American Heart Association®
Hypertrophic Cardiomyopathy Registry
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AHA-HCM (CRF) October 2026

Patient ID	
DEMOGRAPHICS	
Medical Record Number	_____
First Name	_____
Last Name	_____
Sex	○ Male ○ Female ○ Unknown
Patient Gender Identity	○ Male ○ Female ○ Female-to-Male (FTM)/Transgender Male/Trans Man ○ Male-to-Female (MTF)/Transgender Female/Trans Woman ○ Genderqueer, neither exclusively male nor female ○ Additional gender category or other. _____ ○ Did not disclose.
Patient-Identified Sexual Orientation	○ Straight or heterosexual ○ Lesbian or gay ○ Bisexual ○ Queer, pansexual, and/or questioning ○ Something else; please specify: _____ ○ Don't know ○ Declined to answer
Date of Birth	___/___/____ (MM/DD/YYYY)
Age	_____
Street Address	_____
City	_____
State	_____
Zip Code	_____ - _____ ☐ Homeless
Payment Source	☐ Medicare ☐ Medicaid ☐ Medicare – Private/HMO/PPO/Other ☐ Medicaid – Private/HMO/PPO/Other ☐ Private/HMO/PPO/Other ☐ VA/CHAMPVA/Tricare ☐ Self-pay/No Insurance ☐ Other/Not Documented/UTD
MBI:	_____
Race and/or Ethnicity	
Race and/or Ethnicity	☐ American Indian or Alaska Native ☐ Asian ☐ Asian Indian ☐ Chinese ☐ Filipino ☐ Japanese ☐ Korean ☐ Vietnamese ☐ Other Asian ☐ Black or African American ☐ Hispanic of Latino ☐ Mexican, Mexican American, Chicano/a ☐ Puerto Rican ☐ Cuban ☐ Another Hispanic, Latino, or Spanish Origin ☐ Middle Eastern or Northern African

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	☐ Native Hawaiian or Pacific Islander ☐ Native Hawaiian ☐ Guamanian or Chamorro ☐ Samoan ☐ Other Pacific Islander ☐ White ☐ UTD
Diagnosis	
Date of HCM Diagnosis	___/___/____ (MM/DD/YYYY)
Age at HCM Diagnosis (auto calculated)	_____
HCM Type at time of diagnosis	☐ Obstructive ☐ Non-Obstructive ☐ Unspecified
If a patient was referred to your facility, what was the type of practice they were at before?	○ Solo ○ Community/Private Cardiology Practice ○ Academic cardiology practice (non HCM center) ○ HCM center ○ Family practitioner / Primary care practitioner
Date patient started receiving care at your HCM Center	___/___/____ (MM/DD/YYYY)
HISTORIC TAB	
This is the opportunity to enter in any one-time historic patient procedure information. Please only select yes if results are available for the most recent procedure.	
Check yes for any procedures that the patient has had in the past:	☐ None Past Procedures - Ambulatory ECG Monitoring ○ Yes ○ No/ND Arrhythmia Ablation ○ Yes ○ No/ND ☐ AF Ablation ☐ VT Ablation Cardiopulmonary Exercise Stress Test ○ Yes ○ No/ND Cardiac Magnetic Resonance Imaging (MRI) ○ Yes ○ No/ND Past Procedures - Echocardiogram ○ Yes ○ No/ND ☐ Exercise Echocardiogram ☐ Resting Echocardiogram Genetic Testing ○ Yes ○ No/ND ICD Placement ○ Yes ○ No/ND Septal Reduction Therapy ○ Yes ○ No/ND ☐ Alcohol Septal Ablation (ASA) ☐ Septal Myectomy
Ambulatory ECG Monitoring	___/____/_____ MM/DD/YYYY ○ Unknown
AF Ablation	___/____/_____ MM/DD/YYYY ○ Unknown
VT Ablation	___/____/_____ MM/DD/YYYY ○ Unknown

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Cardiopulmonary Exercise Stress Test	___/____/_____ MM/DD/YYYY	○ Unknown
Cardiac Magnetic Resonance Imaging (MRI)	___/____/_____ MM/DD/YYYY	○ Unknown
Exercise Echocardiogram	___/____/_____ MM/DD/YYYY	○ Unknown
Resting Echocardiogram	___/____/_____ MM/DD/YYYY	○ Unknown
Genetic Testing	___/____/_____ MM/DD/YYYY	○ Unknown
ICD	___/____/_____ MM/DD/YYYY	○ Unknown
What was the ICD prevention method?	○ Primary ○ Secondary	
What was ICD type?	○ CRT ○ evICD ○ S-ICD ○ Transvenous ○ Other	
If Transvenous, what sub-type?	○ Bi-ventricular/cardiac resynchronization therapy-defibrillation (CRT-D) ○ Dual chamber ○ Single ventricular lead	
Where was ICD performed?	○ Enrolling center ○ Other center	
Alcohol Septal Ablation (ASA)	___/____/_____ MM/DD/YYYY	○ Unknown
Septal Myectomy	___/____/_____ MM/DD/YYYY	○ Unknown

ADMINISTRATIVE	
Date / Time of Chart Review	___/___/____ ____:_____ (MM/DD/YYYY HH:MM)
Date of HCM Diagnosis *(Read only)*	___/___/____ (MM/DD/YYYY)
Age at chart review (auto calculated)	_____
Diagnosis Type at time of HCM Diagnosis (Read only)	○ Obstructive ○ Non-Obstructive ○ Unspecified
Diagnosis Type at time of chart review	○ Obstructive ○ Non-Obstructive ○ Unspecified
Date patient started receiving care at your HCM center *(Read only)*	___/___/____ (MM/DD/YYYY)
Was there an inpatient admission during the assessment	○ Yes ○ No ○ Unknown

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period?	
Was the patient lost to follow up or deceased?	○ Yes ○ No
Medical History	
Previous known medical history:	☐ No Previous Medical History ☐ Anemia ☐ Asthma ☐ Atrial Fib (chronic or recurrent) ☐ Atrial Flutter (chronic or recurrent) ☐ ATTR-CM ○ Hereditary ○ Wild-Type ☐ Coronary Artery Disease ☐ Cancer ☐ Chronic Obstructive Pulmonary Disease (COPD) ☐ Carotid Stenosis ☐ Current Pregnancy (up to 6 weeks post-partum) ☐ Deep Vein Thrombosis (DVT)/Pulmonary Embolism (PE) ☐ Dementia ☐ Depression ☐ Diabetes Mellitus ○ Type I ○ Type II ○ ND ☐ Duration: ○ < 5 years ○ 5 - < 10 years ○ 10 - < 20 years ○ >= 20 years ○ Unknown ☐ Drugs/Alcohol Abuse ☐ Dyslipidemia ☐ E-Cigarette Use (Vaping) ☐ Familial Hypercholesterolemia ☐ Heart Failure ☐ Hypertension ☐ Migraine ☐ Obesity/Overweight ☐ Myocardial Infarction ○ STEMI ○ NSTEMI ☐ Stroke ○ ICH ○ Ischemic Stroke ○ SAH ○ Not Specified ☐ Transient Ischemic Attack ☐ Peripheral Vascular Disease ☐ Renal Insufficiency - Chronic ☐ Sickle Cell ☐ Sleep Apnea ☐ Smoker ☐ Valvular Heart Disease ○ Aortic valve regurgitation ○ Aortic valve stenosis ○ Mitral valve regurgitation ○ Mitral valve stenosis ○ Pulmonic valve regurgitation ○ Pulmonic valve stenosis ○ Tricuspid valve regurgitation ○ Tricuspid valve stenosis

Previous Genetic Testing Results (set from last assessment form):	☐ Pathogenic/Likely Pathogenic ☐ VUS ☐ Negative ☐ Not tested	
For patients that have had VUS before, was variant reassessed?	○ Yes	○ No
Was there a change in classification?	○ Yes	○ No
If yes, what was the change?	○ VUS to P/LP	○ VUS to likely benign or benign

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Previous Procedure(s):	○ No previous procedures
	☐ Advanced HF Intervention
	  ○ LVAD
	  ○ Transplant
	☐ Ambulatory ECG
	☐ Cardiopulmonary Exercise Stress Test
	☐ CardioMEMs (implantable /hemodynamic monitor)
	☐ Cardiac Magnetic Resonance Imaging (MRI)
	☐ Echocardiogram
	  ☐ Exercise Echocardiogram
	  ☐ Resting Echocardiogram
	○ Electrophysiology
	  ○ Ablation, other: type
	  ○ AF Ablation (with PVI)
	  ○ A flutter ablation
	  ○ AVN ablation
	  ○ Cardioversion
	  ○ CRT- P (cardiac resynchronization therapy-pacing only
	  ○ Implantable Loop Monitor
	  ○ Pacemaker
	  ○ SVT ablation
	  ○ VT ablation
	☐ Genetic Testing
	☐ ICD Placement
	  ○ CRT
	  ○ evICD
	  ○ S-ICD
	  ○ Transvenous ICD
	  ○ Other
	☐ Non-Cardiac Transplant
	  ○ Kidney
	  ○ Liver
	  ○ Lung
	☐ Percutaneous Coronary Intervention (PCI)
	☐ Septal Reduction Therapy
	  ☐ Alcohol Septal Ablation (ASA)
	  ☐ Septal Myectomy
	☐ Valvular Heart Disease
	  ○ Surgical
	  ○ AV replacement
	  ○ MV repair
	  ○ MV replacement
	  ○ TV repair/replacement
	  ○ Transcatheter
	  ○ MV repair
	  ○ MV replacement
	  ○ Transcatheter Aortic Valve Replacement (TAVR)
	  ○ Tricuspid Transcatheter Edge to Edge Repair (TEER)
	  ○ Tricuspid valve replacement

Transvenous ICD Previous Procedures	○ Bi-ventricular/cardiac resynchronization therapy-defibrillation (CRT-D) ○ Dual chamber ○ Single ventricular lead
Did the patient have an ICD therapy or complication during the assessment period?	○ Yes ○ No
Current medications (select all that apply):	☐ No current medications ACEI ○ Yes ○ No/ND ☐ Accupril (Quinapril HCl) ☐ Aceon ☐ Altace (Ramipril) ☐ Capoten (Captopril) ☐ Lotensin (Benazepril HCl) ☐ Mavik ☐ Monopril (Fosinopril sodium) ☐ Prinivil (Lisinopril) ☐ Vasotec (Enalapril maleate) ☐ Zestril (Lisinipril) ☐ Other ACEI ARB ○ Yes ○ No/ND ☐ Atacand (Candesartan) ☐ Avalide, Avapro (Irbesartan)

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	☐ Cozaar, Hyzaar (Losartan) ☐ Diovan, Diovan HCT (Valsartan) ☐ Micardis (Telmisartan) ☐ Teveten (Eprosartan) ☐ Verdia (Tasoartan) ☐ Other ARB ARNI ○ Yes ○ No/ND ☐ Entresto (sacubitril/valsartan) ☐ Other ARNI Antiplatelet ○ Yes ○ No/ND ☐ Aspirin ☐ ASA/dipyridamole (Aggrenox) ☐ clopidogrel (Plavix) ☐ prasugrel (Effient) ☐ ticagrelor (Brilinta) ☐ ticlopidine (Ticlid) ☐ Other Antiplatelet Anticoagulants ○ Yes ○ No/ND ☐ apixaban (Eliquis) ☐ argatroban (Acova) ☐ betrixaban (Bevyxxa) ☐ dabigatran (Pradaxa) ☐ desirudin (lprivask) ☐ edoxaban (Savaysa) ☐ fondaparinux (Arixtra) ☐ full dose LMW heparin ☐ lepirudin (Refludan) ☐ rivaroxaban (Xarelto) ☐ Unfractionated heparin IV ☐ warfarin (Coumadin) ☐ Other Anticoagulant Betablocker ○ Yes ○ No/ND ☐ bisoprolol ☐ timolol maleate (Blocadren) ☐ carvedilol (Coreg) ☐ propanolol HCl (Inderal) ☐ betaxolol HCl (Kerlone) ☐ penbutolol sulfate (Levatol) ☐ metoprolol (Lopressor) ☐ acebutolol HCl (Sectral) ☐ atenolol (Tenormin) ☐ metoprolol succinate CR/XL (Toprol XL) ☐ pindolol (Visken) ☐ Other Beta Blocker Calcium Channel Blockers ○ Yes ○ No/ND ☐ Dihydropryridine (nifedipine) (dicardipine) (amlodipine) ☐ Non-dihydropyridine (verapamil) (diltiazem) ☐ Other calcium channel blocker Diuretics ○ Yes ○ No/ND Antiarrhythmic drug therapy ○ Yes ○ No/ND ☐ amiodarone (Cardarone) ☐ dofetilide (Tikosyn) ☐ dronedarone (Multaq) ☐ flecainide (Tambocor) ☐ mexiletine (Mexitil) ☐ propafenone (Rythmol, Rythmol SR) ☐ quinidine

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	☐ sotalol (Betapace, Betapace AF) ☐ Other Anti-Arrhythmic Antihyperglycemic Medications ○ Yes ○ No/ND ☐ Insulin ☐ Other oral agents ☐ Other injectable/subcutaneous agents Myosin Inhibitor ○ Yes ○ No/ND Ranolazine ○ Yes ○ No/ND DPP-4 Inhibitors ○ Yes ○ No/ND disopyramide (Norpace, Norpace CR) ○ Yes ○ No/ND GLP-1 receptor agonist ○ Yes ○ No/ND SGLT2 Inhibitor ○ Yes ○ No/ND Spironolactone ○ Yes ○ No/ND Statin ○ Yes ○ No/ND
If currently on myosin inhibitor, which drug is patient on?	☐ Mavacamten ☐ Aficamten
Mavacamten dosage?	○ 1 mg ○ 10 mg ○ 2.5 mg ○ 15 mg ○ 5 mg ○ 20 mg
Aficamten dosage?	○ 5 mg ○ 15 mg ○ 10 mg ○ 20 mg
What date was the patient prescribed the myosin inhibitor?	___/___/____ (MM/DD/YYYY)
What date was the patient prescribed disopyramide?	___/___/____ (MM/DD/YYYY)
Labs Since Last Chart Review	
Labs Since Last Chart Review - NT-ProBNP	____ ○ pg/mL ○ ng/L ☐ Unavailable
Labs Since Last Chart Review - BNP	_____ ○ pg/mL ○ pmol/L ○ ng/L ☐ Unavailable
HOSPITALIZATION/ ADMISSION	
Admission Date / Time	____/_____/_____ _____:_____ MM/DD/YYYY HH:MM ☐ Unknown
Potential HCM related reason(s) for admission (select all that apply):	☐ None ☐ Atrial arrhythmia ☐ Adverse side effects of medical therapy ☐ Symptomatic Bradycardia ☐ Chest pain ☐ Congestive heart failure ☐ Infective Endocarditis ☐ Myocardial infarction ☐ Pacemaker/ICD Implantation Complication ☐ Planned procedure ☐ Post operative complication of SRT ☐ Stroke/TIA ☐ Syncope or pre-syncope

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	☐ Ventricular arrhythmia
Point of origin for admission	○ Clinic ○ Elective ○ Emergency room ○ Home ○ Transfer from a hospital (Different Facility) ○ Transfer from a skilled nursing facility (SNF) or intermediate care facility (ICF) ○ Transfer from another health care facility ○ Transfer from hospice and is under a hospice plan of care or enrolled in a hospice program ○ Information not available
Symptoms at presentation (select all that apply):	☐ Chest discomfort/angina ☐ Dyspnea in exertion ☐ Fatigue ☐ Palpitations ☐ Post meal (post prandial) shortness of breath/palpitations/chest tightness ☐ Pre-syncope/syncope ☐ Shortness of breath ☐ None ☐ Other
Procedure(s) that occurred during hospitalization:	☐ None ☐ Advanced HF Intervention ☐ LVAD ___/____/_____ ____:___ MM/DD/YYYY HH:MM ☐ Unknown ☐ Percutaneous Mechanical Circulatory Support ___/____/_____ ____:___ MM/DD/YYYY HH:MM ☐ Unknown ☐ Transplant ___/____/_____ ____:___ MM/DD/YYYY HH:MM ☐ Unknown ○ CardioMEMs (implantable /hemodynamic monitor) ___/____/_____ ____:___ MM/DD/YYYY HH:MM ☐ Unknown ○ Electrophysiology ☐ AF Ablation (with PVI) ___/____/_____ ____:___ MM/DD/YYYY HH:MM ☐ Unknown ☐ AVN ablation ___/____/_____ ____:___ MM/DD/YYYY HH:MM ☐ Unknown ☐ Cardioversion ___/____/_____ ____:___ MM/DD/YYYY HH:MM ☐ Unknown ☐ CRT-D (Cardiac resynchronization therapy with ○ Revascularization ☐ Coronary Artery Bypass Grafting (CABG) ___/____/_____ ____:___ MM/DD/YYYY HH:MM ☐ Unknown ☐ Percutaneous Coronary Intervention (PCI) ___/____/_____ ____:___ MM/DD/YYYY HH:MM ☐ Unknown ☐ Septal Reduction Therapy ☐ Alcohol Septal Ablation (ASA) ___/____/_____ ____:___ MM/DD/YYYY HH:MM ☐ Unknown ☐ Myectomy ___/____/_____ ____:___ MM/DD/YYYY HH:MM ☐ Unknown ☐ Valvular Heart Disease - Surgical ☐ MV repair ___/____/_____ ____:___ MM/DD/YYYY HH:MM ☐ Unknown ☐ MV replacement ___/____/_____ ____:___ MM/DD/YYYY HH:MM ☐ Unknown ☐ AV replacement ___/____/_____ ____:___ ☐ Unknown ☐ TV repair/replacement ___/____/_____ ____:___ ☐ Unknown

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	ICD) ___/____/_____ ____:___ MM/DD/YYYY HH:MM ☐ Unknown ☐ CRT- P (cardiac resynchronization therapy- pacing only) ___/____/_____ ____:___ MM/DD/YYYY HH:MM ☐ Unknown ☐ Implantable Device Option ___/____/_____ ____:___ MM/DD/YYYY HH:MM ☐ Unknown ☐ Pacemaker ___/____/_____ ____:___ MM/DD/YYYY HH:MM ☐ Unknown ☐ Subcutaneous ICD ___/____/_____ ____:___ MM/DD/YYYY HH:MM ☐ Unknown ☐ SVT ablation ___/____/_____ ____:___ MM/DD/YYYY HH:MM ☐ Unknown ☐ Transvenous ICD ___/____/_____ ____:___ MM/DD/YYYY HH:MM ☐ Unknown ☐ VT ablation ___/____/_____ ____:___ MM/DD/YYYY HH:MM ☐ Valvular Heart Disease - Transcatheter ☐ MV repair ___/____/_____ ____:___ MM/DD/YYYY HH:MM ☐ Unknown ☐ MV replacement ___/____/_____ ____:___ MM/DD/YYYY HH:MM ☐ Unknown ☐ Transcatheter Aortic Valve Replacement (TAVR) ___/____/_____ ____:___ MM/DD/YYYY HH:MM ☐ Unknown ☐ Tricuspid Transcatheter Edge to Edge Repair (TEER) ___/____/_____ ____:___ MM/DD/YYYY HH:MM ☐ Unknown ☐ Tricuspid valve replacement ___/____/_____ ____:___ MM/DD/YYYY HH:MM ☐ Unknown Unknown
AF Ablation	___/____/_____ ____:_____ MM/DD/YYYY HH:MM ☐ Unknown
Labs During Admission	
Labs During Admission - NT-ProBNP	____ ○ pg/mL ○ ng/L ☐ Unavailable
Labs During Admission - BNP	____ ○ pg/mL ○ pmol/L ○ ng/L ☐ Unavailable
Troponin	____ ○ ng/L ○ ng/mL ○ ug/L ☐ Unavailable
Social Determinants of Health	
During this admission, was a standardized health related social needs form or assessment completed?	○ Yes ○ No/ND

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If yes, identify the areas of unmet social need (select all that apply):	☐ None ☐ Education ☐ Employment ☐ Financial Strain ☐ Food ☐ Living Situation/ Housing ☐ Mental Health ☐ Personal Safety ☐ Substance Abuse Disorder ☐ Transportation Barriers ☐ Utilities
If unmet social need (s) identified, were resources provided to the patient?	○ Yes ○ No
If yes, what resources were provided?	☐ Access to a Community Health Worker ☐ Access to a Social Worker ☐ Access to another Case Worker/Support Specialist ☐ Resources for a digital-based community platform (e.g., findhelp.org) ☐ Other
If other resources provided:	_____

Discharge Disposition	
Discharge Date / Time	___/___/_____ ____:_____ MM/DD/YYYY HH:MM ☐ Unknown
What was the patient's discharge disposition on the day of discharge?	○ Home ○ Hospice ○ Acute Care Facility ○ Other Health Care Facility ○ Expired ○ Left Against Medical Advice/AMA ○ Not Documented or Unable to Determine (UTD)
If other health care facility, please specify:	○ Skilled Nursing Facility (SNF) ○ Inpatient Rehabilitation Facility (IRF) ○ Long Term Care Hospital (LCTH) ○ Intermediate Care Facility (ICF) ○ Other

ICD therapy or complication	
Date of ICD therapy or complication	___/___/_____ ____:_____ MM/DD/YYYY ☐ Unknown
ICD therapy or complication type	○ Appropriate Shock VT/VF ○ Appropriate ATP VT/VF ○ Inappropriate Shock ○ Infection ○ Lead damage ○ Need for lead extraction ○ Vascular (SVC occlusion, upper extremity, thrombus) ○ Other
What was the inappropriate reason for shock?	○ Atrial Fibrillation (AF) ○ Lead Fracture ○ Supraventricular Tachycardia (SVT) ○ T Wave Oversensing ○ Other _____
What was arrythmia type?	○ VT ○ VF
# of shocks required to terminate VT/VF:	_____
Did ATP terminate episode of VT/VF?	○ Yes ○ No ○ ND

ASSESSMENTS AND SCREENINGS			
During the assessment period, were any of these assessments and screenings offered or recommended? (If multiple, enter data associated with the most recent assessment or screening management)			
Ambulatory ECG monitoring	○ Yes	○ Not Indicated	○ ND

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Cardiac MRI	○ Yes	○ Not Indicated	○ ND
Echocardiogram	○ Yes	○ Not Indicated	○ ND
Clinic/Office Visit	○ Yes	○ Not Indicated	○ ND
Genetic Testing	○ Yes	○ Not Indicated	○ ND
Ambulatory ECG Monitoring			
Was ambulatory monitoring completed?	○ Yes	○ No / ND	
Reason why ambulatory monitoring was not completed?	○ Patient declined ○ Not documented		
Date of Ambulatory Monitoring Started?	___/____/_____ MM/DD/YYYY	☐ Unknown	
What type of Ambulatory test was performed?	○ Event Monitor ○ Extended Patch Monitor ○ Holter Monitor ○ Implantable Loop Recorder	○ Mobile Cardiac Telemetry ○ Other	
If other ambulatory test, please specify type:	_____		
What was the duration of monitoring for the Ambulatory test performed?	○ 24 hr monitor ○ 48 hr monitor ○ 72 hr monitor	○ 4 - 14-day monitor ○ 15-30-day monitor ○ Extended ○ Other	
If other duration, please specify:	_____		
During Ambulatory monitoring, was there an episode of NSVT?	○ Yes	○ No/ND	
What was the number of non-sustained ventricular tachycardia (NSVT) episodes?	_____		
What was the longest NSVT run?	_____		
What was the fastest NSVT run?	_____		
Any NSVT runs ≥ 10 beats or a rate ≥ 200 bpm?	○ Yes	○ No	
Were any of the following present?	☐ None ☐ AFIB ☐ Complete Heart Block	☐ 2nd Degree Heart Block ○ Type I/Wenckebach ○ Type II/Mobitz ☐ Symptomatic Pause ☐ Other (specify):_____	

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If AFIB, what is the longest duration of AFib episode?	_____	○ Seconds ○ Minutes ○ Hours ○ Days
AF burden on monitor	_____%	
Cardiac MRI		
Was a Cardiac MRI performed?	○ Yes	○ No / ND
Was the Cardiac MRI performed at another facility?	○ Yes	○ No
Reason Cardiac MRI was not completed	○ Patient declined ○ Non-conditional device present ○ Insurance coverage denied ○ Ordered, not yet tested	
Date of MRI	___/____/_____ MM/DD/YYYY	☐ Unknown
Body Surface Area (BSA)	_____ m^2	☐ ND
Left Ventricular Ejection Fraction (LV EF)	_____ %	☐ ND
Left Ventricular Mass (LV Mass ED)	_____ g	☐ ND
Right Ventricular Ejection Fraction (RV EF)	_____ %	☐ ND
Maximum wall thickness - MRI	_____ mm	☐ ND
Region of maximal thickness	☐ Anterior ☐ Apex ☐ Inferior	☐ Lateral ☐ Posterior ☐ Septal
LGE Present	○ Yes	○ No/ND
Method for LGE Quantification	○ 5 standard deviation (SD) ○ 6 standard deviation (SD) ○ Full width-half max (FWHM)	○ Manuel thresholding ○ Other ○ Not performed
Extent LGE (%)	_____	☐ ND
Presence of apical aneurysm?	○ Yes	○ No
If yes, was there a thrombus?	○ Yes	○ No
ECHOCARDIOGRAM		
Was an echocardiogram performed?	○ Yes	○ No / ND
Reason why echocardiogram was not completed	○ Patient declined ○ Not due ○ Not documented	
Type of echocardiogram performed	☐ Resting TTE Echo ☐ Exercise TTE Echo	
Exercise TTE		

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Date of Exercise TTE Echocardiogram	___/____/_____ MM/DD/YYYY	☐ Unknown	
Type of exercise TTE performed:	○ Bicycle ○ Treadmill		○ Not Documented
If treadmill, what exercise protocol type?	○ Bruce ○ Modified Bruce		○ Modified Naughton ○ Naughton ○ Other ○ Not Documented
If other exercise protocol type, please specify:	_____		
Peak heart rate	_____		☐ ND
Max predicted heart rate	_____ %		☐ ND
Metabolic equivalents (METs)	_____		☐ ND
Was there an abnormal BP response?	○ Yes ○ No		
If yes, what was the abnormal BP response?	○ Failure to rise 20 mmHg ○ SBP decrease with exercise		☐ ND
LVOT peak gradient, with exercise	_____ mmHg		☐ ND
LVOT peak gradient, at rest	_____ mmHg		☐ ND
Were there any exercise induced arrhythmias?	○ Yes ○ No		
If yes, what were the exercise induced arrhythmias?	○ Atrial fibrillation/flutter ○ VT		☐ ND
Resting TTE Echo			
Date of Resting TTE Echocardiogram	___/____/_____ MM/DD/YYYY	☐ Unknown	
Maximum Wall Thickness - ECHO	_____	○ cm ○ mm	☐ ND
Septal Wall Thickness - ECHO	_____ mm		☐ ND
Posterior Wall Thickness - ECHO	_____ mm		☐ ND
Hypertrophy type	○ Apical ○ Asymmetric Septum	○ Concentric ○ Mid-Cavity ○ Other ○ Not defined	
Other Hypertrophy type	_____		
Left Atrium Diameter	_____ mm		☐ ND
If Left Atrium Diameter ND, how	○ Normal ○ Mild Enlargement		○ Severe Enlargement

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was arterial enlargement described?	○ Moderate Enlargement	○ Unknown
Left Atrium Volume Index	_____ ml/m^2	☐ ND
LVOT peak gradient, at rest	_____ mmHg	☐ ND
LVOT peak gradient, with valsalva	_____ mmHg	☐ ND
Ejection Fraction (LVEF)	_____ %	☐ ND
Mitral Regurgitation	○ None/Minimal ○ Mild ○ Moderate	○ Severe ○ Not Documented
Clinic/Office Visit		
Date of Office Visit	___/____/_____ MM/DD/YYYY	☐ Unknown
Systolic Blood Pressure	_____ mmHg	☐ ND
Diastolic Blood Pressure	_____ mmHg	☐ ND
Heart Rate	_____ bpm	☐ ND
Height	_____ ○ in ○ cm	Weight _____ ○ lb ○ kg
Height - ND	☐	Weight - ND ☐
Body Surface Area (BSA) – Office Visit	_____ m^2	☐ ND
Sudden Cardiac Death (SCD) Risk Assessment		
Was an SCD assessment completed?	○ Yes	○ No / ND
Reason SCD assessment was not completed	○ Patient declined ○ Test results incomplete ○ ICD already implanted ○ Not documented	
Date of SCD Risk Assessment	___/____/_____ MM/DD/YYYY	☐ Unknown
Age at Evaluation (auto populated)	_____	
Massive LVH	○ Yes	○ No/ND
Family History of HCM related SCD, or unexplained SCD at <50 in first degree relative	○ Yes	○ No
Non-sustained ventricular tachycardia on ambulatory monitor	○ Yes	○ No
Unexplained syncope	○ Yes	○ No
Ejection Fraction ≤ 50%	○ Yes	○ No
Apical Aneurysm	○ Yes	○ No

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Extensive Late Gadolinium Enhancement ≥15%	○ Yes ○ No
Was an AHA/ESC Risk Score quantified?	○ Yes ○ No
If yes, what was the score?	_____
What is the outcome of SCD risk assessment?	○ High risk, referred for consideration of ICD ○ High risk, no referral for ICD ○ Low risk ○ Other ○ ND
If high risk, no referral for ICD, what was reasoning for no ICD referral?	○ Patient declined ○ Provider felt risk of ICD outlay benefit ○ Other
If other reason for no ICD referral, please specify:	_____
If other outcome of SCD, please specify:	_____
Atrial Fibrillation Screening	
Was AF Screening completed?	○ Yes ○ No / ND ○ Not applicable (prior AF history)
Date of AFib Screening	___/____/_____ MM/DD/YYYY ☐ Unknown
If yes, was it high risk?	○ Yes ○ No / ND
If yes, how was high risk determined?	○ Clinical risk factors ○ HCM-AF risk score ○ Other
If other reason for how high risk was determined, please specify:	_____
Was monitor ordered?	○ Yes ○ No / ND
NYHA Class	
Was NYHA Class evaluated?	○ Yes ○ No/ND ○ NC
NYHA Class at presentation:	○ NYHA Class I ○ NYHA Class II ○ NYHA Class III ○ NYHA Class IV ○ ND
If the patient was Class III or Class IV, were they offered symptom management?	○ Yes ○ No/ND
Is the patient currently on a Myosin Inhibitor?	○ Yes ○ No/ND

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If currently on myosin inhibitor during office/clinic visit, which drug is patient on?	☐ Mavacamten ☐ Aficamten
Since the last visit, was there a drop in EF to <50% at any point?	○ Yes ○ No ○ ND
Since myosin inhibitor initiation, was there an improvement in symptoms on therapy?	○ Yes ○ No ○ ND
Will the patient continue myosin inhibitor?	○ Yes ○ No/ND
If no, what was the reason for discontinuation of myosin inhibitor?	○ Decision to pursue invasive septal reduction therapy ○ Drug-drug interaction ○ Heart failure or EF concerns ○ Insurance/ cost issues ○ Lack of symptom improvement ○ Other: _____
Activity Level Counseling	
Activity Level/ Recommendation	○ Yes ○ No ○ NC
If yes, what activity type and plan were discussed?	○ Regular moderate; recreational activity ○ Discussed vigorous activity and developed plan ○ Discussed vigorous activity and discouraged participation
Genetic Testing and Family Management	
Was genetic testing completed?	○ Yes ○ No / ND
Reason genetic testing was not completed	○ Concern about insurance implications ○ Cost ○ Patient not interested/declined ○ No genetic counselor available ○ Not documented ○ Ordered, not yet tested
Date of Gene Test	___/____/_____ MM/DD/YYYY ☐ Unknown
What type of testing occurred?	○ Cardiomyopathy panel ○ Company HCM panel ○ Whole exome ○ Whole genome ○ ND
Was genetic testing positive for pathogenic /likely pathogenic or VUS genetic variant?	○ Yes ○ No/ND
Was a pathogenic or likely pathogenic genetic variant identified?	○ Yes ○ No

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Pathogenic / likely pathogenic involved gene?	☐ ACTC ☐ ALPK3 ☐ GLA ☐ LAMP2 ☐ MYBPC3 ☐ MYH7 ☐ MYL2	☐ MYL3 ☐ PRKAG2 ☐ TNNI3 ☐ TNNT2 ☐ TPM1 ☐ TTR ☐ Other
Was a VUS genetic variant identified?	○ Yes	○ No
VUS involved gene?	☐ ACTC ☐ ALPK3 ☐ GLA ☐ LAMP2 ☐ MYBPC3 ☐ MYH7 ☐ MYL2	☐ MYL3 ☐ PRKAG2 ☐ TNNI3 ☐ TNNT2 ☐ TPM1 ☐ TTR ☐ Other
Were recommendations for first-degree relatives to undergo HCM screening reviewed?	○ Yes	○ No ○ ND
Were first-degree relatives screened for HCM?	○ Yes	○ No ○ ND
If no, why did they not receive screening?	○ Relatives not informed ○ Relatives informed but declined screening ○ Not documented	

PROCEDURES AND SYMPTOM MANAGEMENT			
During the assessment period, were any of the below procedures or symptom management options offered or recommended? (If multiple, entera data associated with the most recent procedure / symptom management)			
Atrial Fibrillation Management	○ Yes	○ Not Indicated	○ ND
Advanced Heart Failure Management (Mechanical Circulatory Support Device & Transplant)	○ Yes	○ Not Indicated	○ ND
Internal Cardiac Defibrillator (ICD)	○ Yes	○ Not Indicated	○ ND
Management of Symptomatic Outflow Obstruction	○ Yes	○ Not Indicated	○ ND
Atrial Fibrillation/ Flutter Management			
Was an anticoagulant prescribed?	○ Yes	○ No	
Reason anticoagulant was not prescribed	○ Bleeding risk ○ Not offered ○ Not documented ○ Patient declined		
Anticoagulant prescribed:	☐ apixaban (Eliquis) ☐ betrixaban (Bevyxxa) ☐ dabigatran (Pradaxa) ☐ desirudin (lprivask) ☐ edoxaban (Savaysa) ☐ fondaparinux (Arixtra) ☐ full dose LMW heparin ☐ rivaroxaban (Xarelto)		

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	☐ warfarin (Coumadin) ☐ Other Anticoagulant
If other anticoagulant, please specify:	_____
Was an antiarrhythmic prescribed?	○ Yes ○ No
Reason antiarrhythmic was not prescribed	○ Alternative treatment strategy ○ Not indicated ○ Not documented ○ Patient declined
Antiarrhythmic prescribed	☐ amiodarone (Cardarone) ☐ disopyramide (Norpace, Norpace CR) ☐ dofetilide (Tikosyn) ☐ dronedarone (Multaq) ☐ flecainide (Tambocor) ☐ Propafenone (Rythmol, Rythmol SR) ☐ quinidine ☐ sotalol (Betapace, Betapace AF) ☐ Other Anti-Arrhythmic
If other antiarrhythmic, please specify:	_____
Were any procedures for the management of AF completed during the assessment period?	☐ None ☐ A-Fib Catheter Ablation ☐ A-Fib Surgical Ablation ☐ A-Flutter Ablation ☐ Chemical Cardioversion ☐ Electric Cardioversion ☐ LAA Occlusion
If LAA Occlusion, what type?	○ Transvenous ○ Surgical
Advanced Heart Failure Management	
Was an MCS device placed?	○ Yes, at this facility ○ Yes, at a different facility ○ No
If MCS was placed at a different facility, please choose the facility name.	_____
Date of MCS implantation	___/____/_____ MM/DD/YYYY ☐ Unknown
Type of MCS device	○ Continuous flow Implanted surgical assist device ○ Pulsatile-Flow Implanted surgical assist device ○ Temporary external device ○ Other
MCS indication	○ Bridge to decision ○ Bridge to recovery ○ Bridge to transplant ○ Destination therapy

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Reason no MCS device was placed	○ Medical reason ○ Patient reason ○ System reason ○ Not documented
Did a transplantation occur?	○ Yes, at this facility ○ Yes, at a different facility ○ No
If transplantation was performed at a different facility, please choose the facility name.	_____
Date of Transplantation	___/____/_____ MM/DD/YYYY ☐ Unknown
Has patient been listed for transplantation?	○ Yes ○ No
Reason heart transplantation was not completed	○ Patient reason ○ System reason ○ Medical reason ○ Not documented
Internal Cardiac Defibrillator (ICD)	
Was an ICD placed?	○ Yes, at this facility ○ Yes, at a different facility ○ No
If ICD was placed at a different facility, please choose the facility name.	_____
Date of ICD placement:	___/____/_____ MM/DD/YYYY ☐ Unknown
If yes, what type?	○ CRT ○ evICD ○ S-ICD ○ Transvenous ○ Other
If Transvenous, what sub-type?	○ Bi-ventricular/cardiac resynchronization therapy-defibrillation (CRT-D) ○ Dual chamber ○ Single ventricular lead
Reason for ICD Placement?	☐ 1-BNR ○ Sustained VT ○ Previous documented cardiac arrest ☐ 2b-BNR ○ Extensive LGE by contrast-enhanced CMR (>/= 15% of LV mass) ○ Nonsustained VT on ambulatory monitoring ☐ LV apical aneurysm with transmural scar or LGE ☐ LV systolic dysfunction (EF <50%). ☐ No reason documented Other

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	☐ 2a-BNR: >= 1 major risk factor for SCD ☐ ≥1 recent episodes of syncope suspected by clinical history to be arrhythmic (ie, unlikely to be of neurocardiogenic [vasovagal] etiology, or related to LVOTO) ☐ Sudden death judged definitively or likely attributable to HCM in ≥1 first-degree or close relatives who are ≤50 years of age Massive LVH ≥30 mm in any LV segment
If other reason for ICD placement, please specify:	_____
Reason ICD was not placed	O Borderline risk profile O Medical reason O Patient declined O System Reason O Not documented
Management of Symptomatic Outflow Obstruction	
Was Septal Reduction Therapy performed?	O Yes, at this facility O Yes, at a different facility O No
If SRT was performed at a different facility, please choose the facility name.	_____
If no, reason for not getting SRT?	O Patient reason O System reason O Medical reason O Not documented
Which SRT was performed?	☐ Alcohol Septal Ablation ☐ Surgical Myectomy ☐ Not documented
Date of Surgical Myectomy	___/____/_____ MM/DD/YYYY ☐ Unknown
Concurrent procedures done at time of myectomy (select all that apply):	☐ None ☐ AF surgery ☐ Left atrial appendage clip/oversewing ☐ MV repair

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	☐ MV replacement ☐ Coronary artery bypass surgery ☐ Other
If surgical myectomy, were there any complications from the procedure?	☐ None ☐ Atrial fibrillation ☐ Bleeding or infection at site of catheter insertion ☐ Blood clots ☐ Complete Heart Block or bradyarrhythmia requiring pacemaker placement ☐ Death ☐ Pericardial effusion requiring drainage ☐ Pleural effusion requiring drainage ☐ Renal failure requiring dialysis ☐ Residual or new severe MR ☐ Residual LVOT obstruction (>/= 30mmHg at rest or >/=50mmHg with provocation) ☐ Strokes ☐ Sustained ventricular tachycardia/cardiac arrest ☐ Ventricular septal defect ☐ Other
If other surgical myectomy complication, please specify:	_____
Date of Alcohol Septal Ablation	___/____/_____ MM/DD/YYYY ☐ Unknown
Reason for Alcohol Septal Ablation	O Advanced Age O High Surgical Risk O Personal Preference O Other
If other reason for alcohol septal ablation, please specify:	_____
If alcohol septal ablation, were there any complications from the procedure?	☐ None ☐ Atrial fibrillation ☐ Bleeding or infection at site of catheter insertion ☐ Blood clots ☐ Complete Heart block or bradyarrhythmia requiring pacemaker placement ☐ Death ☐ Pericardial effusion requiring drainage ☐ Pleural effusion requiring drainage ☐ Residual or new severe MR ☐ Residual LVOT obstruction (>/= 30mmHg at rest or >/=50mmHg with provocation) ☐ Renal failure requiring dialysis ☐ Strokes ☐ Sustained ventricular tachycardia/cardiac arrest ☐ Ventricular septal defect ☐ Other
If other alcohol septal ablation complication, please specify:	_____

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NYHA Class at time of SRT	○ NYHA Class I ○ NYHA Class II ○ NYHA Class III ○ NYHA Class IV ○ ND

DISCONTINUATION OF FOLLOW UP		
Date of Discontinued Follow-Up	___/____/_____ MM/DD/YYYY	☐ Unknown
Reason for Discontinuation	☐ Cardiac Transplant ☐ Change of insurance ☐ Other center / physician is continuing longitudinal care ☐ LVAD placement ☐ Patient died ☐ Patient moved, or was travelling through	☐ Patient lost to follow-up after at least 3 attempts to re-engage ☐ Other ☐ Unknown
Other center providing longitudinal care:		
If other reason for discontinuation, please specify:	_____	
If patient died, what was the date/time of death?	___/____/_____ ____:_____ MM/DD/YYYY HH:MM	Unknown
Cause of death?	○ HCM Death ○ Non HCM Death ○ Other ○ Unknown	
If other cause of death, please specify:	_____	
If HCM death, what was cause?	○ CVA Death ○ Heart Failure Death ○ Post Heart Transplant Death ○ Post SRT death (within 30 days of procedure) ○ SCD ○ Other	
If other HCM death cause, please specify:	_____	
If post myectomy or ASA death, please specify complications:	_____	
If non HCM death, what was cause?	○ Advanced Age ○ CAD Related ○ Death related to non-HCM procedure ○ Infection ○ Malignancy ○ Non-cardiovascular, NOS ○ Other	

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	If other non-HCM death cause, please specify:	_____

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