 9999 = Unknown	did the subject use alcohol	
Intox_alc_h	Heavy alcohol usage	radio	1 = Yes; 0 = No; 9999 = Unknown	Heavy = 21 units men & 17 units women/ week (0,8g alc = 1 unit).	Alcohol usage == 1
Intox_drugs	Drugs usage	radio	1 = Yes; 0 = No; 9999 = Unknown	did the subjects use drugs	
Intox_drugs_type	Drugs Type	checkbox	1 = Cocaine; 2 = Cannabis/Marijuana; 3 = Heroine; 4 = XTC; 5555 = Andere drugs, namelijk:		Drugs usage == 1
Intox_drugs_type_oth	Specify other drugs types	string			Drugs Type == 5555

Clinical presentations (repeated measurement)

Variable name	Field label	Field type	Options	Field info	Dependency
Consult_d	Date of consultation	date			
Consult_t	Type of consultation	dropdown	1 = Outpatient visit (poli/CP/NP); 2 = Telephone consultation (TC); 3 = Inpatient visit (during hospitalisation)		
CP_NYHA	NYHA classification	radio	1 = NYHA 1 (No symptoms during ordinary activity); 12 = NYHA 1-2; 2 = NYHA 2 (Mild symptoms during ordinary activity); 23 = NYHA 2-3; 3 = NYHA 3 (Marked limitation; comfortable only at rest); 34 = NYHA 3-4; 4 = NYHA 4 (Symptoms while at rest); 9999 = Unknown		
CP_dyspnea_duration	Duration of dyspnea symptoms (months)	numeric			NYHA classification != 1
CP_fatigue	Fatigue	radio	1 = Yes; 0 = No; 9999 = Unknown		
CP_orthopnea	Orthopnea	radio	1 = Yes; 0 = No; 9999 = Unknown		
CP_nocturnal	Paroxysmal nocturnal dyspnea	radio	1 = Yes; 0 = No; 9999 = Unknown		
CP_nocturia	Nocturia	radio	1 = Yes; 0 = No; 9999 = Unknown		
CP_edema	Edema	radio	1 = Yes; 0 = No; 9999 = Unknown		
CP_weight_ch	Recent weight change	dropdown	0 = stable weight; 1 = markedly weight loss (>3kg); 2 = weight loss (≤3kg); 3 = increased weight (≤3kg); 4 = markedly increased weight (>3kg); 9999 = unknown		
CP_ChP_type	Chest pain	dropdown	0 = None; 1 = Aspecific; 2 = Atypical angina; 3 = partially atypical/partially typical angina; 4 = Typical angina; 5 = Chest pain, type unknown; 9999 = Unknown		

Variable name	Field label	Field type	Options	Field info	Dependency
CP_ChP_CCS	CCS classification	radio	0 = CCS 0 (mild myocardial ischemia with no symptoms); 1 = CCS 1 (angina only with streneous exertion); 2 = CCS 2 (angina with moderate exertion); 3 = CCS 3 (angina with mild exertion; one stairs at normal pace); 4 = CCS 4 (angina at rest); 9999 = unknown		Chest pain calculation == 1
CP_palp	Palpitations	radio	1 = Yes; 0 = No; 9999 = Unknown		
CP_dizziness	Dizziness	radio	1 = Yes; 0 = No; 9999 = Unknown		
CP_orthostasis	Complaints of orthostasis	radio	1 = Yes; 0 = No; 9999 = Unknown		Dizziness == 1
CP_sync	Recent syncope	radio	1 = Yes; 0 = No; 9999 = Unknown		
CP_wheezing	Wheezing at rest	radio	1 = Yes; 0 = No; 9999 = Unknown		
CP_Flu	Flu like symptoms	radio	1 = Yes; 0 = No; 9999 = Unknown		
CP_Sd_symptoms	Symptoms of systemic disease	radio	1 = Yes; 0 = No; 9999 = Unknown	Arguments for inflammatory disease at joints, skin, gastro-intestinal tract, lungs	
CP_physical	Physical activity	dropdown	1 = very poor (ADL dependent); 2 = poor (ADL independent); 3 = moderate (1km walking/day); 4 = fair (>1km walking/day); 5 = good (exercise 2x/week); 9999 = unknown		
CP_other	Other relevant symptoms	textarea			
PE_height	Height (cm)	numeric			Type of consultation != 2
PE_weight	Weight (kg, use 1 decimal)	numeric			Type of consultation != 2

