## Minimum of yearly (+/3 months) scheduled return visit with a cardiologist with ACHD expertise as defined in the guideline\* for patients with Fontan surgery.

Measure Description: Scheduled return visit with a cardiologist with ACHD expertise as defined by the guideline\* at least yearly (+3/months).

Metric Question: Are ACHD cardiologists scheduling patients with Fontan for yearly visits?

Numerator Denominator	Fontan patients with a visit, referral to, or scheduled return visit with a cardiologist with ACHD expertise every 12 months (+3/months); Note: "Had" or were "scheduled to have" accounts for patient non-compliance. Fontan patients
	Excluded Populations:
	<ul> <li>Patient refusal or inability to travel</li> </ul>
Period of Assessment	Reporting year
Sources of Data	Medical records, scheduling
Rationale	

Patients with single ventricle and Fontan surgery are some of the most complex of CHD patients with multiple cardiac and non-cardiac complications. All guidelines recommend regular follow up.

\*A cardiologist with ACHD expertise as defined by the Building Quality Indicators to Improve Care for Adults with Congenital Heart Disease Guideline: A cardiologist who has received level 2 or level 3 ACHD training as per published definitions OR for those who have not received formal training. A cardiologist who spends at least 20% over 9 years or 50% over 5 years of his/her time in ACHD practice.

#### Clinical Recommendation(s)

 Stout KK, Daniels CJ, Aboulhosn JA, et al. 2018 AHA/ACC Guideline for the Management of Adults With Congenital Heart Disease: A Report of the American College of Cardiology/American Heart Association Task Force on Clinical Practice Guidelines. Circulation. 2019 Apr 2; 139 (14):e698-800

Note: Visit is defined as a check-up independent of acute care issues

#### Attribution

This measure should be reported by ACHD specialists

#### Method of Reporting

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#### **Challenges to Implementation**

Differentiation of a patient not following up due to (1) physician not recommending follow up or (2) patient not showing for appointment

# Minimum of yearly (+/3 months) scheduled return visit with a cardiologist, but the cardiologist does not have the ACHD expertise as defined in the guideline\* for patients with Fontan surgery.

Measure Description: Scheduled return visit with a cardiologist, but the cardiologist does not have the ACHD expertise as defined in the guidelines, at least yearly (+/3 months).

Period of AssessmentReporting yearSources of DataMedical records, sche	eduling
Period of Assessment Reporting year	
Excluded Population     Patient refus	<u>s</u> : al or inability to travel
Denominator Fontan patients	
cardiologist, but the defined in the guidel	a visit, referral to, or scheduled return visit with a cardiologist does not have the ACHD expertise as ine*, every 12 months (+/3 months); Note: "Had" o have" accounts for patient non-compliance.

Metric Question: Are cardiologists scheduling patients with Fontan for yearly visits?

Patients with single ventricle and Fontan surgery are some of the most complex of CHD patients with multiple cardiac and non-cardiac complications. All guidelines recommend regular follow up.

\*Patient received counseling or treatment from a cardiologist, but the cardiologist does not have the ACHD expertise as defined in the Guideline by the Building Quality Indicators to Improve Care for Adults with Congenital Heart Disease Guideline: A cardiologist who has received level 2 or level 3 ACHD training as per published definitions OR for those who have not received formal training. A cardiologist who spends at least 20% over 9 years or 50% over 5 years of his/her time in ACHD practice.

#### Clinical Recommendation(s)

 Stout KK, Daniels CJ, Aboulhosn JA, et al. 2018 AHA/ACC Guideline for the Management of Adults With Congenital Heart Disease: A Report of the American College of Cardiology/American Heart Association Task Force on Clinical Practice Guidelines. Circulation. 2019 Apr 2; 139 (14):e698-800

Note: Visit is defined as a check-up independent of acute care issues

#### Attribution

This measure should be reported by pediatric cardiologists, general adult cardiologists

#### Method of Reporting

#### **Challenges to Implementation**

Differentiation of a patient not following up due to (1) physician not recommending follow up or (2) patient not showing for appointment

Oxygen satu	ration at rest at least annually (adult patients age >18)	
Measure Description: Measurement of oxygen saturation at rest in Fontan patients at least every 12 months (+3/months)		
Numerator	Patients with a Fontan who have measurement of oxygen saturation at rest documented in the EMR within the past 12 months (+3/months)	
Denominator	Patients with Fontan surgery and a clinic visit withing the past 12 months (+3/months)	
	Excluded Populations:	
	System	
	None	
Period of Assessment	Reporting year	
Sources of Data	Medical records, physical exam	
	Rationale	
Patients with Fontan procedures are at risk for hypoxia for multiple reasons including veno-venous collaterals, baffle leaks, and pulmonary AVMs.		
	Clinical Recommendation(s)	
<ul> <li><u>ACC/AHA Guidelines</u> <ol> <li>Stout KK, Daniels CJ, Aboulhosn JA, et al. 2018 AHA/ACC Guideline for the Management of Adults With Congenital Heart Disease: A Report of the American College of Cardiology/American Heart Association Task Force on Clinical Practice Guidelines. Circulation. 2019 Apr 2; 139 (14):e698-800</li> <li>*Note: frequency of measurement not noted in guidelines</li> </ol> </li> <li><u>Other guidelines:</u></li> </ul>		
Attribution		
This measure should be reported by pediatric cardiologists, ACHD specialists, general adult cardiologists		
Method of Reporting		
Challenges to Implementation		

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## Annual (+3 months) and comprehensive imaging read by cardiologist with CHD imaging expertise as defined by the guideline\*

Measure Description: Complete transthoracic echocardiogram (TTE) read by cardiologist with CHD imaging expertise as defined by the guideline\* annually (+3 months) (MRI or CT may be substituted for TTE, i.e. either would constitute a pass of the metric)

Numerator	Fontan patients with complete TTE performed or attempted at least every 12 (+3 months) months and read by a cardiologist with CHD imaging expertise as defined by the guideline*
Denominator	All Fontan patients Excluded Populations:
	None
Period of Assessment	Reporting year
Sources of Data	Medical records, imaging reports

#### Rationale

Patients with Fontan operation are at risk for ventricular or valve dysfunction as well as baffle obstruction or leak. Imaging can identify these lesions. As complex single ventricle anatomy is difficult to interpret, the imaging should be performed by an expert in CHD imaging

\*A cardiologist with ACHD expertise as defined by the Building Quality Indicators to Improve Care for Adults with Congenital Heart Disease Guideline

1. An adult cardiologist with ACHD expertise who has level 3 training in echocardiography,

MRI, or cardiac catheterization as defined by the adult training guidelines. OR

2. A pediatric cardiologist with ACHD expertise and with advanced echocardiography, MRI, or cardiac catheterization expertise as defined in the pediatric training guidelines. OR

3. A pediatric cardiologist with advanced technical training or adult cardiologist with level 3 technical training, both as defined by training guidelines, who work in a team with at least 1 ACHD specialist immediately available, on site, for face to face consultation.

\*\*if an MRI or CT is performed in the preceding 12 months, this can substitute for the echo that reporting period

#### Clinical Recommendation(s)

- 1) Stout KK, Daniels CJ, Aboulhosn JA, et al. 2018 AHA/ACC Guideline for the Management of Adults With Congenital Heart Disease: A Report of the American College of Cardiology/American Heart Association Task Force on Clinical Practice Guidelines. Circulation. 2019 Apr 2; 139 (14):e698-800
- 2) Eicken A, Fratz S, Gutfried C, Balling G, Schwaiger M, Lange R, et al. Hearts late after fontan operation have normal mass, normal volume, and reduced systolic function: a magnetic resonance imaging study. J Am Coll Cardiol 2003;42(6):1061-5.

Note: US and Canada support 'periodic' imaging without a specification of type or a frequency recommended. The ESC recommends yearly echocardiography.

#### Attribution

This measure should be reported by pediatric cardiologists, ACHD specialists, general adult cardiologists

#### Method of Reporting

#### **Challenges to Implementation**

#### Annual (+3/months) and comprehensive imaging read by cardiologist, but the cardiologist does not have the ACHD expertise as defined in the guideline\*

Measure Description: Complete transthoracic echocardiogram (TTE) read by cardiologist annually (+/3 months) (MRI or CT may be substituted for TTE, i.e. either would constitute a pass of the metric) but the cardiologist does not have the ACHD expertise as defined in the guideline\*

Numerator	Fontan patients with complete TTE performed or attempted at least every 12 months (+/3 months) and read by a cardiologist but the cardiologist does not have the ACHD expertise as defined in the guideline*
Denominator	All Fontan patients Excluded Populations:
	None
Period of Assessment	Reporting year
Sources of Data	Medical records, imaging reports

#### Rationale

Patients with Fontan operation are at risk for ventricular or valve dysfunction as well as baffle obstruction or leak. Imaging can identify these lesions. As complex single ventricle anatomy is difficult to interpret, the imaging should be performed by an expert in CHD imaging

\*Counseled by a cardiologist but the cardiologist does not have the ACHD expertise as defined in the Guideline Building Quality Indicators to Improve Care for Adults with Congenital Heart Disease 1. An adult cardiologist with ACHD expertise who has level 3 training in echocardiography, MRI, or cardiac catheterization as defined by the adult training guidelines. OR

2. A pediatric cardiologist with ACHD expertise and with advanced echocardiography, MRI, or cardiac catheterization expertise as defined in the pediatric training guidelines. OR

3. A pediatric cardiologist with advanced technical training or adult cardiologist with level 3 technical training, both as defined by training guidelines, who work in a team with at least 1 ACHD specialist immediately available, on site, for face to face consultation.

\*\*if an MRI or CT is performed in the preceding 12 months, this can substitute for the echo that reporting period.

#### **Clinical Recommendation(s)**

1) Stout KK, Daniels CJ, Aboulhosn JA, et al. 2018 AHA/ACC Guideline for the Management of Adults With Congenital Heart Disease: A Report of the American College of Cardiology/American Heart Association Task Force on Clinical Practice Guidelines. Circulation. 2019 Apr 2; 139 (14):e698-800  Eicken A, Fratz S, Gutfried C, Balling G, Schwaiger M, Lange R, et al. Hearts late after fontan operation have normal mass, normal volume, and reduced systolic function: a magnetic resonance imaging study. J Am Coll Cardiol 2003;42(6):1061-5.

Note: US and Canada support 'periodic' imaging without a specification of type or a frequency recommended. The ESC recommends yearly echocardiography.

#### Attribution

This measure should be reported by pediatric cardiologists, ACHD specialists, general adult cardiologists

#### **Method of Reporting**

#### **Challenges to Implementation**

	(adult matients and (10)
Anticoagulati	(adult patients age >18) on for atrial shunt, atrial thrombus, or atrial arrhythmia
Measure Description: A	Anticoagulation with warfarin or other FDA approved anticoagulant for 5, atrial arrhythmia recommended or being taken.
Numerator	Fontan patients with atrial thrombus, history of thromboembolism, or atrial arrhythmia and without contraindication to anticoagulation taking anticoagulation with warfarin or other FDA approved anticoagulant or with anticoagulation recommended
Denominator	Fontan patients with atrial shunt, atrial thrombus or atrial arrhythmia without specified anticoagulation contraindication.
	Excluded Populations:
	None
Period of Assessment	Reporting year
Sources of Data	Medical records, imaging results, medications
	Rationale
Patients with the listed co Fontan circuit	onditions are at high risk for thrombus formation in an already high -risk
	Clinical Recommendation(s)
ACC/AHA Guidelines	
of Adults With Co Cardiology/Amer	CJ, Aboulhosn JA, et al. 2018 AHA/ACC Guideline for the Management ongenital Heart Disease: A Report of the American College of ican Heart Association Task Force on Clinical Practice Guidelines. Apr 2; 139 (14):e698-800
	Attribution
This measure should be re cardiologists	eported by pediatric cardiologists, ACHD specialists, general adult
	Method of Reporting
Challenges to Implementation	
Differentiation between recommendation	recommended anticoagulation and patient non-adherence to that

(adult patients age >18) Pregnancy or contraception counseling by cardiologist with ACHD expertise as defined by the guideline* annually (+/3 months)	
Measure Description: Pregnancy or contraception counseling for female Fontan patients of child- bearing age by cardiologist with ACHD expertise as defined by the guideline* annually (+/3 months)	
Numerator	Female Fontan patients between ages 12 – 50 years who had pregnancy or contraception counseling documented within the past 12 months (+/3 months)
Denominator	<ul> <li>Female Fontan patients between ages 12-50 years</li> <li><u>Excluded Populations</u>:</li> <li>Documented infertility or hysterectomy</li> </ul>
Period of Assessment	Reporting year
Sources of Data	Medical record
Rationale	

Pregnancy is a high -risk endeavor in patients with a Fontan surgery and patients should be counseled as to the risks prior to conception. Certain contraceptives (containing Estrogen) may have risks in Fontan patients and should be readdressed on a regular basis as therapies and medication recommendations may change over time.

#### Clinical Recommendation(s)

#### ACC/AHA Guidelines

 Stout KK, Daniels CJ, Aboulhosn JA, et al. 2018 AHA/ACC Guideline for the Management of Adults With Congenital Heart Disease: A Report of the American College of Cardiology/American Heart Association Task Force on Clinical Practice Guidelines. Circulation. 2019 Apr 2; 139 (14):e698-800

\* A cardiologist with ACHD expertise as defined by the Building Quality Indicators to Improve Care for Adults with Congenital Heart Disease Guideline: A cardiologist who has received level 2 or level 3 ACHD training as per published definitions OR for those who have not received formal training. A cardiologist who spends at least 20% over 9 years or 50% over 5 years of his/her time in ACHD practice.

#### Other guidelines:

None

\*\*Note: Pre-pregnancy evaluation and consultation recommended in US and Canadian guidelines but no frequency provided. Risk of pregnancy in patients with Fontan and general recommendations for multidisciplinary care discussed in ESC guidelines but no specific Fontan prepregnancy counseling noted.

# Other guidelines: None Attribution This measure should be reported by pediatric cardiologists, ACHD specialists, general adult cardiologists Method of Reporting Challenges to Implementation

Ability to measure the documentation of pregnancy or contraception counseling as it is a conversation and not typically an objective finding

## Pregnancy or contraception counseling by cardiologist annually (+/3 months) but the cardiologist does not have the ACHD expertise as defined in the guideline\*

Measure Description: Pregnancy or contraception counseling for female Fontan patients of childbearing age by cardiologist annually (+/3 months), but the cardiologist does not have the ACHD expertise as defined in the guideline\*

Numerator	Female Fontan patients between ages 12 – 50 years who had pregnancy or contraception counseling documented within the past 12 months (+/3 months)
Deneminator	
Denominator	Female Fontan patients between ages 12-50 years
	Excluded Populations:
	<ul> <li>Documented infertility or hysterectomy</li> </ul>
Period of Assessment	Reporting year
Sources of Data	Medical record

#### Rationale

Pregnancy is a high -risk endeavor in patients with a Fontan surgery and patients should be counseled as to the risks prior to conception. Certain contraceptives (containing Estrogen) may have risks in Fontan patients and should be readdressed on a regular basis as therapies and medication recommendations may change over time.

#### Clinical Recommendation(s)

#### ACC/AHA Guidelines

 Stout KK, Daniels CJ, Aboulhosn JA, et al. 2018 AHA/ACC Guideline for the Management of Adults With Congenital Heart Disease: A Report of the American College of Cardiology/American Heart Association Task Force on Clinical Practice Guidelines. Circulation. 2019 Apr 2; 139 (14):e698-800

\* A cardiologist with ACHD expertise as defined by the Building Quality Indicators to Improve Care for Adults with Congenital Heart Disease Guideline : A cardiologist who has received level 2 or level 3 ACHD training as per published definitions OR for those who have not received formal training. A cardiologist who spends at least 20% over 9 years or 50% over 5 years of his/her time in ACHD practice.

\*\*Note: Pre-pregnancy evaluation and consultation recommended in US and Canadian guidelines but no frequency provided. Risk of pregnancy in patients with Fontan and general recommendations for multidisciplinary care discussed in ESC guidelines but no specific Fontan prepregnancy counseling noted.

## Other guidelines: None Attribution

This measure should be reported by pediatric cardiologists, ACHD specialists, general adult cardiologists

#### Method of Reporting

#### **Challenges to Implementation**

Ability to measure the documentation of pregnancy or contraception counseling as it is a conversation and not typically an objective finding

(adult patients age >18)	
Annual measurement of liver function	
Measure Description: Measurement of transaminases (AST, ALT), total protein, albumin, alkaline	
phosphatase and bilirubin in all Fontan patients annually (+3 months)	
Numerator	Fontan patients with measurement of transaminases (AST, ALT), total protein, albumin, alkaline phosphatase and bilirubin documented in the record in the last 12 months (+3 months)
Denominator	Fontan patients
	Excluded Populations:
	None
Period of Assessment	Reporting year
Sources of Data	Medical records, lab
Rationale	
Patients with a Fontan operation are at risk of developing hepatic congestion and fibrosis. Some patients may also proceed to cirrhosis	

#### Clinical Recommendation(s)

1)	Curt J. Daniels, Elisa A. Bradley, Mike J. Landzberg, Jamil Aboulhosn, Robert H. Beekman III, Wendy Book, Michelle Gurvitz, Anitha John, Binu John, Ariane Marelli, Bradley S. Marino, L. LuAnn Minich, John J. Poterucha, Elizabeth B. Rand and Gruschen R. Veldtman. Fontan-Associated Liver Disease
	Proceedings from the American College of Cardiology Stakeholders Meeting, October 1 to 2, 2015, Washington DC. J Am Coll Cardiol. 2017 Dec 26;70(25):3173-3194. doi: 10.1016/j.jacc.2017.10.045.
2)	Kiesewetter CH, Sheron N, Vettukattill JJ, Hacking N, Stedman B, Millward-Sadler H, Haw M, Cope R, Salmon AP, Sivaprakasam MC, Kendall T, Keeton BR, Iredale JP, Veldtman GR. Hepatic changes in the failing Fontan circulation. Heart. 2007 May;93(5):579-84
3)	Kendall TJ, Stedman B, Hacking N, Haw M, Vettukattill JJ, Salmon AP, Cope R, Sheron N, Millward-Sadler H, Veldtman GR, Iredale JP. Hepatic fibrosis and cirrhosis in the Fontan circulation: a detailed morphological study. J Clin Pathol. 2008 Apr;61(4):504-8.
4)	Shah H, Kuehl K, Sherker AH. Liver disease after the Fontan procedure: what the hepatologist needs to know. J Clin Gastroenterol. 2010 Jul;44(6):428-31.
5)	Camposilvan S, Milanesi O, Stellin G, Pettenazzo A, Zancan L, D'Antiga L. Liver and cardiac function in the long term after Fontan operation. Ann Thorac Surg. 2008 Jul;86(1):177-82.
	SC states "Annual blood tests should include haematology, serum albumin, and liver and inction" with no level of evidence applied. Testing for Protein, albumin and hepatic

function mentioned in Canadian guidelines with no frequency or level of evidence. Hepatic function or lab testing not mentioned in US guidelines Other guidelines:

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Curt J. Daniels, Elisa A. Bradley, Mike J. Landzberg, Jamil Aboulhosn, Robert H. Beekman III, Wendy Book, Michelle Gurvitz, Anitha John, Binu John, Ariane Marelli, Bradley S. Marino, L. LuAnn Minich, John J. Poterucha, Elizabeth B. Rand and Gruschen R. Veldtman. Fontan-Associated Liver Disease

Proceedings from the American College of Cardiology Stakeholders Meeting, October 1 to 2, 2015, Washington DC. J Am Coll Cardiol. 2017 Dec 26;70(25):3173-3194. doi: 10.1016/j.jacc.2017.10.045.

#### Attribution

This measure should be reported by... pediatric cardiologists, ACHD specialists, general adult cardiologists

#### Method of Reporting

#### Challenges to Implementation

Labs may be drawn at outside hospitals or labs which may make it difficult to track down the data or more time to look through a clinic note.

