

Supplementary File 1: Adaptation of the FH KAP Questionnaire

Adaptation of the FH KAP Questionnaire for Knowledge Domain

Item No.	Area	Original Question and Answer	Modification/ Addition
3	Description of FH	<p>Question:</p> <p>Which one description below best describes FH?</p> <p>Answer:</p> <ul style="list-style-type: none">- The presence of family members with diagnosed high cholesterol- A genetic disorder that is characterized by very high cholesterol and a family history of premature heart disease- The presence of multiple lipid abnormalities that may be genetic in nature- An ultra-rare, potentially fatal condition caused by cholesterol levels that can be up to six times the normal level- Don't know- Others (please specify)	<p>Question: Rephrased</p> <p>Which one of the following descriptions best describes FH?</p> <p>Answer: No change</p>
4	Lipid profile of FH	<p>Question:</p> <p>Which one of the following lipid profiles is most consistent with the diagnosis of FH? (Reference intervals: Total cholesterol < 5.5mmol/L; Triglyceride < 1.7mmol/L; HDL-cholesterol >1.0mmol/L; LDL-cholesterol < 3.5mmol/L)</p>	<p>Question: No change</p>

Answer:

- Total cholesterol 6.0mmol/L; Triglyceride 3.4mmol/L; HDL-cholesterol 0.8mmol/L; LDL-cholesterol 3.8mmol/L
- Total cholesterol 6.3mmol/L; Triglyceride 12.2mmol/L; HDL-cholesterol 1.0mmol/L; LDL- - mmol/L
- Total cholesterol 8.0mmol/L; Triglyceride 1.1mmol/L; HDL-cholesterol 1.0mmol/L; LDL-cholesterol 6.5mmol/L
- Total cholesterol 5.4mmol/L; Triglyceride 1.3mmol/L; HDL-cholesterol 1.7mmol/L; LDL-cholesterol 3.1mmol/L
- Total cholesterol 7.1mmol/L; Triglyceride 1.0mmol/L; HDL-cholesterol 3.5mmol/L; LDL-cholesterol 3.2mmol/L

Answer: Rephrased

- Total cholesterol 6.3mmol/L; Triglyceride 12.2mmol/L; HDL-cholesterol 1.0mmol/L; LDL-cholesterol not reported

6 Prevalence of FH

Question:

What is the prevalence of FH in Australia?

Answer:

- 1 in 100 persons
- 1 in 500 persons
- 1 in 1000 persons
- 1 in 2000 persons
- 1 in 5000 persons
- Don`t know

Question: Modified

What is the prevalence of FH globally?

Answer: No change

7	Inheritance of FH	<p>Question:</p> <p>What is the likelihood that first-degree relatives (i.e. parents, siblings and children) of someone who has FH will also have the condition themselves?</p>	Question: No change
		Answer:	Answer: No change
		<ul style="list-style-type: none"> - 0% - 25% - 50% - 75% - 100% - Don` t know 	
8	CAD risk in FH	<p>Question</p> <p>How much greater is the risk of premature coronary artery disease (CAD) in untreated FH patients compared to the general population?</p>	Question: No change
		Answer:	Answer: No change
		<ul style="list-style-type: none"> - 2 times greater - 5 times greater - 10 times greater - 20 times greater - 50 times greater - Don` t know 	
9	Premature CAD age	<p>Question:</p> <p>When you are assessing a patient`s family history, at what age for males and females do you consider CAD to be `premature`? Leave blank if you wish to answer `Don` t know`</p>	<p>Question: Rephrased</p> <p>When you are assessing a patient`s family history, at what cut-off age for males and females do you consider CAD to be `premature`? Leave blank if you wish to answer `Don` t know`</p>

11	Genetic test in FH	<p>Question:</p> <p>Is the following statement true or false? An accurate diagnosis of FH can only be made via genetic test.</p> <p>Answer:</p> <ul style="list-style-type: none"> - True - False - Don`t know 	<p>Question: No change</p> <p>Answer: No change</p>
22	Target LDL-c in FH	*Nil	<p>New Question:</p> <p>What is the target LDL-c following maximum tolerated dose of high intensity statin for patients diagnosed with FH?</p> <p>Answer:</p> <ul style="list-style-type: none"> - < 1.8 mmol/L - < 2.6 mmol/L - < 3.4 mmol/L - > 50% reduction from baseline LDL-c concentration - > 30% reduction from baseline LDL-c concentration - Don`t know
23	Family history in FH	*Nil	<p>New Question:</p> <p>Which of the following options are important to obtain from family history in patients with FH? (Please select all that apply)</p> <p>Answer:</p> <ul style="list-style-type: none"> - Consanguinity - Family history of premature CAD (age of

onset)