Variable name	Field label	Field type	Options	Field info	Dependency
PE_CDC	Signs of cardiac decompensation	radio	1 = Yes; 0 = No	such as pulmonary crackles, peripheral edema or elevated central venous pressure.	Type of consultation != 2
PE_Pulm_cr	Pulmonary crackles	dropdown	0 = no, normal breathing sounds; 1 = yes, pulmonary crackles present; 9999 = unknown		Signs of cardiac decompensation == 1
PE_Ed	Peripheral edema	dropdown	0 = no; 1 = yes, ankle level; 2 = yes, tibial level; 3 = yes, knee level; 4 = yes, higher than knee level; 5 = yes, level unknown; 9999 = unknown		Signs of cardiac decompensation == 1
PE_CVP	Central venous pressure	dropdown	0 = normal; 1 = elevated; 50 = inconclusive/not judgeable; 9999 = unknown		Signs of cardiac decompensation == 1
PE_dehydr	Signs of dehydration	radio	1 = Yes; 0 = No; 9999 = Unknown		Signs of cardiac decompensation == 0
PE_RR_sys	Systolic blood pressure	numeric			
PE_RR_dia	Diastolic blood pressure	numeric			

Medication (repeated measurement)

Variable name	Field label	Field type	Options	Field info	Dependency
Med_d	Date Medication	date			
Med_moment	Medication moment	dropdown	5 = Last medication list before patient died; 6 = Not last medication list before patient died		
med_bb	Beta-blocker	radio	1 = Yes; 0 = No		
med_bb_type	Beta-blocker type	dropdown	1 = Atenolol; 2 = Bisoprolol; 3 = Carvedilol; 4 = Celiprolol; 5 = Labetalol; 6 = Metoprolol; 7 = Nebivolol; 8 = Pindolol; 9 = Propranolol; 10 = Sotalol; 5555 = Other		Beta-blocker == 1
med_bb_dose	Beta-blocker daily dose	numeric			Beta-blocker == 1
med_acei	ACE-inhibitor	radio	1 = Yes; 0 = No		
med_acei_type	ACE-inhibitor type	dropdown	1 = Captopril; 2 = Enalapril; 3 = Fosinopril; 4 = Lisinopril; 5 = Perindopril; 6 = Quinapril; 7 = Ramipril; 8 = Zofenopril; 5555 = Other		ACE-inhibitor == 1
med_acei_dose	ACE-inhibitor daily dosage	numeric			ACE-inhibitor == 1
med_arb	Angiotensin receptor antagonist	radio	1 = Yes; 0 = No		
med_arb_type	Angiotensin receptor antagonist type	dropdown	1 = Candesartan; 2 = Eprosartan; 3 = Irbesartan; 4 = Losartan; 5 = Olmesartan; 6 = Telmisartan; 7 = Valsartan; 5555 = Other		Angiotensin receptor antagonist == 1
med_arb_dose	Angiotensin receptor antagonist daily dosage	numeric			Angiotensin receptor antagonist == 1

Variable name	Field label	Field type	Options	Field info	Dependency
med_mra	Mineralocorticoid receptor antagonist (kaliumsparend diureticum)	radio	1 = Yes; 0 = No		
med_mra_type	Mineralocorticoid antagonist type	dropdown	1 = Eplereonne; 2 = Spironolactone; 5555 = Other		Mineralocorticoid receptor antagonist (kaliumsparend diureticum) == 1
med_mra_dose	Mineralocorticoid antagonist daily dosage	numeric		Target dose (mg) Eplerenone 50 o.d. Spironolactone 50 o.d.	Mineralocorticoid receptor antagonist (kaliumsparend diureticum) == 1
med_ARNI	Angiotensin receptor-neprilysin inhibitor	radio	1 = Yes; 0 = No		
med_ARNI_dose	Angiotensin receptor-neprilysin inhibitor dosage	dropdown	1 = 24/26 2dd1; 2 = 49/51 2dd1; 3 = 97/103 2dd1; 5555 = Other		Angiotensin receptor-neprilysin inhibitor == 1
med_ifbl	Ivabradine	radio	1 = Yes; 0 = No		
med_ifbl_dose	Ivabradine daily dosage	numeric			Ivabradine == 1
med_diu_loop	Loop diuretics use	dropdown	0 = None; 1 = Furosemide; 2 = Bumetanide		
med_diu_loop_dose	Loop diuretics daily dose (bumetanide/furosemide)	numeric			Loop diuretics use != 0
med_diu_thiaz	Thiazide diuretics use	dropdown	0 = None; 1 = Thiazide diuretic; 2 = Chloorthalidon		
med_ccb	Calcium channel blockers	radio	1 = Yes; 0 = No		
med_dig	Digoxin	radio	1 = Yes; 0 = No		
med_noac	NOAC	radio	1 = Yes; 0 = No		

