

Supplementary material

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Supplementary Table 1: Cost of additional investigations based on the UK NHS tariff

Secondary Investigations	Cost (€)
Hospital appointment for consultation following screening (<i>includes repeat ECG</i>)	185
Transthoracic echocardiography	83
Exercise stress test	192
Holter	192
Cardiac magnetic resonance imaging	237
24 hour blood pressure monitoring	192
Signal average ECG	30
Electrophysiological study (\pm ablation)	2,250
Implantable loop recorder	2,340
Tilt testing	192
Cardiac computed tomography	124
Transoesophageal echocardiography	326
Chest radiograph	28
Lung function testing	42
Myocardial perfusion nuclear scan	419
Provocation testing for Brugada syndrome	452
Genetic testing: Arrhythmogenic right ventricular cardiomyopathy (8 gene panel)	1,152
Genetic testing: Brugada Syndrome (13 gene panel)	791
Genetic testing: Catecholaminergic polymorphic ventricular tachycardia (5 gene panel)	791
Genetic testing: Dilated cardiomyopathy (28 gene panel)	1,152
Genetic testing: Hypertrophic cardiomyopathy (16 gene panel)	735
Genetic testing: Long QT syndrome (12 gene panel)	848
Genetic testing: Marfan syndrome	961

Supplementary Table 2: Further investigations triggered by cardiovascular screening

	HQ N (%) (95% CI)	HQ and ECG N (%) (95% CI)	ECG N (%) (95% CI)	TOTAL N (%) (95% CI)
Hospital appointment for consultation	675 (2.5%) (2.3%-2.7%)	114 (0.4%) (0.4%-0.5%)	2,175 (8.1%) (7.8%-8.4%)	2,964 (11.0%) (10.5%-11.6%)
Transthoracic echocardiography	623 (2.3%) (2.2%-2.5%)	101 (0.4%) (0.3%-0.5%)	2,136 (7.9%) (7.6%- 8.3%)	2,860 (10.6%) (10.1%-11.2%)
Exercise stress test	132 [‡] (0.5%) (0.4%-0.6%) -	37 [‡] (0.1%) (0.1%-0.2%) 2 [†] (0.01%) (0.0%-0.03%)	314 [‡] (1.2%) (1.1%-1.3%) 44 [†] (0.2%) (0.1%-0.2%)	483 (1.8%) (1.6%-2.1%) 46 [†] (0.2%) (0.1%-0.2%)
Holter	155 [‡] (0.6%) (0.5%-0.7%) 1 [†] (0.01%) (0.0%-0.02%)	41 [‡] (0.1%) (0.1%-0.2%) 2 [†] (0.01%) (0.0%-0.03%)	291 [‡] (1.1%) (1.0%-1.2%) 33 [†] (0.1%) (0.08%-0.2%)	487 (1.8%) (1.6%-2.1%) 36 (0.1%) (0.09%-0.2%)
Cardiac magnetic resonance imaging	25 (0.09%)	25 (0.09%)	183 (0.7%)	233 (0.9%)

	(0.06%-0.1%)	(0.06%-0.1%)	(0.6%-0.8%)	(0.7%-1.1%)
24 hour blood pressure monitoring	2 (0.01%) (0.0%-0.03%)	1 (0.004%) (0.0%-0.02%)	-	3 (0.01%) (0.0%-0.03%)
Signal average ECG	6 (0.02%) (0.01%-0.05%)	3 (0.004%) (0.0-0.03%)	31 (0.1%) (0.09%-0.2%)	40 (0.2%) (0.1%-0.3%)
Electrophysiological study (\pm ablation)	3 (0.01%) (0.0-0.03%) -	- -	- 28* (0.1%) (0.07%-0.2%)	3 (0.01%) (0.0-0.03%) 28* (0.1%) (0.07%-0.2%)
Implantable loop recorder	2 (0.01%) (0.0%-0.03%)	3 (0.01%) (0.0-0.03%)	-	5 (0.02%) (0.01%-0.05%)
Tilt testing	10 (0.04%) (0.02%-0.07%)	1 (0.004%) (0.0%-0.01%)	-	11 (0.04%) (0.02%-0.08%)
Cardiac computed tomography	4 (0.01%) (0.0-0.03%)	1 (0.004%) (0.0%-0.01%)	2 (0.01%) (0.0%-0.03%)	7 (0.03%) (0.0%-0.07%)
Transoesophageal echocardiography	-	-	6 (0.02%)	6 (0.02%)