- Family history of hypercholesterolaemia (TC and/ or LDL-c)
- Family history of tendon xanthomata
- Family history of unexplained childhood death
- Three-generation pedigree chart
- None of the above
- Don` t know

24 Exclusion of FH diagnosis *Nil

New Question:

Which of the following options would exclude the diagnosis of FH? (Please select all that apply)

Answer:

- Normal LDL-c concentration before puberty
- Absence of clinical signs (e.g. tendon xanthomata)
- Absence of mutation on genetic testing
- Absence of ultrasound finding of tendon xanthomata
- None of the above
- Don` t know

25 Management options in FH *Nil

New Question:

Which of the following are the management options for FH patients? (Please select all that apply)

Answer:

- Lifestyle modification is a substitute for lipid lowering medication
 - Ezetimibe co-administered with statin therapy
-

is recommended as an option for adult heterozygous FH

- Lipid lowering drug therapy is considered by the age of 10 years

- Lipid modifying therapy should be continued during pregnancy

- Progress of cascade screening in FH patients should be recorded

- None of the above

- Don't know

Total items: 7

Total items: 11

Adaptation of the FH KAP Questionnaire for Awareness Domain

Item No.	Area	Original Question and Answer	Modification/ Addition
1	Familiarity with FH	<p>Question:</p> <p>On a scale of 1 to 7; how familiar are you with FH? (1-Never heard about it to 7-very familiar)</p> <p>Answer:</p> <p>7-point Likert scale (score of 5,6,7 is considered familiar)</p>	<p>Question: No change</p> <p>Answer: No change</p>
2	Awareness of FH guideline	<p>Question:</p> <p>Are you aware of the National Heart Foundation/ Cardiac Society of Australian and New Zealand guidelines on the detection and management of Familial Hypercholesterolaemia?</p> <p>Answer:</p> <p>- Yes</p> <p>- No</p>	<p>Question: Modified</p> <p>Are you aware of the National Institute for Health and Care Excellence (NICE) on Identification and Management of Familial Hypercholesterolaemia (2008)?</p> <p>Answer: No change</p>
16	Awareness of lipid specialist	<p>Question:</p> <p>Are you aware of any specialist-clinical services for lipid disorders to whom you can refer patients?</p> <p>Answer:</p> <p>- Yes</p> <p>- No (Go to question 18)</p>	<p>Question: No change</p> <p>Answer: No change except for question number</p> <p>- Yes</p> <p>- No (Go to question 17)</p>

*This item was re-numbered to 15

19 Awareness *Nil
of other
international
FH
guideline

New Question:

Which of the following FH clinical guidelines that you are aware of? (Please select all that apply)

Answer:

- Integrated Guidance on the Care of Familial Hypercholesterolaemia by the International FH Foundation (2014)
- Homozygous Familial Hypercholesterolaemia: New Insight and Guidance for Clinicians to Improve Detection and Clinical Management. A Position Paper from the Consensus Panel on Familial Hypercholesterolaemia of the European Atherosclerosis Society (EAS) (2014)
- Guidelines for the Management of Familial Hypercholesterolemia (Harada-Shiba, 2012)
- Clinical Guidance by the National Lipid Association (NLA) Expert Panel on Familial Hypercholesterolaemia (2011)
- None
- Others (please specify)

20 Awareness *Nil
of FH
diagnostic
criteria

New Question:

Which of the following FH diagnostic criteria that you are aware of? (Please select all that apply)

Answer:

- Dutch Lipid Clinic Network Criteria
 - Simon Broome Register Criteria
 - US MED-PED Criteria
-

- Japanese Criteria

- None

- Others (please specify)

