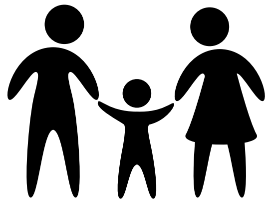
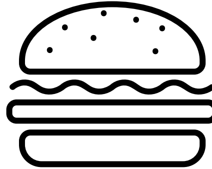
Understanding your Cholesterol

Why do I have High Cholesterol?

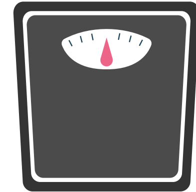


FH

Family History



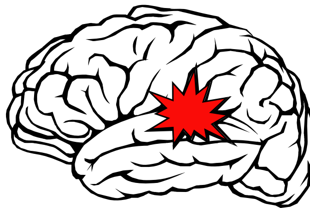
High Saturated Fat Diet



High Body Weight

What are the consequences of High Cholesterol?

Heart Attack



Stroke

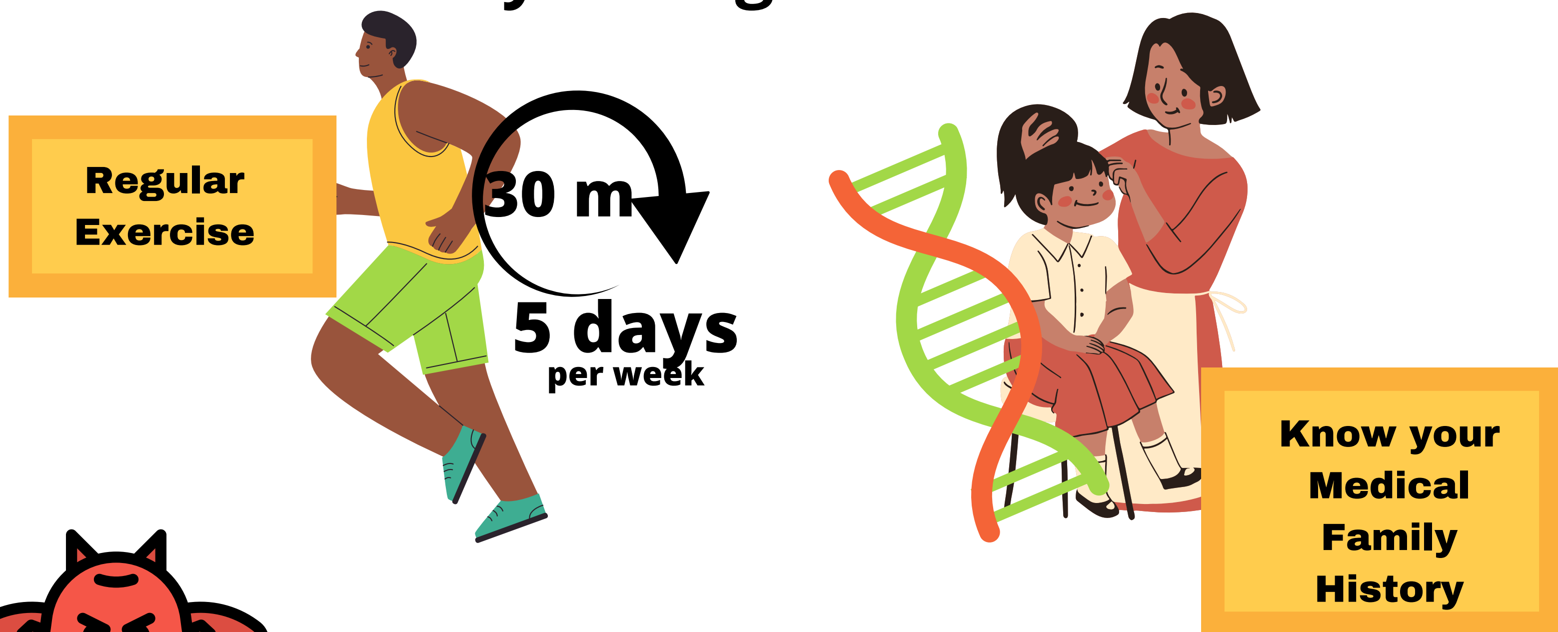
Early Death

Why should I take my medications?

Your medications help lower your cholesterol in combination with a healthy diet and exercise. Keep taking them even after your cholesterol levels decrease.

What foods are healthy?

Other Healthy Changes



Treatment Goals

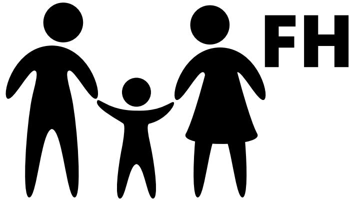
Everyone **LDL-C less than 100 mg/dL**

If you have Cardiovascular Disease **LDL-C less than 70 mg/dL**

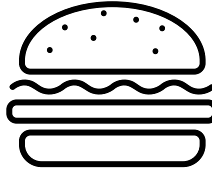
FH FOUNDATION®

Entendiendo su Colesterol

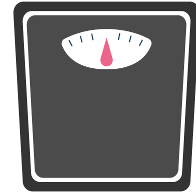
¿Por que sufro del Colesterol Alto?