			(0.01%-0.05%)	(0.01%-0.05%)
Chest radiograph	3 (0.01%) (0.0-0.03%)	-	-	3 (0.01%) (0.0-0.03%)
Lung function testing	1 (0.004%) (0.0%-0.02%)	-	-	1 (0.004%) (0.0%-0.02%)
Myocardial perfusion nuclear scan	-	1 (0.004%) (0.0%-0.01%)	-	1 (0.01%) (0.0%-0.02%)
Provocation testing for Brugada syndrome	32 (0.1%) (0.09%-0.2%)	5 (0.02%) (0.01%-0.05%)	-	37 (0.1%) (0.1%-0.2%)
Genetic testing:				
Arrhythmogenic right ventricular cardiomyopathy (8 gene panel)	-	-	3 (0.01%) (0.0-0.03%)	3 (0.01%) (0.0-0.03%)
Brugada Syndrome (13 gene panel)	6 (0.02%) (0.01%-0.05%)	-	-	6 (0.02%) (0.01%-0.05%)
Catecholaminergic polymorphic ventricular tachycardia (5 gene panel)	2 (0.01%) (0.0%-0.03%)	-	-	2 (0.01%) (0.0%-0.03%)

Dilated cardiomyopathy (28 gene panel)	-	-	3 (0.01%) (0.0-0.03%)	3 (0.01%) (0.0-0.03%)
Hypertrophic cardiomyopathy (16 gene panel)	-	-	11 (0.04%) (0.02%-0.07%)	11 (0.04%) (0.02%-0.07%)
Long QT syndrome (12 gene panel)	1 (0.01%) (0.0%-0.02%)	2 (0.01%) (0.0%-0.03%)	7 (0.03%) (0.02%-0.06%)	10 (0.04%) (0.02%-0.08%)
Marfan syndrome	3 (0.01%) (0.0-0.03%)	-	-	3 (0.01%) (0.0-0.03%)

Key: * risk stratification and treatment for Wolff-Parkinson-White syndrome ECG pattern, †non-invasive risk stratification indication, ‡ diagnostic indication

Supplementary Table 3: Characteristics of individuals identified with cardiovascular disease associated with SCD

Disease	Demographics (Age/Gender)	Health Questionnaire abnormality	ECG abnormality	Diagnostics	Risk stratification	Other tests	Treatment beyond lifestyle advice
BrS	17/F	FH of SCD < 50 years	none	ECHO, Holter, AJM	-	-	-
BrS	32/F	FH of SCD <50 years	none	ECHO, EST, Holter, AJM	-	Gene testing	-
BrS	21/M	FH of SCD < 50 years	none	ECHO, EST, Holter, AJM	-	Gene testing	-
CHB	17/M	FH of PPM at 34 years	none	ECHO, EST, Holter, MRI	-	-	PPM implantation
BrS	24/M	FH of SCD < 50 years	none	ECHO, EST, Holter, AJM	-	Gene testing	-
BrS	26/F	FH of BrS	none	ECHO, EST, Holter, AJM	-	Gene testing	-
CPVT	16/M	Syncope	none	ECHO, EST, Holter	-	Gene testing	Pharmacological treatment
BrS	19/F	FH of SCD < 50 years	none	Holter, AJM	-	-	-
BrS	24/M	FH of SCD < 50 years	none	ECHO, EST, Holter, AJM	-	Gene testing	-
LQTS	22/M	FH of SCD < 50 years	none	EST, Holter	-	Gene testing	Pharmacological treatment
CPVT	18/M	Syncope	none	ECHO, EST, Holter	-	Gene testing	Pharmacological treatment
BrS	29/F	FH of SCD < 50 years	none	ECHO, EST, Holter, AJM	-	Gene testing	-
Marfan syndrome (3)	23/M, 25/F, 31/M	FH of Marfan syndrome	none	ECHO, CXR	-	Gene testing	Pharmacological treatment
LQTS	17/M	FH SCD < 50 years	QTc 480msec, TWI V1-2	ECHO	EST, Holter	Gene testing	Pharmacological treatment
LQTS	19/F	Syncope	QTc 495msec, TWI V1-2	ECHO	EST, Holter	Gene testing	Pharmacological treatment
ARVC	18/M	None	Ventricular Ectopy	ECHO, CMR	Holter	Gene testing	Pharmacological treatment + ICD
ARVC	22/M	none	TWI V1-3	ECHO, SAECG, CMR	Holter	Gene testing	Pharmacological treatment
ARVC	19/F	none	TWI V1-2; Epsilon wave	ECHO,SAECG,CMR	EST, Holter	Gene testing	Pharmacological treatment
DCM	20/F	none	TWI 2,3,avF	ECHO, CMR	EST, Holter	Gene testing	Pharmacological treatment