Total items: 3

Total items: 5

Adaptation of the FH KAP Questionnaire for Practice Domain

Item No.	Area	Original Question and Answer	Modification/Addition
5	Assistance in FH detection	<p>Question:</p> <p>Which one of the following options could usefully assist you in detection of FH in your practice?</p> <p>Answer:</p> <ul style="list-style-type: none"> - Laboratory report on a lipid profile alerting possible FH - Alert by the clinical software system in your practice - Direct telephone call from the laboratory - All of the above - None of the above - Don` t know - Others (please specify) 	<p>Question: No change</p> <p>Answer: No change</p>
10	Family screening of FH	<p>Question:</p> <p>In patients with documented premature CAD, which of the following do you routinely carry out? (Please tick all that apply)</p> <p>Answer:</p> <ul style="list-style-type: none"> - Look for arcus cornealis - Look for tendon xanthomata - Take a detailed family history of CAD - Screen close relatives for hypercholesterolaemia - All of the above 	<p>Question: Rephrased</p> <p>In patients with documented premature CAD, which of the following options do you routinely carry out? (Please tick all that apply)</p> <p>Answer: No change</p>

		- None of the above	
12	Number of FH patients under care	<p>Question:</p> <p>How many patients currently under your care, if any, have been formally diagnosed with FH?</p> <p>*Fill in answer</p>	Moved to demography
13	Screening of relatives in FH	<p>Question:</p> <p>If you have patients with FH under your care, do you routinely screen close relatives for this condition with a lipid profile?</p> <p>Answer:</p> <ul style="list-style-type: none"> - Yes, patient's children only - Yes, patient's children and other close relatives - No - Not applicable 	<p>Question: No change</p> <p>Answer: No change</p> <p>*This item was re-numbered to 12</p>
14	Effective healthcare provider in FH	<p>Question:</p> <p>In your view, which healthcare providers would be most effective at early detection of FH and screening first-degree relatives? (Please tick up to two options)</p> <p>Answer:</p> <ul style="list-style-type: none"> - Lipid specialists - General practitioners - Cardiologists - Nurses with experience in cardiac 	<p>Question: No change</p> <p>Answer: No change</p>

		<p>risk prevention</p> <ul style="list-style-type: none"> - Paediatricians - Obstetricians/ Gynaecologists - Endocrinologists - Others (please specify) 	*This item was re-numbered to 13
15	Age for FH screening in young person	<p>Question:</p> <p>At what age would you test young individuals for hypercholesterolaemia in a family with premature CAD?</p> <p>Answer:</p> <ul style="list-style-type: none"> - 0 - 6 years - 7 - 12 years - 13 - 18 years - None of the above - Don` t know 	<p>Question: No change</p> <p>Answer: No change</p> <p>*This items was re-numbered to 14</p>
17	Referral to lipid specialist	<p>Question:</p> <p>If yes to question 16, have you referred patients with FH to this service?</p> <p>Answer:</p> <ul style="list-style-type: none"> - Yes - No - Don` t know 	<p>Question: No change except for question number</p> <p>If yes to question 15, have you referred patients with FH to this service?</p> <p>Answer: No change</p> <p>*This item was re-numbered to 16</p>
18	Pharmacotherapy used in hypercholesterolaemia	<p>Question:</p> <p>Which drugs do you use to treat hypercholesterolaemia? (Please select all that apply)</p> <p>Answer:</p>	<p>Question: Rephrased</p> <p>Which pharmacological agent(s) do you commonly used to treat hypercholesterolaemia? (Please select all that apply)</p>

- Exchange resins / bile acid sequestrants
- Ezetimibe
- Statins
- Fibrates
- Nicotinic acid
- None of the above
- Others (please specify)

Answer: No change

*This item was re-numbered to 17

19	Combined pharmacotherapy used in severe hypercholesterolaemia (FH)	<p>Question:</p> <p>Which drug combinations do you use to treat severe hypercholesterolaemia? (Please select all that apply)</p> <p>Answer:</p> <ul style="list-style-type: none"> - Statin + exchange resins / bile acid sequestrants - Statin + nicotinic acid - Statin + ezetimibe - Statin + ezetimibe + nicotinic acid - Statin + ezetimibe + exchange resins / bile acid sequestrants - None of the above - Others (please specify) 	<p>Question: Rephrased</p> <p>Which pharmacological combination(s) do you use to treat severe hypercholesterolaemia? (Please select all that apply)</p> <p>Answer: No change</p>
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*This item was re-numbered to 18

21	CAD risk stratification in FH	*Nil	<p>New Question:</p> <p>How would you risk stratify patients diagnosed with FH clinically?</p> <p>Answer:</p>
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- Perform coronary risk scoring e.g. Framingham Risk Score
 - Classify patients as high risk irrespective of other risk factors
 - Calculate calcium score using cardiac CT scan
 - Determine serum hsCRP concentration
 - Don't know

Total items: 9

Total items: 9