Variable name	Field label	Field type	Options	Field info	Dependency
med_amy	Amyloidosis treatment	radio	1 = Yes; 0 = No		
med_amy_trt	Which Amyloidosis treatment?	radio	1 = Tafamidis; 2 = Patisaran; 3 = Inotersen; 9 = Chemotherapy; 5555 = Other; 9999 = Unknown		Amyloidosis treatment == 1
med_vitk	Vitamin K antagonist	radio	1 = Yes; 0 = No		
med_asp	Platelet aggregation inhibitors	radio	1 = Yes; 0 = No		
med_sta	Statin	radio	1 = Yes; 0 = No		
med_sta_type	Statin type	radio	1 = simvastatine; 2 = rosuvastatin; 3 = atorvastatin; 4 = pravastatin; 5 = fluvastatin; 6 = only ezetimib; 7 = only red yeast rice		Statin == 1
med_sta_dose	Statin daily dose	numeric			Statin type != 7
med_nitr	Nitrates use	radio	1 = Yes; 0 = No		
med_amio	Amiodarone	radio	1 = Yes; 0 = No		
med_ablock	Alpha blockers (only doxazosine or terazosine)	radio	1 = Yes; 0 = No	only doxazosine/Cardura or terazosine/Hytrin	
med_antidm	Anti-diabetic medication	radio	1 = Yes; 0 = No		
med_SGLT2i	SGLT-2 inhibitor	radio	1 = Yes; 0 = No		
med_thyroid	Thyroid medication	radio	1 = Yes; 0 = No		
med_iron_oral	Oral iron suppletion	radio	1 = Yes; 0 = No		
med_resp	Respiratory medication	radio	1 = Yes; 0 = No		
med_colch	Colchicine	radio	1 = Yes; 0 = No		

Variable name	Field label	Field type	Options	Field info	Dependency
med_imu	immunosuppressive therapy	radio	1 = Yes; 0 = No		
med_imu_type	Which immunosuppresiva did the patient use	checkbox	9999 = Unknown; 1 = Prednison; 2 = Azathioprin; 3 = Ciclosporin; 4 = Mycofenolate; 5 = Cyclophoshamide; 5555 = Other		immunosuppressive therapy == 1
med_imu_type_other	Other immunosuppressive drug	textarea			Which immunosuppresiva did the patient use == 5555
Med_other	Other medication	textarea		Other medication (type name, dose, unit and frequency)	

Additional Diagnostics (repeated measurements)

Additional Diagnostics- Echocardiography

Variable name	Field label	Field type	Options	Field info	Dependency
echo_d	Date echocardiography	date			
echo_type	Type of echocardiography	dropdown	1 = TTE; 2 = TEE; 3 = TTE & TEE; 4 = Excercise echocardiography; 5 = High-dose dobutamine test; 6 = Low-dose dobutamine test; 7 = Contrast echocardiography; 9999 = Unknown type		
echo_loc	Location echocardiography performed	dropdown	1 = Heart function; 2 = Operating room; 3 = ICU; 4 = ICU CTC; 5 = ICCU; 6 = First heart-aid; 7 = Outpatient clinic; 8 = General ward; 5555 = Other		
echo_rhythm	Cardiac rhytm during echocardiography	dropdown	9999 = Unknown; 1 = sinusrhytm; 2 = atrial fibrillation; 3 = atrial flutter; 4 = AVNR; 5 = Escape rhythm; 6 = AV-pacing; 7 = V-pacing; 8 = Biv-Pacing; 678 = Paced, type pacing unknown		
echo_HF	Heart frequency	numeric			
echo_height	Height	numeric			
echo_weight	Weight	numeric			
echo_bsa	BSA	numeric			
echo_LVEF_teich	LVEF assessed by Teichholz method	numeric			
echo_LVEF_teich_man	LVEF assessed by Teichholz method	numeric			

Variable name	Field label	Field type	Options	Field info	Dependency
	manually added				
echo_LVEF_visual	LVEF visually assessed / eyeballing	numeric		If only a descriptive value has been registered (eg moderate), provide the following percentage: Good = 55% Moderate = 40% Poor = 25% Very poor = 20% If a percentage range has been reported, provide the average of this range (eg 50-55% must be supplied as 53%).	
echo_LVEF_bip	LVEF assessed by biplane/2D	numeric			
echo_LVEF_bip_man	LVEF assessed by biplane/2D manually added	numeric			
echo_LVEDD	Left ventricular end-diastolic diameter	numeric			
echo_LVESD	Left ventricular end-systolic diameter	numeric			
echo_EDV	Left ventricular end-diastolic volume	numeric			
echo_ESV	Left ventricular end-systolic volume	numeric			
echo_RVFunc	RV function	dropdown	1 = Good; 2 = Moderate; 3 = Bad; 9999 = Unknown	Eyeballing. An empty value cannot be interpreted as normal RV function but should be checked again (evaluation often present in free text form).	
echo_RVD_basal	Basal right ventricle diameter	numeric			

Variable name	Field label	Field type	Options	Field info	Dependency
echo_IVS	Intraventricular septal thickness	numeric			
echo_LVPW	Left ventricular posterior wall thickness	numeric			
echo_LVmass	Left ventricular mass	numeric			
echo_LVMI	Left ventricular mass index	numeric			
echo_LA_d	Left atrial diameter	numeric			
echo_LA_vol	Left atrial volume	numeric			
echo_LAVI	Left atrial volume index	numeric			
echo_RA_vol	Right atrial volume	numeric			
echo_VCI_Exp	Vena cava inferior diameter during expiration	numeric			
echo_VCIcol	Vena cava collapse	numeric			
echo_EstRVP	Estimated right ventricular pressure	numeric			
echo_Etop	Mitral early filling	numeric			
echo_Atop	Mitral active filling	numeric			
echo_EA	Mitral E/A ratio	numeric			
echo_ea_t	Type diastolic dysfunction based on	radio	1 = normal; 2 = type 1 (abnormal); 3 = type 2 (pseudonormal); 4 = type 3		

Variable name	Field label	Field type	Options	Field info	Dependency
	E/A ratio		(restrictive); 9999 = unknown		
echo_DT	Mitral early deceleration time	numeric			
echo_Ti	Tricuspidal regurgitation	numeric			
echo_eprim_IVS	Peak e' speed IVS	numeric			
echo_Eeprim_IVS	E/e' IVS	numeric			
echo_eprim_lvlat	Peak e' speed LV lateral	numeric			
echo_eeprim_lvlat	E/e' LV lateral	numeric			
echo_eeprim_ave	E/e' average ivs and LV lat	numeric			
echo_TAPSE	TAPSE	numeric		Tricuspid annular plane systolic excursion	
echo_pv_s2	S2-top of pulmonary vein	numeric			
echo_pv_d	D-top of pulmonary vein	numeric			
echo_pv_d_decel	Deceleration time D-top of pulmonary vein	numeric			
echo_pv_sd	PV S/D ratio	numeric			
echo_pv_ar	PV ar flow reversal	numeric			
echo_wall_abn	Regional wall	radio	1 = Yes; 0 = No; 9999 = Unknown		

Variable name	Field label	Field type	Options	Field info	Dependency
	abnormalities				
echo_aov_move	Aortic valve movement	checkbox	1 = Normal valvular motion; 2 = Prolaps of any valve-leaflet; 3 = Aortic sclerosis without restricted valve-leaflets; 4 = Aortic sclerosis with restricted valve-leaflets; 9999 = Unknown		
echo_aov_outflow	Aortic outflowtract narrowing	checkbox	1 = valvular AS (> 2 m/s); 2 = LVOT stenosis (dynamic end-systolic gradient); 3 = intraventricular gradient (dynamic end-systolic gradient); 4 = subvalvular AS; 5 = supravalvular AS; 9999 = unknown		
echo_aov_maxgrad	Maximum gradient aortic valve	numeric			
echo_aov_meangrad	Mean gradient aortic valve	numeric			
echo_aov_ava	Aortic valve area (AVA)	numeric			
echo_aov_eoa	Aortic Effective orifice area (EOA)	numeric			
echo_aov_insuf	Seriousness of aortic valve insufficiency	dropdown	0 = Trace of AI; 1 = Moderate AI (ERO <0,1 cm2); 2 = Considerable AI (ERO 0,1-0,2); 3 = Fairly Severe AI (ERO0,2-0,3cm2); 4 = Severe AI (ERO>0,3cm2); 8 = No AI; 9999 = Unknown		
echo_miv_insuf	Seriousness of mitral valve insufficiency	dropdown	0 = Trace of MI; 1 = Slightly (ERO<0,2cm2); 2 = Moderate MI (ERO 0,2-0,3cm2); 3 = Fairly severe		

Variable name	Field label	Field type	Options	Field info	Dependency
			MI (ERO 0,3-0,4); 4 = Severe MI (ERO>0,4cm2); 8 = No; 9999 = Unknown		
echo_miv_calc	Mitral annulus calcification	radio	0 = None; 1 = Slight; 2 = Moderate; 3 = Severe; 9999 = Unknown	When the mitral annulus calcification is graded as "slight-moderate", please choose "moderate", and when it is graded as "moderate-severe", please choose "severe".	
echo_miv_grad	Mitral valve gradient	checkbox	1 = Rheumatic MS (Carpentier IIIa); 2 = Mitral ostium reduction; 3 = Mitral valve reconstruction; 9999 = Unknown		
echo_miv_maxgrad	Maximum gradient mitral valve	numeric			
echo_miv_meangrad	Mean gradient mitral valve	numeric			
echo_miv_area	Mitral valve area	numeric			
echo_puv_sten	Pulmonary valve stenosis	checkbox	1 = Subvalvular; 2 = Valvular; 3 = Supravalvular; 8 = No; 9999 = Unknown		
echo_puv_maxgrad	Maximum gradient pulmonic valve	numeric			
echo_puv_meangrad	Mean gradient pulmonic valve	numeric			
echo_puv_insuf	Seriousness of pulmonic valve insufficiency	dropdown	1 = Slightly; 2 = Moderate; 3 = Severe; 0 = None; 9999 = Unknown		
echo_trv_sten	Tricuspid valve	checkbox	1 = Rheumatic TS; 2 = Tricuspid valve reconstruction; 3 = Tricuspid		

Variable name	Field label	Field type	Options	Field info	Dependency
	stenosis		valve prosthesis; 0 = None; 9999 = Unknown		
echo_trv_maxgrad	Maximum gradient tricuspid valve	numeric			
echo_trv_meangrad	Mean gradient tricuspid valve	numeric			
echo_trv_insuf	Seriousness of tricuspid valve insufficiency	dropdown	1 = Slightly; 2 = Moderate; 3 = Severe; 0 = None; 9999 = Unknown		

Additional Diagnostics- Electrocardiography

Variable name	Field label	Field type	Options	Field info	Dependency
ecg_d	Date ECG	date			
ecg_rhytm	Rhytm	dropdown	0 = Sinus-/atrial- rhytm; 1 = Atrial fibrillation/flutter; 2 = Nodal Rhytm; 3 = Pacemaker Rhytm; 4 = Ventricular tachycardia; 5555 = Other		
ecg_rhytm_other	Rhytm other	textarea			Rhytm == 5555
ecg_vr	Ventricular rate (average)	numeric			
ecg_axis_p	P axis	numeric			
ecg_axis_r	R axis	numeric			
ecg_axis_t	T axis	numeric			
ecg_PR	PR duration	numeric			
ecg_QRS	QRS duration	numeric			
ecg_QT	QT duration	numeric			
ecg_comments	Comments	textarea			
ecg_RR_sys	Systolic blood pressure	numeric			
ecg_RR_dia	Diastolic blood pressure	numeric			

Additional Diagnostics- Genetics

Only available for subjects if additional informed consent is provided

Variable name	Field label	Field type	Options	Field info	Dependency
gen_permission	Subject provided informed consent to store genetic information in castor environment	radio	1 = Yes; 0 = No		
gen_p	Subject received Genetic diagnostic screening	radio	1 = Yes; 0 = No	Genetic diagnostic screening involves examining the patient's genome through blood analysis	Subject provided informed consent to store genetic information in castor environment == 1
gen_lpp1	Class 4 or 5 mutation	radio	1 = Yes; 0 = No		Subject received Genetic diagnostic screening == 1
gen_lpp1_gene	Gene name of 4/5 mutation	dropdown	1 = TTN; 2 = LMNA; 3 = MYH7; 4 = FLNC; 5 = RBM20; 6 = DSP; 7 = BAG3; 8 = TNNT2; 9 = TNNC1; 10 = PLN; 11 = ACTC1; 12 = NEXN; 13 = TPM1; 14 = VCL; 15 = SCN5A; 16 = ACTN2; 17 = ANKRD1; 18 = CAV3; 19 = CRYAB; 20 = CSRP3; 21 = CTNNA3; 22 = DES; 23 = DSC2; 24 = DSG2; 25 = EMD; 26 = FHL1; 27 = GLA; 28 = JPH2; 29 = JUP; 30 = LAMA4; 31 = LAMP2; 32 = LDB3; 33 = MIB1; 34 = MYBPC3; 35 = MYL2; 36 = MYL3; 37 = MYOZ2; 38 = MYPN; 39 = PKP2; 40 = PRDM16; 41 = PRKAG2; 42 = TAZ; 43 = TCAP; 44 = TMEM43; 45 = TNNI3; 46 = TTR; 47 = MYH6; 48 = CALR3; 5555 = Other		Class 4 or 5 mutation == 1
gen_lpp1_gene_TTN	TTN variant	dropdown	1 = A-band; 2 = Z-disk; 3 = I-band; 4 = M-band		Gene name of 4/5

Variable name	Field label	Field type	Options	Field info	Dependency
	position				mutation == 1
gen_lpp_gene1_other	gene LPP other	textarea			Gene name of 4/5 mutation == 5555
gen_lpp1_cpos	Nucleotide change of mutation	string			Class 4 or 5 mutation == 1
gen_lpp1_ppos	Amino acid change of mutation	string			Class 4 or 5 mutation == 1
gen_lpp2	second Class 4 or 5 mutation	radio	1 = Yes; 0 = No		Class 4 or 5 mutation == 1
gen_lpp2_gene	Gene name of second class 4/5 mutation	dropdown	1 = TTN; 2 = LMNA; 3 = MYH7; 4 = FLNC; 5 = RBM20; 6 = DSP; 7 = BAG3; 8 = TNNT2; 9 = TNNC1; 10 = PLN; 11 = ACTC1; 12 = NEXN; 13 = TPM1; 14 = VCL; 15 = SCN5A; 16 = ACTN2; 17 = ANKRD1; 18 = CAV3; 19 = CRYAB; 20 = CSRP3; 21 = CTNNA3; 22 = DES; 23 = DSC2; 24 = DSG2; 25 = EMD; 26 = FHL1; 27 = GLA; 28 = JPH2; 29 = JUP; 30 = LAMA4; 31 = LAMP2; 32 = LDB3; 33 = MIB1; 34 = MYBPC3; 35 = MYL2; 36 = MYL3; 37 = MYOZ2; 38 = MYPN; 39 = PKP2; 40 = PRDM16; 41 = PRKAG2; 42 = TAZ; 43 = TCAP; 44 = TMEM43; 45 = TNNI3; 46 = TTR; 47 = MYH6; 48 = CALR3; 5555 = Other		second Class 4 or 5 mutation == 1
gen_lpp2_gene_TTN	TTN variant position of second class 4/5 mutation	dropdown	1 = A-band; 2 = Z-disk; 3 = I-band; 4 = M-band		Gene name of second class 4/5 mutation == 1
gen_lpp_gene2_other	gene second LPP other	textarea			Gene name of second class 4/5 mutation == 5555
gen_lpp2_cpos	Nucleotide change of second class 4/5	string			second Class 4 or 5 mutation == 1

Variable name	Field label	Field type	Options	Field info	Dependency
	mutation				
gen_lpp2_ppos	Amino acid change of second class 4/5 mutation	string			second Class 4 or 5 mutation == 1
gen_vus1	Class 3 mutation	radio	1 = Yes; 0 = No		Subject received Genetic diagnostic screening == 1
gen_vus1_gene	Gene name of class 3 mutation	dropdown	1 = TTN; 2 = LMNA; 3 = MYH7; 4 = FLNC; 5 = RBM20; 6 = DSP; 7 = BAG3; 8 = TNNT2; 9 = TNNC1; 10 = PLN; 11 = ACTC1; 12 = NEXN; 13 = TPM1; 14 = VCL; 15 = SCN5A; 16 = ACTN2; 17 = ANKRD1; 18 = CAV3; 19 = CRYAB; 20 = CSRP3; 21 = CTNNA3; 22 = DES; 23 = DSC2; 24 = DSG2; 25 = EMD; 26 = FHL1; 27 = GLA; 28 = JPH2; 29 = JUP; 30 = LAMA4; 31 = LAMP2; 32 = LDB3; 33 = MIB1; 34 = MYBPC3; 35 = MYL2; 36 = MYL3; 37 = MYOZ2; 38 = MYPN; 39 = PKP2; 40 = PRDM16; 41 = PRKAG2; 42 = TAZ; 43 = TCAP; 44 = TMEM43; 45 = TNNI3; 46 = TTR; 47 = MYH6; 48 = CALR3; 5555 = Other		Class 3 mutation == 1
gen_vus1_gene_TTN	TTN variant position	dropdown	1 = A-band; 2 = Z-disk; 3 = I-band; 4 = M-band		Gene name of class 3 mutation == 1
gen_vus1_cpos	Nucleotide change of class 3 mutation	string			Class 3 mutation == 1
gen_vus1_ppos	Amino acid change of class 3 mutation	string			Class 3 mutation == 1
gen_vus2	Second Class 3 mutation	radio	1 = Yes; 0 = No		Class 3 mutation == 1
gen_vus2_gene	Gene name of class 3 mutation	dropdown	1 = TTN; 2 = LMNA; 3 = MYH7; 4 = FLNC; 5 = RBM20; 6 = DSP; 7 = BAG3; 8 = TNNT2; 9 =		Second Class 3 mutation == 1

Variable name	Field label	Field type	Options	Field info	Dependency
			TNNC1; 10 = PLN; 11 = ACTC1; 12 = NEXN; 13 = TPM1; 14 = VCL; 15 = SCN5A; 16 = ACTN2; 17 = ANKRD1; 18 = CAV3; 19 = CRYAB; 20 = CSRP3; 21 = CTNNA3; 22 = DES; 23 = DSC2; 24 = DSG2; 25 = EMD; 26 = FHL1; 27 = GLA; 28 = JPH2; 29 = JUP; 30 = LAMA4; 31 = LAMP2; 32 = LDB3; 33 = MIB1; 34 = MYBPC3; 35 = MYL2; 36 = MYL3; 37 = MYOZ2; 38 = MYPN; 39 = PKP2; 40 = PRDM16; 41 = PRKAG2; 42 = TAZ; 43 = TCAP; 44 = TMEM43; 45 = TNNI3; 46 = TTR; 47 = MYH6; 48 = CALR3; 5555 = Other		
gen_vus2_gene_TTN	TTN variant position	dropdown	1 = A-band; 2 = Z-disk; 3 = I-band; 4 = M-band		Gene name of class 3 mutation == 1
gen_vus2_cpos	Nucleotide change of class 3 mutation	string			Second Class 3 mutation == 1
gen_vus2_ppos	Amino acid change of class 3 mutation	string			Second Class 3 mutation == 1
gen_vus3	Third Class 3 mutation	radio	1 = Yes; 0 = No		Second Class 3 mutation == 1
gen_vus3_gene	Gene name of class 3 mutation	dropdown	1 = TTN; 2 = LMNA; 3 = MYH7; 4 = FLNC; 5 = RBM20; 6 = DSP; 7 = BAG3; 8 = TNNT2; 9 = TNNC1; 10 = PLN; 11 = ACTC1; 12 = NEXN; 13 = TPM1; 14 = VCL; 15 = SCN5A; 16 = ACTN2; 17 = ANKRD1; 18 = CAV3; 19 = CRYAB; 20 = CSRP3; 21 = CTNNA3; 22 = DES; 23 = DSC2; 24 = DSG2; 25 = EMD; 26 = FHL1; 27 = GLA; 28 = JPH2; 29 = JUP; 30 = LAMA4; 31 = LAMP2; 32 = LDB3; 33 = MIB1; 34 = MYBPC3; 35 = MYL2; 36 = MYL3; 37 = MYOZ2; 38 = MYPN; 39 = PKP2; 40 = PRDM16; 41 = PRKAG2; 42 = TAZ; 43 = TCAP; 44 = TMEM43; 45 = TNNI3; 46 = TTR; 47 = MYH6; 48 = CALR3; 5555 = Other		Third Class 3 mutation == 1

Variable name	Field label	Field type	Options	Field info	Dependency
gen_vus3_gene_TTN	TTN variant position	dropdown	1 = A-band; 2 = Z-disk; 3 = I-band; 4 = M-band		Gene name of class 3 mutation == 1
gen_vus3_cpos	Nucleotide change of class 3 mutation	string			Third Class 3 mutation == 1
gen_vus3_ppos	Amino acid change of class 3 mutation	string			Third Class 3 mutation == 1

Adverse Events & Interventions

Adverse Events & Interventions - Hospitalization

Variable name	Field label	Field type	Options	Field info	Dependency
HTx	Heart transplantation	radio	1 = Yes; 0 = No		
HTx_d	Heart transplantation date	date			Heart transplantation == 1
VAD	Ventricular assist device	radio	1 = Yes; 0 = No		
VAD_d	VAD date	date			Ventricular assist device == 1
Hosp_yn	Hospitalisation	radio	1 = Yes; 0 = No		

Adverse Events & Interventions - Hospitalization (Repeated measurement)

Variable name	Field label	Field type	Options	Field info	Dependency
Hosp_d_adm	Admission date (see info in case of referred admission)	date		First day of hospitalization. If patient is referred from other hospital use admission date of referring hospital.	
Hosp_d_dis	Discharge date	date		Last date of hospitalization (16th of the month if exact day is unknown, or July 2st when only the year is known).	
Hosp_car	Admitted at cardiology department	radio	1 = Yes; 0 = No		
Hosp_car_icc	Cardiology consultation during hospitalisation	radio	1 = Yes; 0 = No		Admitted at cardiology department == 0
Hosp_r	Reason for hospitalization	checkbox	1 = Decompensatio cordis (heart failure); 2 = (Suspicion of) acute coronary syndrome; 3 = Life-threatening	Select all applicable options. Life-threatening Ventricular Arrhythmia= Ventricular	

Variable name	Field label	Field type	Options	Field info	Dependency
			Ventricular Arrhythmia (LTA); 4 = None Life-threatening Ventricular Arrhytmia (e.g NSVT, VES); 5 = Supraventricular arrhytmia; 5555 = Other cardiac; 7777 = Other non-cardiac; 9999 = Unknown	fibrillation -with or without ICD-shock- and/or sustained ventricular tachycardia. Including Out of Hospital Cardiac Arrest.	
Hosp_r_oth_car	Specify other cardiac reason for hospitalization	string			Reason for hospitalization == 5555
Hosp_r_oth_ncar	Specify other non-cardiac reason for hospitalization	string			Reason for hospitalization == 7777
Hosp_rem	Remarks	textarea			
Hosp_inhospital_DC	Was the patient decompensated during hospitalisation?	radio	1 = Yes; 0 = No	e.g. required further intensification of diuretics	Reason for hospitalization != 1
Hosp_inhospital_LTA	Did a Life-threatening Arrhythmia occur during the hospitalisation?	radio	1 = Yes; 0 = No	Ventricular fibrillation (with or without ICD-shock), and/or sustained ventricular tachycardia. if multiple LTA occurred during hospitalisation, please mention the first LTA	
Hosp_inhospital_LTA_d	Date of Life-threatening Arrhythmia during hospitalisation?	date		ventricular fibrillation (with or without ICD-shock), and/or sustained ventricular tachycardia	Did a Life-threatening Arrhythmia occur during the hospitalisation? == 1

Adverse Events & Interventions - Devices & device therapy

Variable name	Field label	Field type	Options	Field info	Dependency
Dev_yn	Device implantation (ICD/PM)	radio	1 = Yes; 0 = No	ILR/reveal is not considered a cardiac device	
Dev_d	Device implantation(s) (includes information regarding device type, implantation/explantation-date, and indication)	grid			Device implantation (ICD/PM) == 1
Dev_shocks_ATP_yn	Received (un)justified shock(s)/anti-tachypacing (ATP)	radio	1 = Yes; 0 = No		Device implantation (ICD/PM) == 1
Dev_shocks_ATP_d	Shocks/ATP (includes information regarding (un)justified ATP/Shocks and related dates)	grid			Received (un)justified shock(s)/anti-tachypacing (ATP) == 1

Autopsy

Autopsy - report during autopsy

Variable name	Field label	Field type	Options	Field info	Dependency
Mor_d	Date of death	date			
Mor_time	Time of death	time			
Mor_hosp_yn	Died during hospitalisation	radio	1 = Yes; 0 = No		
Mor_GPcontact_yn	GP contacted for cause of death?	radio	-1 = No, GP still needs to be contacted; 0 = No, GP will not be contacted (cause of death is clear); 1 = Yes, GP contacted		Died during hospitalisation == 0
Mor_sudden_yn	Sudden death	radio	1 = Yes; 0 = No	Non-traumatic, unexpected fatal event occurring within 1 hour of the onset of symptoms (or within 24h if not witnessed).	
Mor_y_car	Cardiac death	radio	1 = Yes; 0 = No	• Autopsy shows a cardiac or vascular anomaly as the probable cause of the event; OR • No obvious extra-cardiac causes have been found by post-mortem examination and therefore an arrhythmic event is a likely cause of death.	
Mor_oth	Reason death	textarea			
Autop_start_d	Date Autopsy started	date			
Autop_start_time	Time autopsy started	time			

Variable name	Field label	Field type	Options	Field info	Dependency
Autop_end_d	Date Autopsy finished	date			
Autop_end_time	Time autopsy finished	time			
Autop_cardevice_removed	ICD/CRTD/PM removed during autopsy	radio	1 = Yes; 0 = No		
Autop_cardevice_stored	ICD/CRTD/PM stored for research purposes	radio	1 = Yes; 0 = No		ICD/CRTD/PM removed during autopsy == 1
Autop_protocol_version	Which protocol version was used for the autopsy	dropdown	12 = V12; 13 = V13	please contact study admin if version of protocol is not in the list	
Autop_heart_weight	Weight heart	numeric			
Autop_LV_ant_mm	LV anterior thickness	numeric			
Autop_LV_post_mm	LV posterior thickness	numeric			
Autop_LV_lat_mm	LV lateral free-wall thickness	numeric			
Autop_sep_mm	Septal thickness	numeric			
Autop_RV_ant_mm	RV anterior thickness	numeric			
Autop_RV_post_mm	RV posterior thickness	numeric			
Autop_RV_lat_mm	RV lateral free-wall	numeric			

Variable name	Field label	Field type	Options	Field info	Dependency
	thickness				
Autop_remarks	Additional findings during autopsy	textarea			
NA	Tissue cranial/apical slice	image			
Autop_protocol_violations	Where there any violations of the protocol?	radio	1 = Yes; 0 = No	this also includes mislabelling of the samples OR storage of additional samples	
Autop_protocol_violations_remarks	Which violations? (please mention them in detail)	textarea			Where there any violations of the protocol? == 1

Autopsy - final report

Under construction