Historial Familiar



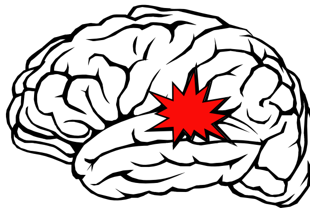
Dieta de Grasas Saturadas



Peso Alto

¿Cuales son las consecuencias del Colesterol Alto?

Ataque al Corazón



Derrame Cerebral

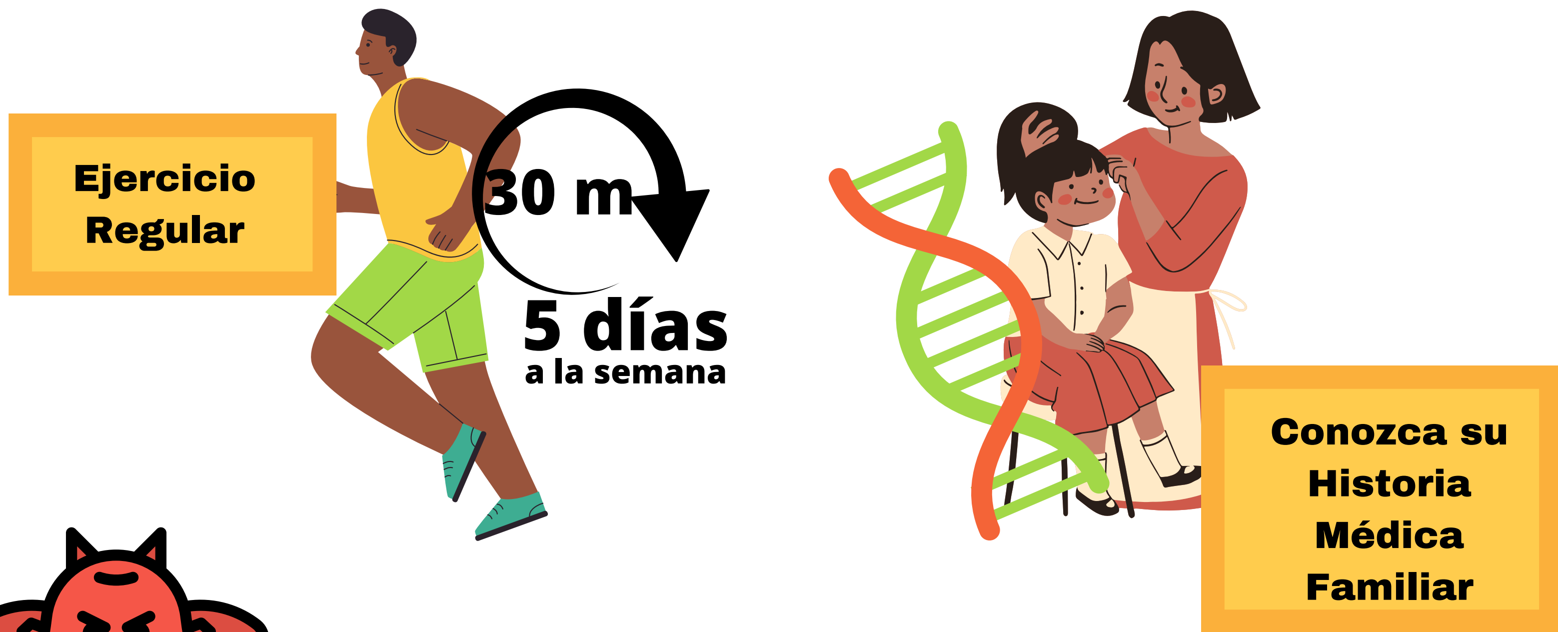
Muerte Temprana

¿Por que debo tomar mis medicamentos?

Sus medicamentos ayudan a bajar su colesterol en combinación con su dieta y nivel de actividad. Siga tomándolos aún después de que sus niveles de colesterol bajen.

¿Que comidas son saludables?

Otros Cambios Saludables



Metas de Tratamiento

Todos LDL-C menos de 100 mg/dL

Si tiene problemas Cardiovasculares LDL-C menos de 70 mg/dL

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Please indicate if the next 9 statements are True or False

	True	False
1. My diet is the only cause of my high cholesterol	☐	☐
2. One reason I have high cholesterol is that I inherited it from my family	☐	☐
3. High cholesterol increases my risk of heart attack	☐	☐
4. I can control my high cholesterol with medication	☐	☐
5. My diet affects my cholesterol levels even more than my medication	☐	☐
6. Avocado is a healthy snack for someone with high cholesterol	☐	☐
7. If I have high cholesterol, I should exercise	☐	☐
8. My children do not need to worry about their cholesterol	☐	☐
9. I do not understand what cholesterol means	☐	☐

Please answer the next 3 questions to the best of your ability

	Extremely	Quite a bit	Somewhat	A little bit	Not at all
How confident are you filling out medical forms by yourself?	☐	☐	☐	☐	☐
	Always	Often	Sometimes	Occasionally	Never
How often do you have problems learning about your medical condition because of difficulty understanding written information?	☐	☐	☐	☐	☐
How often do you have someone (like a family member, friend, hospital/clinic worker, or caregiver) help you read hospital materials?	☐	☐	☐	☐	☐

Please answer a few questions about yourself

Age (years):

Gender: Female ☐ Male ☐ Prefer not to respond ☐

Race:	American Indian/Alaska Native	☐
	Asian	☐
	Native Hawaiian or Other Pacific Islander	☐
	Black or African American	☐
	White	☐
	More Than One Race	☐
	Unknown/Not Reported	☐
Ethnicity:	Hispanic or Latino	☐
	NOT Hispaic or Latino	☐
	Unknown/Not Reported	☐

Por favor indique si las siguientes 9 declaraciones son Verdaderas o Falsas

	Verdadero	Falso
1. Mi dieta es la única causa de mi colesterol alto	☐	☐
2. La herencia genética de mi familia es una causa de mi colesterol alto	☐	☐
3. El colesterol alto aumenta mi riesgo de ataque al corazón	☐	☐
4. Puedo controlar mi colesterol alto con medicamentos	☐	☐
5. Mi dieta afecta mi nivel de colesterol más que mis medicamentos	☐	☐
6. El aguacate es una merienda saludable para alguien con colesterol alto	☐	☐
7. Si tengo el colesterol alto, debo hacer ejercicio	☐	☐
8. Mis hijos no deben preocuparse por sus niveles de colesterol	☐	☐
9. No entiendo que significa el colesterol	☐	☐

Por favor responda a las proximas 3 preguntas como pueda

	Exremad amente	Bastante	Neutral	Un poco	Nada
¿Qué tan seguro(a) se siente al llenar formas usted solo(a)?	◻	◻	◻	◻	◻
	Siempre	Frecuente mente	Ocasional mente	Raramente	Nunca
¿Qué tan seguido tiene problemas aprendiendo sobre su condición médica porque es difícil entender información escrita?	◻	◻	◻	◻	◻
¿Qué tan seguido tiene usted, un familiar, un amigo(a), un empleado(a) del hospital o la clínica u otra persona que le ayude a leer materiales del hospital?	◻	◻	◻	◻	◻

Por favor responda unas preguntas sobre usted mismo(a)

Edad (años):

Sexo: Mujer ◻ Hombre ◻ Prefiero no responder ◻

Raza:	Indígeno de las Américas o nativo de Alaska	◻
	Asiático	◻
	Indígeno de Hawaii o Otra de las islas del Pacífico	◻
	Negro o Afroamericano	◻
	Blanco	◻
	Más de Una Raza	◻
	Desconocido / No Reportado	◻
Etnicidad:	Hispano(a) o Latino(a)	◻
	NO Hispano(a) o Latino(a)	◻
	Desconocido/ No Reportado	◻

Lambert, Mara. "ACC/AHA Release Updated Guideline on the Treatment of Blood Cholesterol to Reduce ASCVD Risk." *American Family Physician*, vol. 90, no. 4, Aug. 2014, pp. 260–64.

Patients with any form of **clinical ASCVD**	Patients with primary **LDL-C levels of 190 mg per dL or greater**	Patients with **diabetes mellitus**, 40 to 75 years of age, with LDL-C levels of 70 to 189 mg per dL	Patients without diabetes, 40 to 75 years of age, with an estimated 10-year **ASCVD risk ≥ 7.5%**

FAMILIAL HYPERCHOLESTEROLEMIA (FH) QUESTIONNAIRE

Thank you for agreeing to participate in this important study. The aim is to study the views and opinions of people with FH about their condition, their health, their treatment, and their clinic attendance. The study is important as it will help us improve the service and care of FH patients.

We will ask you a number of questions about your experiences with FH, your clinic attendance, your treatment and other activities related to FH. Some of the questions will be facts about you and your clinic treatment. Some of the questions will be asking you for your opinions, attitudes, and beliefs. For these questions, there are no right or wrong answers. So just give the answer that is right for your and best describes how you feel. All responses are strictly **confidential**, and please answer **all the questions** as best you can.

This questionnaire can also be completed online by going to

Name and address of the clinic you attend *(please write in the box below*)

Please write the name of the consultant *(please write in the box below*)

This study has been approved by the Human Research Ethics Committee of Royal Perth Hospital
REG 14-087 (15/05/2014) *and Curtin University* HR 116/2014 (19/06/2014)

PART 1: ABOUT YOU

Are you <u>male</u> or <u>female</u>? *(Please tick one box)*

Male ☐ Female ☐

What is your <u>age</u>? *(Please write number in box)* ☐

What is your <u>marital status</u>? *(Please tick one box)*

☐ Single ☐ In a Relationship ☐ Married/Civil Partnership ☐ Divorced/Separated

What Is Your Highest Educational Qualification?

A University Degree/Masters or Doctorate ☐

Post-school training or college or equivalent ☐

Secondary /High School or equivalent ☐

Other Qualification ☐

No Qualifications ☐

What Is Your Average Total Household Income Per Year Before Taxes in AUD?

Under $30,000 ☐

$30,001- $52,000 ☐

$52,001 - $104,000 ☐

$104,001 - $156,000 ☐

$156,001 - $208,000 ☐

$208,001 - $260,000 ☐

More than $260,001 ☐

Are you currently receiving treatment for FH? *(Please tick one box)*

Yes ☐ No ☐

If you answered 'yes' to the previous question, please give exact details of your treatment for FH? Please give as much information as you can. *(Please write your response on the lines below)*

Do you currently have any form of cardiovascular disease? *(Please tick one box)*

Yes	No
☐	☐

If you answered 'yes' to the question above, please indicate the type of cardiovascular disease *(Please tick all that apply)*

Coronary heart disease	☐	**Atherosclerosis** *(hardening of the arteries)*	☐
Angina	☐		
Stroke	☐		
Peripheral vascular disease *(e.g., deep vein thrombosis)*	☐		

Do you have any of the following conditions or risk factors for cardiovascular disease? *(Please tick all that apply)*

Smoker	☐
High blood pressure	☐
Depression	☐
High stress	☐

How important are the following aspects of FH to you?

(Please tick one circle on each line)

	Not important at all	Not important	Neutral	Important	Very important
Cholesterol level	○	○	○	○	○
Genetic nature of the condition	○	○	○	○	○
Presence or risk of atherosclerosis or cardiovascular disease	○	○	○	○	○
Lifestyle change	○	○	○	○	○

PART 2: HEALTH COMMUNICATION QUESTIONNAIRE

The following questions ask you about your understanding of medical advice. Please complete the questions below by circling the option that best describes you. There are no right or wrong answers, we are interested in your opinions. Please respond to all of the questions.

(Please tick one circle on each line)

	Always	**Often**	**Sometimes**	**Occasionally**	**Never**
How often are appointment slips written in a way that is easy to read and understand?	○	○	○	○	○
How often are medical forms written in a way that is easy to read and understand?	○	○	○	○	○
How often are medication labels written in a way that is easy to read and understand?	○	○	○	○	○
How often are patient educational materials written in a way that is easy to read and understand?	○	○	○	○	○
How often are hospital or clinic signs difficult to understand?	○	○	○	○	○
How often are appointment slips difficult to understand?	○	○	○	○	○
How often are medical forms difficult to understand and fill out?	○	○	○	○	○
How often are directions on medication bottles difficult to understand?	○	○	○	○	○
How often do you have difficulty understanding the written information your health care provider (like a doctor, nurse, nurse practitioner) gives you?	○	○	○	○	○
How often do you have problems getting to your clinic appointments at the right time because of difficulty understanding written instructions?	○	○	○	○	○
How often do you have problems completing medical forms because of difficulty understanding the instructions?	○	○	○	○	○
How often do you have problems learning about your medical condition because of difficulty understanding written information?	○	○	○	○	○
How often are you unsure on how to take your medication(s) correctly because of problems understanding written instructions on the bottle label?	○	○	○	○	○

Continued on next page

	Always	Often	Sometimes	Occasionally	Never
How confident are you filling out medical forms by yourself?	○	○	○	○	○
How confident do you feel you are able to follow the instructions on the label of a medication bottle?	○	○	○	○	○
How often do you have someone (like a family member, friend, hospital/clinic worker, or caregiver) help you read hospital materials?	○	○	○	○	○

PART 3: YOUR THOUGHTS ABOUT FH

This section involves questions concerning your thoughts about Familial Hypercholesterolemia (FH). All answers are completely **confidential,** please be as **honest** and **accurate** as you can. There are no right or wrong answers, we are simply interested in your opinions and feelings.

Have you ever experienced any of the following symptoms as a result of FH? *(Please tick one circle on each line)*

Symptom	All the time	Frequently	Occasionally	Never
Chest pain	○	○	○	○
Nausea	○	○	○	○
Breathlessness	○	○	○	○
Weight Loss	○	○	○	○
Fatigue	○	○	○	○
Stiff Joints	○	○	○	○
Sore Eyes	○	○	○	○
Wheeziness	○	○	○	○
Headaches	○	○	○	○
Upset Stomach	○	○	○	○
Sleep Difficulties	○	○	○	○
Dizziness	○	○	○	○
Loss of Strength	○	○	○	○

For the next three pages, tick the box to indicate whether you agree or disagree with the following statements about your FH.

(Please tick one circle on each line)

Do you agree/ disagree?	**Disagree** very strongly	**Disagree** strongly	**Disagree** moderately	**Agree** moderately	**Agree** strongly	**Agree** very strongly
There is a lot that I can do to control the symptoms of my FH	○	○	○	○	○	○
My FH will last a short time	○	○	○	○	○	○
My FH is a serious condition	○	○	○	○	○	○
Treatment will be effective in curing my FH	○	○	○	○	○	○
FH has major consequences on my life	○	○	○	○	○	○
I feel that my FH is likely to be permanent rather than temporary	○	○	○	○	○	○
The symptoms of my FH change a great deal from day to day	○	○	○	○	○	○
What I do will determine whether my FH gets better or worse	○	○	○	○	○	○
The negative effects of my FH can be prevented (avoided) by treatment	○	○	○	○	○	○
The symptoms of my FH are puzzling to me	○	○	○	○	○	○
The symptoms of my FH are distressing to me	○	○	○	○	○	○
FH is easy to live with	○	○	○	○	○	○
My FH will last a long time	○	○	○	○	○	○
Recovery from my FH is largely dependent on chance or fate	○	○	○	○	○	○
Treatment can control my FH	○	○	○	○	○	○
My FH is a mystery to me	○	○	○	○	○	○
I get depressed when I think about my FH	○	○	○	○	○	○

Continued on next page

	Disagree very strongly	**Disagree** strongly	**Disagree** moderately	**Agree** moderately	**Agree** strongly	**Agree** very strongly
The symptoms of my FH come and go in cycles	○	○	○	○	○	○
My FH does not have much effect on my life	○	○	○	○	○	○
The course of my FH depends upon me	○	○	○	○	○	○
When I think about FH I get upset	○	○	○	○	○	○
My FH strongly affects the way others see me	○	○	○	○	○	○
My FH is very unpredictable	○	○	○	○	○	○
Nothing I do affects my FH	○	○	○	○	○	○
My FH will pass quickly	○	○	○	○	○	○
My FH has serious financial consequences	○	○	○	○	○	○
My FH makes me feel angry	○	○	○	○	○	○
My FH will improve with the passage of time	○	○	○	○	○	○
I don’t understand FH	○	○	○	○	○	○
My FH strongly affects the way I view myself as a person	○	○	○	○	○	○
My FH does not worry me	○	○	○	○	○	○
I have the power to influence the state of my FH	○	○	○	○	○	○
I feel like my FH will last for the rest of my life	○	○	○	○	○	○
There is nothing I can do to help improve my FH	○	○	○	○	○	○
My FH causes difficulties for those who are close to me	○	○	○	○	○	○
I go through cycles in which my FH gets better and then worse	○	○	○	○	○	○
Having FH makes me feel anxious	○	○	○	○	○	○

Continued on next page

	Disagree very strongly	**Disagree** strongly	**Disagree** moderately	**Agree** moderately	**Agree** strongly	**Agree** very strongly
My actions have no effect on the outcome of my FH	○	○	○	○	○	○
My FH doesn’t make any sense to me	○	○	○	○	○	○
There was very little that can be done to improve my FH	○	○	○	○	○	○
My FH has a negative impact on me	○	○	○	○	○	○
I experience the symptoms of my FH all of the time	○	○	○	○	○	○
The symptoms of my FH are beyond my control	○	○	○	○	○	○
I have a clear picture and understanding of my FH	○	○	○	○	○	○
I worry a lot about my FH	○	○	○	○	○	○
FH is not a problem for me	○	○	○	○	○	○
I feel that my FH will persist regardless of anything I do	○	○	○	○	○	○
My FH makes me feel afraid	○	○	○	○	○	○
My FH doesn’t bother me much	○	○	○	○	○	○
I expect to have FH for an extended period of time	○	○	○	○	○	○

Which of the following do you think caused your FH?

(Please tick one circle on each line)

	Disagree very strongly	**Disagree** strongly	**Disagree** moderately	**Agree** moderately	**Agree** strongly	**Agree** very strongly
Stress or worry	○	○	○	○	○	○
Genetic – it runs in the family	○	○	○	○	○	○
A germ or virus	○	○	○	○	○	○
Diet or eating habits	○	○	○	○	○	○
Chance or bad luck	○	○	○	○	○	○
Poor medical care in my past	○	○	○	○	○	○
My own behaviour	○	○	○	○	○	○
My mental attitude e.g. thinking about life negatively	○	○	○	○	○	○
Family problems or worries caused my condition	○	○	○	○	○	○
Overwork	○	○	○	○	○	○
My emotional state e.g. feeling down, lonely, anxious, empty	○	○	○	○	○	○
Ageing	○	○	○	○	○	○
Alcohol abuse	○	○	○	○	○	○
Smoking	○	○	○	○	○	○
Accident or unfortunate event	○	○	○	○	○	○
My personality	○	○	○	○	○	○
Altered immunity	○	○	○	○	○	○
Low resistance to illness	○	○	○	○	○	○
Fatigue	○	○	○	○	○	○

PART 4: QUALITY OF LIFE

This part of the survey asks how you feel about your quality of life, health, or other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response.

How would you rate your quality of life?

Very poor	Poor	Neither poor nor good	Good	Very good
○	○	○	○	○

How often do you have negative feelings such as sadness, despair, anxiety, or depression?

Never	Seldom	Quite often	Very often	Always
○	○	○	○	○

How well are you able to get around? *(go about your daily activities, eg. walking from place to place)*

Very poorly	Poorly	Neither poor nor well	Well	Very well
○	○	○	○	○

(Please tick one circle on each line)

	Not at all	**A little**	**A moderate amount**	**Very much**	**An extreme amount**
To what extent do you feel that physical pain prevents you from doing what you need to do?	○	○	○	○	○
How much do you need any medical treatment to function in your daily life?	○	○	○	○	○
How much are you bothered by any physical problems related to your FH?	○	○	○	○	○
How much do you enjoy life?	○	○	○	○	○
To what extent do you feel your life to be meaningful?	○	○	○	○	○
How much do you fear the future?	○	○	○	○	○

Continued on next page

	Not at all	A little	A moderate amount	Very much	An extreme amount
How much do you worry about death?	○	○	○	○	○
How well are you able to concentrate?	○	○	○	○	○
How safe do you feel in your daily life?	○	○	○	○	○
How healthy is your physical environment?	○	○	○	○	○

(Please tick one circle on each line)

	Not at all	A little	Moderately	Mostly	Completely
Do you have enough energy for everyday life?	○	○	○	○	○
Are you able to accept your bodily appearance?	○	○	○	○	○
Have you enough money to meet your needs?	○	○	○	○	○
How available to you is the information that you need in your day-to-day life?	○	○	○	○	○
To what extent do you have the opportunity for leisure activities?	○	○	○	○	○

(Please tick one circle on each line)

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
How satisfied are you with your health?	○	○	○	○	○
How satisfied are you with your sleep?	○	○	○	○	○
How satisfied are you with your ability to perform your daily living activities?	○	○	○	○	○
How satisfied are you with your capacity for work?	○	○	○	○	○
How satisfied are you with yourself?	○	○	○	○	○
How satisfied are you with your personal relationships?	○	○	○	○	○

Continued on next page

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
How satisfied are you with your sex life?	○	○	○	○	○
How satisfied are you with the support you get from your friends?	○	○	○	○	○
How satisfied are you with the conditions of your living place?	○	○	○	○	○
How satisfied are you with your access to health services?	○	○	○	○	○

In general, how do you rate your overall health?

Poor	Fair	Good	Very Good	Excellent
○	○	○	○	○

(Please tick one circle on each line)

How much of the time …	Not at all	Not very often	Most of the time	All of the time
…do you feel that your physical health is excellent	○	○	○	○
…do you experience bodily pain	○	○	○	○
…do you feel that your physical health is poor	○	○	○	○
…do you feel ill	○	○	○	○
…do you feel that you are as physically healthy as anybody else your age	○	○	○	○

PART 5: PHYSICAL ACTIVITY

This part of the survey asks you about your **opinions** about doing **vigorous** physical activity regularly over the next three months. Vigorous physical activities are active pass times that raise your heart rate/pulse and make you breathe deeply. Everyone feels differently about this so there are no right or wrong answers, we are interested in your **opinions**. Do not spend too long on any one statement and give the response that best describes your feelings.

I intend to participate in physical activity at least three or more times per week in the next three months.
(Please tick one circle)

Extremely unlikely	Very unlikely	Quite unlikely	Quite likely	Very likely	Extremely likely
○	○	○	○	○	○

My doing physical activity at least three or more times per week over the next three months is…

(Please tick one circle on every line below)

	Extremely	Very	Quite	Quite	Very	Extremely	
Bad	○	○	○	○	○	○	**Good**
Boring	○	○	○	○	○	○	**Exciting**
Unpleasant	○	○	○	○	○	○	**Fun**

Most people important to me think I should do physical activity at least three or more times per week over the next three months. *(Please tick one circle)*

Disagree very strongly	Disagree strongly	Disagree moderately	Agree moderately	Agree strongly	Agree very strongly
○	○	○	○	○	○

To what extent does your family support you when it comes to doing physical activity at least three or more times per week over the next three months? *(Please tick one circle)*

No support at all	Very little support	A moderate amount of support	A lot of support	An extreme amount of support
○	○	○	○	○

Whether or not I participate in physical activity at least three or more times per week over the next three months is entirely up to me. *(Please tick one circle)*

Disagree very strongly	Disagree strongly	Disagree moderately	Agree moderately	Agree strongly	Agree very strongly
○	○	○	○	○	○

How much personal control do you feel you have over participating in physical activity at least three or more times per week over the next three months? *(Please tick one circle)*

	1	**2**	**3**	**4**	**5**	**6**	
Very little control	○	○	○	○	○	○	**Complete control**

What (if any) is the greatest barrier or impediment to you doing physical activity at least three times per week over the next three months? ***(Please write your response on the line below)***

____

Now, considering the barrier you have written above, how confident are you in doing physical activity at least three times per week when that barrier is present? *(Please tick one circle)*

10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
○	○	○	○	○	○	○	○	○	○

In the course of the past three months, how often have you participated in vigorous physical activities? *(Please tick one circle)*

Everyday	Most days	On about half the days	A few times, but less than half	A few times	Almost never
○	○	○	○	○	○

I engaged in vigorous physical activity over the past three months with the following regularity: *(Please tick one circle)*

Never	Very seldom	Occasionally	Some days	Most days	Everyday
○	○	○	○	○	○

PART 6: DIET AND HEALTHY EATING

This part of the survey asks you about your **opinions** about choosing healthy (low saturated fat, low cholesterol) options for the majority of your regular meals to manage your FH in next three months. We define a low fat as a diet where 30% or less of the total calories is derived from fat.

I intend to eat healthy (low fat) options for most of my regular meals over the next three months. *(Please tick one circle)*

Extremely unlikely	Very unlikely	Quite unlikely	Quite likely	Very likely	Extremely likely
○	○	○	○	○	○

Eating healthy (low fat) options for most of my regular meals over the next three months is…

(Please tick one circle on every line below)

	Extremely	Very	Quite	Quite	Very	Extremely	
Bad	○	○	○	○	○	○	**Good**
Boring	○	○	○	○	○	○	**Exciting**
Unpleasant	○	○	○	○	○	○	**Fun**

Most people important to me think I should eat healthy (low fat) options for most of my regular meals over the next three months. *(Please tick one circle)*

Disagree very strongly	Disagree strongly	Disagree moderately	Agree moderately	Agree strongly	Agree very strongly
○	○	○	○	○	○

To what extent does your family support you when it comes to eating healthy (low fat) options for most of my regular meals over the next three months? *(Please tick one circle)*

No support at all	Very little support	A moderate amount of support	A lot of support	An extreme amount of support
○	○	○	○	○

Whether or not I stick to eating healthy (low fat) options for most of my regular meals over the next three months is entirely up to me. *(Please tick one circle)*

Disagree very strongly	Disagree strongly	Disagree moderately	Agree moderately	Agree strongly	Agree very strongly
○	○	○	○	○	○

How much personal control do you feel you have over eating healthy (low fat) options for most of your regular meals over the next three months? *(Please tick one circle)*

	1	2	3	4	5	6	
Very little control	○	○	○	○	○	○	**Complete control**

What is the greatest barrier or impediment to you eating healthy (low fat) options for most of my regular meals over the next three months? ***(Please write your response on the line below)***

____

Now, considering the barrier you have written above, how confident are you in eating healthy (low fat) options for most of your regular meals over the next three months when that barrier is present? *(Please tick one circle)*

10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
○	○	○	○	○	○	○	○	○	○

In the course of the past three months, how often have you eaten healthy (low fat) options for most of your regular meals? *(Please tick one circle)*

Almost never	A few times	A few times, but less than half	On about half the days	Most days	Almost everyday	Every day
○	○	○	○	○	○	○

Over the past three months, I ate healthy (low fat) options for most of my regular meals with the following regularity: *(Please tick one circle)*

Never	Very seldom	Occasionally	Some days	Most days	Everyday
○	○	○	○	○	○

PART 7: YOUR MEDICATION

This part of the survey asks you about your **opinions** about taking your medication as prescribed by your GP/doctor/physician to manage your FH over next three months. You need to be aware of the exact prescription of your medication. Please indicate the extent to which you agree or disagree with them by placing a tick in the appropriate circle. There are no right or wrong answers. We are interested in your personal views.

First, we would like to ask you about your personal views about medicines prescribed for you.

	Strongly Disagree	Disagree	Uncertain	Agree	Strongly Agree
My health, at present, depends on my medicines	○	○	○	○	○
Having to take medicines worries me	○	○	○	○	○
My life would be impossible without my medicines	○	○	○	○	○
Without my medicines I would be very ill	○	○	○	○	○
I sometimes worry about long-term effects of my medicines	○	○	○	○	○
My medicines are a mystery to me	○	○	○	○	○
My health in the future will depend on my medicine	○	○	○	○	○
My medicines disrupt my life	○	○	○	○	○
I sometimes worry about becoming too dependent on my medicines	○	○	○	○	○
My medicines protect me from becoming worse	○	○	○	○	○

Now, we would like to ask you about your views about medicines in general.

Doctors use too many medicines.

Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
○	○	○	○	○

People who take medicines should stop their treatment for a while every now and again.

Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
○	○	○	○	○

Most medicines are addictive.

Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
○	○	○	○	○

Natural remedies are safer than medicines.

Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
○	○	○	○	○

Medicines do more harm than good.

Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
○	○	○	○	○

All medicines are poisons.

Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
○	○	○	○	○

Doctors place too much trust on medicines.

Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
○	○	○	○	○

If doctors had more time with patients they would prescribe fewer medicines.

Strongly disagree	Disagree	Uncertain	Agree	Strongly agree
○	○	○	○	○

The following questions refer specifically to the medication you take for your FH (Statins).

Have you ever experienced any of the following side effects as a result of taking your FH medication, and how regularly do you experience them?

(Please tick one circle on each line

Side effect	Never	Occasionally	Frequently	All the time
Muscle pain	○	○	○	○
Nausea	○	○	○	○
Skin rash	○	○	○	○
Forgetfulness	○	○	○	○
Fatigue	○	○	○	○
Joint ache	○	○	○	○
Upset Stomach	○	○	○	○
Sleep Difficulties	○	○	○	○
Dizziness	○	○	○	○
Loss of Strength	○	○	○	○
Other (please specify)	○	○	○	○

(Please tick one circle on each line)

	Never true	**Almost never true**	**Seldom true**	**Often true**	**Almost always true**	**Always true**
I have concerns about the side effects of my FH medication	○	○	○	○	○	○
I am afraid that I do not know enough about side effects of my FH medication	○	○	○	○	○	○
I find it hard to put up with the side effects from my FH medication	○	○	○	○	○	○
Side effects have made me want to stop taking my FH medication	○	○	○	○	○	○
I find it hard to tolerate side effects of my FH medication	○	○	○	○	○	○

I intend to take my medication as prescribed over the next three months. *(Please tick one circle)*

Extremely unlikely	Very unlikely	Quite unlikely	Quite likely	Very likely	Extremely likely
○	○	○	○	○	○

Taking my medication as prescribed over the next three months is…

(Please tick one circle on every line below)

	Extremely	Very	Quite	Quite	Very	Extremely	
Bad	○	○	○	○	○	○	**Good**
Unpleasant	○	○	○	○	○	○	**Pleasant**
Useless	○	○	○	○	○	○	**Useful**

Most people important to me think I should take my medication as prescribed over the next three months. *(Please tick one circle)*

Disagree very strongly	Disagree strongly	Disagree moderately	Agree moderately	Agree strongly	Agree very strongly
○	○	○	○	○	○

To what extent does your family support you when it comes to taking your medication as prescribed over the next three months? *(Please tick one circle)*

No support at all	Very little support	A moderate amount of support	A lot of support	An extreme amount of support
○	○	○	○	○

Whether or not I take my medication as prescribed over the next three months is entirely up to me. *(Please tick one circle)*

Disagree very strongly	Disagree strongly	Disagree moderately	Agree moderately	Agree strongly	Agree very strongly
○	○	○	○	○	○

How much personal control do you feel you have over taking your medication as prescribed over the next three months? *(Please tick one circle)*

	1	**2**	**3**	**4**	**5**	**6**	
Very little control	○	○	○	○	○	○	**Complete control**

What is the greatest barrier or impediment to you taking your medication as prescribed over the next three months? ***(Please write your response on the line below)***

____

Now, considering the barrier you have written above, how confident are you in taking your medication as prescribed over the next three months when that barrier is present? *(Please tick one circle)*

10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
○	○	○	○	○	○	○	○	○	○

Do you sometimes forget to take your medication? *(Please tick one box)*

Yes	No
☐	☐

In the last 30 days, on how many days did you miss at least one dose of any of your medication?

Number of days: ☐ **(0–30 days)** *(Please write the number in the box)*

In the last 30 days, how good a job did you do at taking your medication in the way you were supposed to? *(Please tick one box)*

Very poor	Poor	Fair	Good	Very good	Excellent
○	○	○	○	○	○

In the last 30 days, how often did you take your medication in the way you were supposed to? *(Please tick one box)*

Never	Rarely	Sometimes	Usually	Almost always	Always
○	○	○	○	○	○

In the course of the past 3 months, how often have you taken your medication?

Never	Rarely	Occasionally	Most days	Almost every day	Everyday
○	○	○	○	○	○

PART 8: REFERRING YOUR RELATIVES FOR FH SCREENING

As part of the FH screening program, you may be asked to give permission for the FH clinic to ask your relatives to be contacted so that they can be screened for FH. In this part of the survey we ask you about your **opinions** about giving permission to the FH clinic to contact relatives to be screened as part of the program.

I intend to give the FH clinic permission to contact my relatives so they can be invited for FH screening *(Please tick one circle)*

Extremely unlikely	Very unlikely	Quite unlikely	Quite likely	Very likely	Extremely likely
○	○	○	○	○	○

Giving my permission for the FH clinic to contact my relatives so they can be invited for FH screening is…

(Please tick one circle on every line below)

	Extremely	Very	Quite	Quite	Very	Extremely	
Bad	○	○	○	○	○	○	**Good**
Useless	○	○	○	○	○	○	**Useful**
Wrong	○	○	○	○	○	○	**Right**

I think the people important to me would want me to give permission for the FH clinic to contact my relatives so they can be invited for FH screening. *(Please tick one circle)*

Disagree very strongly	Disagree strongly	Disagree moderately	Agree moderately	Agree strongly	Agree very strongly
○	○	○	○	○	○

To what extent do you think your family supports you in giving permission for the FH clinic to contact my relatives so they can be invited for FH screening? *(Please tick one circle)*

No support at all	Very little support	A moderate amount of support	A lot of support	An extreme amount of support
○	○	○	○	○

It is up to me whether or not I give my permission for the FH clinic to contact my relatives so they can be invited for FH screening. *(Please tick one circle)*

Disagree very strongly	Disagree strongly	Disagree moderately	Agree moderately	Agree strongly	Agree very strongly
○	○	○	○	○	○

How much personal control do you feel you have over giving for the FH clinic to contact your relatives so they can be invited for FH screening? *(Please tick one circle)*

	1	2	3	4	5	6	
Very little control	○	○	○	○	○	○	**Complete control**

What is the greatest barrier to you giving permission for the FH clinic to contact your relatives so they can be invited for FH screening? *(Please write your response on the line below)*

____

Now, considering the barrier you have written above, how confident are you in giving permission for the FH clinic to contact your relatives so they can be invited for FH screening? *(Please tick one circle)*

10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
○	○	○	○	○	○	○	○	○	○

What is the next most important barrier to you giving permission for the FH clinic to contact your relatives so they can be invited for FH screening? *(Please write your response on the line below)*

____

Again, considering the barrier you have written above, how confident are you in giving permission for the FH clinic to contact your relatives so they can be invited for FH screening? *(Please tick one circle)*

10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
○	○	○	○	○	○	○	○	○	○

THANK YOU FOR YOUR HELP