DCM	18/F	none	Ventricular Ectopy	ECHO, CMR	EST, Holter	Gene testing	Pharmacological treatment
DCM	22/M	none	LAE; LBBB	ECHO	EST, Holter	Gene testing	Pharmacological treatment
HCM	16/M	none	TWI V1-6	ECHO, CMR	EST, Holter	-	-
HCM	22/M	none	ST depression 2,3,avF	ECHO	Holter	Gene testing	-
HCM	17/M	none	ST depression 1,V4-6	ECHO	Holter	Gene testing	Pharmacological treatment
HCM	28/M	none	TWI V1-4	ECHO, CMR	EST, Holter	Gene testing	-
HCM	21/M	none	TWI 2,3,avF	ECHO, CMR	EST, Holter	-	-
HCM	29/F	none	TWI 2,3,avF, V4-6	ECHO, CMR	EST, Holter	Gene testing	-
HCM	30/M	none	TWI 2,3,avF	ECHO, CMR	EST, Holter	Gene testing	-
HCM	34/M	none	TWI 1,V5-6; LAD	ECHO	EST, Holter	Gene testing	-
HCM	35/M	none	TWI 2,3,avF,V4-6	ECHO, CMR	EST, Holter	Gene testing	-
HCM	19/F	none	TWI V1-2, 3,avF	ECHO	Holter	Gene testing	-
HCM	19/M	none	TWI V4-6	ECHO, CMR	EST, Holter	Gene testing	-
HCM	24/M	none	TWI 1,2,3,avF,V4-6	ECHO, CMR	EST, Holter	Gene testing	-
HCM	22/M	none	TWI 1,2,3,avF,V4-6	ECHO, CMR	Holter	Gene testing	-
HCM	16/M	none	TWI 2,3,avF,V4-6	ECHO	Holter	-	-
LQTS	22/F	none	QTc 511 msec	-	Holter	Gene testing	Pharmacological treatment
LQTS	21/F	none	QTc 491 msec	-	Holter	Gene testing	Pharmacological treatment
LQTS	24/M	none	QTc 527 msec	-	Holter	Gene testing	Pharmacological treatment
LQTS	18/F	none	QTc 480msec	EST	Holter	Gene testing	Pharmacological treatment
LQTS	19/M	none	QTc 530 msec	-	Holter	Gene testing	Pharmacological treatment
LQTS	27/F	none	QTc 490 msec	EST	Holter	Gene testing	Pharmacological treatment
LQTS	21/M	none	QTc 486 msec	EST	Holter	Gene testing	Pharmacological treatment
NCCM	30/F	none	TWI V1-5	ECHO, CMR	Holter	-	Pharmacological treatment + ICD

NCCM	28/F	none	ST depression 3,avF,V5-6	ECHO, CMR	Holter	-	Pharmacological treatment
WPW (42)	Mean age: 22 31/42 M (74%)	none	Short PR, Delta wave	ECHO (23)	EST (20) Holter (15) EPS (28)	-	Conservative management (16) Ablation treatment (26)

Key:

AJM: Ajmaline provocation testing; ARVC: Arrhythmogenic right ventricular cardiomyopathy; BrS: Brugada syndrome; CHB: Complete heart block; CPVT: Catecholaminergic polymorphic ventricular tachycardia; CMR; Cardiac magnetic resonance imaging; DCM: Dilated cardiomyopathy; ECHO: Echocardiography; EPS: Electrophysiology study; EST: Exercise stress test; F: Female; FH: Family history; HCM: Hypertrophic cardiomyopathy; ICD: Implantable cardioverter defibrillator; LAD: Left axis deviation; LAE: Left atrial enlargement; LBBB: Left bundle branch block; LQTS: Long QT syndrome; M: Male; NCCM: Non-compaction left ventricular cardiomyopathy; PR: PR interval; PPM: Permanent pacemaker; SAECG: Signal average electrocardiography; SCD: Sudden cardiac death; TWI: T-wave inversions; WPW: Wolff-Parkinson-White (WPW) ECG pattern.