(adult nationte ago >10)	
	(adult patients age >18)
Hepatitis C Status	
Measure Description: Measurement of hepatitis C antibody for evidence of hepatitis C infection	
or hepatitis C status documented in the chart	
Numerator	All Fontan patients with measurement of hepatitis C antibody since
Numerator	1992 or HCV status documented in chart
Denominator	All Fontan patients with heart surgery prior to 1992
	Excluded Populations:
	<ul> <li>Patients for whom refusal to be tested for Hepatitis C is documented</li> </ul>
Period of Assessment	Reporting year
Sources of Data	Medical record notes / labs
Rationale	
Patients with a Fontan operation are at risk for liver disease. Concomitant hepatitis C infection will cause even further liver damage and is a treatable condition	
Clinical Recommendation(s)	

- 1) Wang A, Book WM, McConnell M, Lyle T, Rodby K, Mahle WT. Prevalence of hepatitis C infection in adult patients who underwent congenital heart surgery prior to screening in 1992. Am J Cardiol. 2007 Oct 15;100(8):1307-9.
- Vogt M, Lang T, Frösner G, Klingler C, Sendl AF, Zeller A, Wiebecke B, Langer B, Meisner H, Hess J. Prevalence and clinical outcome of hepatitis C infection in children who underwent cardiac surgery before the implementation of blood-donor screening. J Infect. 2006 Apr;52(4):305-8.

Note: Hepatitis C testing is not noted in any of the Fontan guidelines, however given the potential for liver disease in Fontan patients and the potential treatments for Hepatitis C, we thought it was a reasonable metric to propose.

Other guidelines:

Curt J. Daniels, Elisa A. Bradley, Mike J. Landzberg, Jamil Aboulhosn, Robert H. Beekman III, Wendy Book, Michelle Gurvitz, Anitha John, Binu John, Ariane Marelli, Bradley S. Marino, L. LuAnn Minich, John J. Poterucha, Elizabeth B. Rand and Gruschen R. Veldtman. Fontan-Associated Liver Disease

Proceedings from the American College of Cardiology Stakeholders Meeting, October 1 to 2, 2015, Washington DC. J Am Coll Cardiol. 2017 Dec 26;70(25):3173-3194. doi: 10.1016/j.jacc.2017.10.045.

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This measure should be reported by pediatric cardiologists, ACHD specialists, general adult cardiologists

#### Method of Reporting

#### **Challenges to Implementation**

Labs may be drawn at outside hospitals or labs which may make it difficult to track down the data or more time to look through a clinic note.

# Minimum of yearly (+/3 months) scheduled return visit with cardiologist who has an ACHD expertise as defined by the guideline\* in patients with TOF repair and physiologic class B, C, or D[GM1]

Measure Description: Scheduled return visit with a cardiologist with ACHD expertise as defined by the guideline\* at least yearly (+/3 months)–

Question: Are ACHD cardiologists scheduling patients with TOF repair and physiologic class B, C, or D for yearly visits?

Rationale	
Sources of Data	Medical record
Period of Assessment	Reporting year
	· None
Denominator	Patients with TOF repair and physiologic class B, C, or D Excluded Populations:
Numerator	Patients with TOF repair and physiologic class B, C, or D who had, were referred, or were scheduled to have a visit with a cardiologist with ACHD expertise* within the last 15 months. Note: "Had" or were "scheduled to have" accounts for patient non-compliance

Provide rationale for measure: ACHD guidelines recommend yearly surveillance visits in TOF patients given the late sequelae that may occur.

\*A cardiologist with ACHD expertise as defined by the Building Quality Indicators to Improve Care for Adults with Congenital Heart Disease Guideline: A cardiologist who has received level 2 or level 3 ACHD training as per published definitions OR for those who have not received formal training. A cardiologist who spends at least 20% over 9 years or 50% over 5 years of his/her time in ACHD practice.

Clinical Recommendation(s)
ACC/AHA Guidelines
1) Stout KK, Daniels CJ, Aboulhosn JA, et al. 2018 AHA/ACC Guideline for the Management of Adults With Congenital Heart Disease: A Report of the American College of Cardiology/American Heart Association Task Force on Clinical Practice Guidelines. Circulation. 2019 Apr 2; 139 (14):e698-800
Notes: In terms of visit, US Guidelines do not specify the components of the visit but indicate in the text features of the physical exam to be sought. <u>A visit here is defined as a check-up independent of acute care issues.</u>
Other guidelines:
None
Attribution
This measure should be reported by pediatric cardiologists, ACHD cardiologists and general adult cardiologists
Method of Reporting
Challenges to Implementation
Differentiation between scheduled or recommended visits and a patient not showing up

# Minimum of yearly (+/3 months) scheduled return visit with cardiologist but the cardiologist does not have the ACHD expertise as defined in the guideline\*, in patients with TOF repair and physiologic class B, C, or D[GM1]

Measure Description: Scheduled return visit with a cardiologist but the cardiologist does not have the ACHD expertise as defined in the guideline\*, at least yearly (+3/months) –

Question: Are cardiologists scheduling patients with TOF repair and physiologic class B, C, or D for yearly visits?

Rationale		
Sources of Data	Medical record	
Period of Assessment	Reporting year	
	· None	
Denominator	Patients with TOF repair and physiologic class B, C, or D Excluded Populations:	
Numerator	Patients with TOF repair and physiologic class B, C, or D who had, were referred, or were scheduled to have a visit with a cardiologist, but the cardiologist does not have ACHD expertise as defined in the guideline*, within the last 15 months. Note: "Had" or were "scheduled to have" accounts for patient non-compliance	

Provide rationale for measure: ACHD guidelines recommend yearly surveillance visits in TOF patients given the late sequelae that may occur.

\*The patient received counseling by a cardiologist, but the cardiologist does not have ACHD expertise as defined by the Building Quality Indicators to Improve Care for Adults with Congenital Heart Disease Guideline: A cardiologist who has received level 2 or level 3 ACHD training as per published definitions OR

for those who have not received formal training. A cardiologist who spends at least 20% over 9 years or 50% over 5 years of his/her time in ACHD practice.	
Clinical Recommendation(s)	
ACC/AHA Guidelines	
1) Stout KK, Daniels CJ, Aboulhosn JA, et al. 2018 AHA/ACC Guideline for the Management of Adults With Congenital Heart Disease: A Report of the American College of Cardiology/American Heart Association Task Force on Clinical Practice Guidelines. Circulation. 2019 Apr 2; 139 (14):e698-800	
Notes: In terms of visit, US Guidelines do not specify the components of the visit but indicate in the text features of the physical exam to be sought. <u>A visit here is defined as a check-up independent of acute care issues.</u>	
Other guidelines:	
None	
Attribution	
This measure should be reported by pediatric cardiologists, ACHD cardiologists and general adult cardiologists	
Method of Reporting	
Challenges to Implementation	
Differentiation between scheduled or recommended visits and a patient not showing up	

(adult patients age >18) At least yearly (+/3 months) surveillance with electrocardiogram (ECG) in patients with tetralogy of Fallot (TOF) repair and physiologic class B, C, or D		
Measure Description: Annual 12 lead EKG Tracing		
Numerator	Patients with TOF repair and physiologic class B, C, or D who had a 12 lead ECG tracing documented in the medical record within the last 15 months	
Denominator	Patients with TOF repair and physiologic class B, C, or D <u>Excluded Populations</u> : Patients unable to have a reliable ECG performed	
Period of Assessment	Reporting year	
Sources of Data	Medical record	
	Rationale	
Patients with TOF r	repair are prone to both tachy- and bradyarrhythmia as well as sudden death.	
	Clinical Recommendation(s)	
ACC/AHA Guidelines 1) Stout KK, Daniels CJ, Aboulhosn JA, et al. 2018 AHA/ACC Guideline for the Management of Adults With Congenital Heart Disease: A Report of the American College of Cardiology/American Heart Association Task Force on Clinical Practice Guidelines. Circulation. 2019 Apr 2; 139 (14):e698 Other guidelines: None		
	Attribution	
This measure shou cardiologists	This measure should be reported by pediatric cardiologists, ACHD cardiologists and general adult cardiologists	
Method of Reporting		
Challenges to Implementation		

(adult patients age >18) Surveillance of width of QRS complex on 12-lead ECG in patients with repaired TOF	
Measure Description: Clinic note reporting QRS duration from ECG	
Numerator	Patients with TOF repair who have QRS duration noted in msec in clinic note (This is not the same as having the QRS duration automatically generated on the 12 lead ECG report i.e., the latter would not constitute a pass)
Denominator	Number of patients with TOF repair <u>Excluded Populations</u> : Patients who are chronically ventricularly paced
Period of Assessment	Reporting year
Sources of Data	Medical record
	Rationale
QRS duration >180msec H	nas been reported as a risk factor for sudden death in patients with TOF
	Clinical Recommendation(s)
<ul> <li><u>ACC/AHA Guidelines</u> <ol> <li>Gatzoulis M et al. Depolarization-repolarization inhomogeneity after repair of tetralogy of Fallot. The substrate for malignant ventricular tachycardia? Circulation 1997;95:401-4</li> <li>Gatzoulis M et al Mechanoelectrical interaction in tetralogy of Fallot. QRS prolongation relates to right ventricular size and predicts malignant ventricular arrhythmias and sudden death. Circulation 1995; 92: 231-7</li> <li>Notes: US, Canadian and European guidelines discuss the relation between QRS width and ventricular arrhythmia but do not specify a recommendation integrating this measurement in the follow-up.</li> </ol> </li> <li>Other guidelines:         <ul> <li>None</li> </ul> </li> </ul>	
Attribution	
This measure should be reported by pediatric cardiologists, ACHD cardiologists and general adult cardiologists	
Method of Reporting	

#### **Challenges to Implementation**

May be hard to search or document from the medical record as is a text measure rather than objective data in record

## Magnetic resonance imaging (MRI) assessment of RV ejection fraction in adults with TOF repair by CHD specialist with imaging expertise as defined by the guideline\*

Measure Description: At least 1 MRI with measurement of RV ejection fraction performed by CHD specialist with imaging expertise as defined by the guideline\* every 3 years.

Numerator	TOF patients with measured RV ejection fraction on MRI performed by a CHD specialist documented in the last 36 months
Denominator	Patients with TOF repair who do not have a pacemaker or ICD <u>Excluded Populations</u> : · Unable to have MRI for other reasons (e.g. metal implant, claustrophobia [JK2])
Period of Assessment	Reporting year
Sources of Data	Medical record

#### Rationale

CMR is the method of choice for assessment of RV volume and function

\* A cardiologist with ACHD expertise as defined by the Building Quality Indicators to Improve Care for Adults with Congenital Heart Disease Guideline: A cardiologist who has received level 2 or level 3 ACHD training as per published definitions OR for those who have not received formal training. A cardiologist who spends at least 20% over 9 years or 50% over 5 years of his/her time in ACHD practice.

#### Clinical Recommendation(s)

#### ACC/AHA Guidelines

1) Stout KK, Daniels CJ, Aboulhosn JA, et al. 2018 AHA/ACC Guideline for the Management of Adults With Congenital Heart Disease: A Report of the American College of Cardiology/American Heart Association Task Force on Clinical Practice Guidelines. Circulation. 2019 Apr 2; 139 (14):e698-800.

2) van Straten A, Vliegen HW, Hazekamp MG, de Roos A. Right ventricular function late after total repair of tetralogy of Fallot. *European Radiology*.2005;15:702-707

3) Knauth AL, Gauvreau K, Powell AJ, Landzberg MJ, Walsh EP, Lock JE, del Nido PJ, Geva T. Ventricular size and function assessed by cardiac MRI predict major adverse clinical outcomes late after tetralogy of Fallot repair. *Heart*.2008;94:211-216.

4) Alpendurada F, Kilner PJ. Cardiovascular magnetic resonance in the assessment of repaired tetralogy of Fallot. *The International Journal of Cardiovascular Imaging*.2008;24:87

5) **Notes:** All Guideline documents discuss the importance of MRI in follow-up. The US guidelines, indicate that "MRI is now seen as the reference standard". The ESC guidelines indicate that "CMR is the method of choice for assessment of RV volume and function". None however, explicitly designate a surveillance protocol.

Other guidelines:

None[AMD3]

#### Attribution

This measure should be reported by pediatric cardiologists, ACHD cardiologists and general adult cardiologists

#### **Method of Reporting**

#### **Challenges to Implementation**

May be a challenge to define an imager with CHD expertise and should probably be left to the measuring institutions to define that person

#### Magnetic resonance imaging (MRI) assessment of RV ejection fraction in adults with TOF repair by a cardiologist, but the cardiologist does not have imaging expertise as defined by the guideline\*

Measure Description: At least 1 MRI with measurement of RV ejection fraction performed by a cardiologist, but the cardiologist does not have with imaging expertise as defined by the guideline\* every 3 years.

Rationale	
Sources of Data	Medical record
Period of Assessment	Reporting year
Denominator	Patients with TOF repair who do not have a pacemaker or ICD <u>Excluded Populations</u> : · Unable to have MRI for other reasons (e.g. metal implant, claustrophobia [JK2])
Numerator	TOF patients with measured RV ejection fraction on MRI performed by a CHD specialist documented in the last 36 months

CMR is the method of choice for assessment of RV volume and function

\* A cardiologist with ACHD expertise as defined by the Building Quality Indicators to Improve Care for Adults with Congenital Heart Disease Guideline: A cardiologist who has received level 2 or level 3 ACHD training as per published definitions OR for those who have not received formal training. A cardiologist who spends at least 20% over 9 years or 50% over 5 years of his/her time in ACHD practice.

#### **Clinical Recommendation(s)**

### <u>ACC/AHA Guidelines</u> Stout KK, Daniels CJ, Aboulhosn JA, et al. 2018 AHA/ACC Guideline for the Management of Adults With Congenital Heart Disease: A Report of the American College of Cardiology/American Heart Association Task Force on Clinical Practice Guidelines. Circulation. 2019 Apr 2; 139 (14):e698-800. van Straten A, Vliegen HW, Hazekamp MG, de Roos A. Right ventricular function late after total repair of tetralogy of Fallot. *European Radiology*.2005;15:702-707 Knauth AL. Gauvreau K. Powell AJ. Landzberg MJ. Walsh EP. Lock JE. del Nido PJ.

3) Knauth AL, Gauvreau K, Powell AJ, Landzberg MJ, Walsh EP, Lock JE, del Nido PJ, Geva T. Ventricular size and function assessed by cardiac MRI predict major adverse clinical outcomes late after tetralogy of Fallot repair. *Heart*.2008;94:211-216.

4) Alpendurada F, Kilner PJ. Cardiovascular magnetic resonance in the assessment of repaired tetralogy of Fallot. *The International Journal of Cardiovascular Imaging*.2008;24:87

5) **Notes:** All Guideline documents discuss the importance of MRI in follow-up. The US guidelines, indicate that "MRI is now seen as the reference standard". The ESC guidelines indicate that "CMR is the method of choice for assessment of RV volume and function". None however, explicitly designate a surveillance protocol.

Other guidelines:

None[AMD3]

#### Attribution

This measure should be reported by pediatric cardiologists, ACHD cardiologists and general adult cardiologists

#### **Method of Reporting**

#### **Challenges to Implementation**

May be a challenge to define an imager with CHD expertise and should probably be left to the measuring institutions to define that person

(adult patients age >18) In patients with repaired TOF, endocarditis prophylaxis should be recommended if VSD patch leak and/or prosthetic pulmonary valve		
Measure Description: Do	cumentation of SBE prophylaxis counseling or prescription	
Numerator	Patients with SBE prophylaxis counseling or prescription given	
Denominator	Patients with TOF repair and prior endocarditis, VSD patch leak or prosthetic PVR Excluded Populations: · None	
Period of Assessment	Reporting year	
Sources of Data	Medical record	
	Rationale	
Patients with these lesion	ns are at risk for SBE and prophylaxis is recommended.	
	Clinical Recommendation(s)	
<ul> <li><u>ACC/AHA Guidelines</u> <ol> <li>Stout KK, Daniels CJ, Aboulhosn JA, et al. 2018 AHA/ACC Guideline for the Management of Adults WiCongenital Heart Disease: A Report of the American College of Cardiology/American Heart Association Task Force on Clinical Practice Guidelines. Circulation. 2019 Apr 2; 139 (14):e698-800.</li> <li>Wilson W, et al. Prevention of infective endocarditis: guidelines from the American Heart Association (short title) Circulation. 2007 Oct 9;116(15):1736-54.</li> </ol> </li> <li><u>Other guidelines:</u> None</li> </ul>		
	Attribution	
This measure should be reported by pediatric cardiologists, ACHD cardiologists and general adult cardiologists		
Method of Reporting		
Challenges to Implementation		
This will likely be in text a	and thus may be hard to document	

Diagnostic or interventional cardiac catheterization in TOF patients should be performed by CHD specialist with cardiac catheterization expertise as defined by the guideline \*

Measure Description: Diagnostic or interventional cardiac catheterization on the patient with TOF should be performed by CHD specialist with cardiac catheterization expertise as defined in the guideline\*

Numerator	TOF patients having diagnostic or interventional cardiac catheterization by CHD specialist with cardiac catheterization expertise as defined in the guideline*
Denominator	TOF patients having diagnostic or interventional cardiac catheterization <u>Excluded Populations</u> : · None
Period of Assessment	Reporting year
Sources of Data	Medical record/Cardiac catheterization report

Rationale

Patients with TOF may have more difficult anatomy for catheterization than the typical adult and interventional providers should be familiar with these differences to do appropriate studies.

\*A cardiologist with ACHD expertise as defined by the Building Quality Indicators to Improve Care for Adults with Congenital Heart Disease Guideline: A cardiologist who has received level 2 or level 3 ACHD training as per published definitions OR for those who have not received formal training. A cardiologist who spends at least 20% over 9 years or 50% over 5 years of his/her time in ACHD practice.

#### **Clinical Recommendation(s)**

#### ACC/AHA Guidelines

1) Stout KK, Daniels CJ, Aboulhosn JA, et al. 2018 AHA/ACC Guideline for the Management of Adults With Congenital Heart Disease: A Report of the American College of Cardiology/American Heart Association Task Force on Clinical Practice Guidelines. Circulation. 2019 Apr 2; 139 (14):e698-800.

Notes: US guidelines specify that the procedure should be performed in "centers with expertise in cardiac catheterization and management of ACHD patients". Canadian and European guidelines discuss the indications for cardiac catheterization but do not specify the operator/ site expertise.

Other guidelines:

None

#### Attribution

This measure should be reported by pediatric cardiologists, ACHD cardiologists and general adult cardiologists

#### **Method of Reporting**

#### **Challenges to Implementation**

[GM1]Physiologic stage is now in the US guidelines – so not sure how to incorporate. For those who are best TOF (stage A) the guidelines are now 12-24mos.

[JK2]Should these patients have a CT? CT is hard to quantify as the radiation exposure for ejection fraction remains high.

# Diagnostic or interventional cardiac catheterization in TOF patients performed by a cardiologist but the cardiologist does not have expertise as defined by the guideline\*

Measure Description: Diagnostic or interventional cardiac catheterization on the patient with TOF performed by a cardiologist but the cardiologist does not have expertise as defined in the guideline\*

Numerator	TOF patients having diagnostic or interventional cardiac catheterization by a cardiologist but the cardiologist does not have expertise as defined in the guideline*
Denominator	TOF patients having diagnostic or interventional cardiac catheterization <u>Excluded Populations</u> : · None
Period of Assessment	Reporting year
Sources of Data	Medical record/Cardiac catheterization report

Rationale

Patients with TOF may have more difficult anatomy for catheterization than the typical adult and interventional providers should be familiar with these differences to do appropriate studies.

\*A cardiologist with ACHD expertise as defined by the Building Quality Indicators to Improve Care for Adults with Congenital Heart Disease Guideline: A cardiologist who has received level 2 or level 3 ACHD training as per published definitions OR for those who have not received formal training. A cardiologist who spends at least 20% over 9 years or 50% over 5 years of his/her time in ACHD practice.

#### **Clinical Recommendation(s)**

#### ACC/AHA Guidelines

1) Stout KK, Daniels CJ, Aboulhosn JA, et al. 2018 AHA/ACC Guideline for the Management of Adults With Congenital Heart Disease: A Report of the American College of Cardiology/American Heart Association Task Force on Clinical Practice Guidelines. Circulation. 2019 Apr 2; 139 (14):e698-800.

Notes: US guidelines specify that the procedure should be performed in "centers with expertise in cardiac catheterization and management of ACHD patients". Canadian and European guidelines discuss the indications for cardiac catheterization but do not specify the operator/ site expertise.

Other guidelines:

None

#### Attribution

This measure should be reported by pediatric cardiologists, ACHD cardiologists and general adult cardiologists

#### **Method of Reporting**

#### **Challenges to Implementation**

[GM1]Physiologic stage is now in the US guidelines – so not sure how to incorporate. For those who are best TOF (stage A) the guidelines are now 12-24mos.

[JK2]Should these patients have a CT? CT is hard to quantify as the radiation exposure for ejection fraction remains high.