Supplementary Table 4: Characteristics of individuals identified with other cardiac disease requiring surveillance

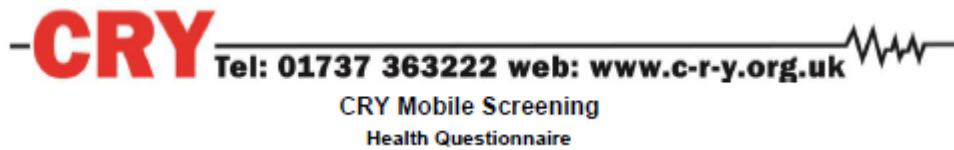
Disease	N	Method of identification	Diagnostics	Comments
Atrial fibrillation	6	HQ (2) ECG (4)	ECHO (4) Holter (1)	Cardioversion was performed in 3 individuals Ablation was performed in 1 individual
Atrial septal defect	13	HQ (2) ECG (11)	ECHO (11) TOE (4)	All individuals managed conservatively with no evidence of pulmonary hypertension.
Atrial tachycardia	2	HQ (0) ECG (2)	ECHO (2) EPS (1)	One individual treated with ablation
AV nodal re-entry tachycardia	1	HQ (1) ECG (0)	EST (1) EPS (1) Holter (1)	Individual treated with ablation
Bicuspid aortic valve	26	HQ (10) HQ/ECG (2) ECG (14)	ECHO (22)	None with >mild aortic valve functional disease None with concomitant aortopathy
Cor-triatriatum	2	HQ (0)	ECHO (2)	Conservative management

		ECG (2)	CMR (1)	
Hypertension	5	HQ (4) HQ/ECG (1) ECG (0)	ECHO (5) CMR (1)	All individuals commenced on antihypertensive agents
Mitral valve prolapse	3	HQ (1) ECG (2)	ECHO (2)	All individuals conservatively managed

Key:

CMR; Cardiac magnetic resonance imaging; ECHO: Echocardiography; EST: Exercise stress test; HQ: Health questionnaire; TOE: Trans-oesophageal echocardiography.

Supplementary Figure 1: Health questionnaire



For Office Use Only			
Payment Received:	Questionnaire Checked:	Info box ticked:	Consent Signed:
Seen By Doctor:	Follow-up Required: Yes		No
Additional Notes:			
Result:			

Patient ID no (for office use only):

Full Name:	Date of Screening:
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Parents names if under 16:

Personal Details

Home (correspondence) address:		Doctors name and Address:	
POSTCODE:		POSTCODE:	
Phone Number:		Phone Number:	
E-mail:			
Date of Birth:	Age:	Gender:	Main Sport(s):
Have you had an ECG test before?		If so, when and where?	
Are you taking any medication:		If so, please describe?	

Ethnicity (please tick the appropriate box)

White	Mixed	Black	Asian	Other
British <input type="checkbox"/>	White and Black Caribbean <input type="checkbox"/>	Caribbean <input type="checkbox"/>	Indian <input type="checkbox"/>	Chinese <input type="checkbox"/>
Irish <input type="checkbox"/>	White and Black African <input type="checkbox"/>	East African <input type="checkbox"/>	Pakistani <input type="checkbox"/>	Filipino <input type="checkbox"/>
Turkish /Cypriot <input type="checkbox"/>	White and Asian <input type="checkbox"/>	West African <input type="checkbox"/>	Bangladeshi <input type="checkbox"/>	Vietnamese <input type="checkbox"/>
Greek /Cypriot <input type="checkbox"/>		North African <input type="checkbox"/>		Other <input type="checkbox"/>
If other, please state your ethnic origin:				

Heightcm	WeightKg
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1. Have you ever fainted?

During Exercise	Yes / No	How recently did this occur?	If yes, please describe the circumstances
Following Exercise	Yes / No	How recently did this occur?	
Unrelated to exercise	Yes / No	How recently did this occur?	

2. Do you experience dizzy turns?

During Exercise	Yes / No	How recently did this occur?	If yes, please describe the circumstances
Following Exercise	Yes / No	How recently did this occur?	
Unrelated to exercise	Yes / No	How recently did this occur?	

Do you experience palpitations? (*palpitations are a fluttering in your chest that you can notice whilst resting*)

Yes / No	If yes, how recently and please describe the circumstances
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3. Do you experience chest pain, heaviness or tightness?

During Exercise	Yes / No	If yes, please describe the circumstances
Following Exercise	Yes / No	
Unrelated to exercise	Yes / No	

4. Do you feel that you are more breathless or more easily tired than your team mates?

Yes / No	If yes, please describe the circumstances
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5. Is there a family history of heart disease in anyone under the age of 50?

Yes / No	If yes, how are they related to you, what is the diagnosis? Please state the age of onset
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6. Has anyone died suddenly in your family under the age of 50?

Yes / No	If yes, how were they related to you? Please describe the circumstances and at what age did the death occur
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7. Approximately, how many days per week are you physically active (playing sport)?

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8. On average, how many hours per week are you physically active (playing sport)?

.....

9. If you are competitive athlete what sports do you play and at what level?

e.g. International,
National, County,

(Main sport).....

Level: