

UAE Healthy Future Study

Participant Information Leaflet



Thank you for your interest in the UAE Healthy Future study.

You are being invited to join a medical research study on the causes and prevention of obesity, diabetes and heart disease among the Emirati national population. This leaflet will give you information about the study.

WHAT IS THE PURPOSE OF THE UAE HEALTHY FUTURE STUDY?

The United Arab Emirates (UAE) has some of the highest rates of obesity, diabetes and heart disease in the world but the reasons for this are unclear. Until now, there have been no studies done in the UAE, or the region, which can give us reliable answers as to why these diseases are so common.

Now, for the first time in the UAE, investigators from the leading universities and hospitals have come together to find out why by setting up the UAE Healthy Future study. The UAE Healthy Future study is a medical research study which seeks to determine how the health of 20,000 UAE national men and women, currently aged 18 to 40 is affected by their lifestyle, environment and genes.

To answer these questions reliably, we need long-term studies which follow thousands of people over many years to see how their lifestyle and environment affects the risk of developing these diseases – these are called ‘cohort studies’. Previous cohort studies showed that smoking causes lung cancer; high blood pressure and cholesterol cause heart attacks and strokes, etc.

Although the findings of this research may not benefit you directly, the results

This study will help us to find out:

- Why are obesity, diabetes and heart disease so common in the UAE?
- What are the most important causes of these diseases?
- What is the relative importance of our genes, lifestyle (including diet, physical activity and tobacco use) and the environment?
- What can we do to prevent them?

of this study should give future generations a better chance to live a long life, free of disease and disability. Furthermore, it will be a national resource for the UAE, enabling researchers and policy makers to help build a healthier society for generations to come.

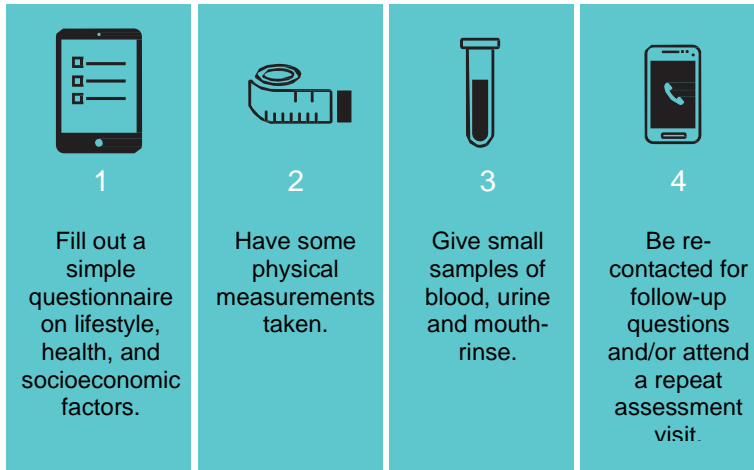
WHO IS ORGANIZING AND FUNDING THE UAE HEALTHY FUTURE STUDY?

The UAE Healthy Future study is funded by the generous contribution of the Abu Dhabi government. The study is being led by investigators from New York University Abu Dhabi (NYUAD) working in collaboration with a number of partners including Tamkeen, Department of Health - Abu Dhabi (DOH), Abu Dhabi Health Services Company (Sheikh Khalifa Medical City (SKMC), Abu Dhabi Blood Bank, Alain Regional Blood Bank), UAE University, Zayed University, Khalifa University, Higher Colleges of Technology, Etisalat-British Telecom Innovation Center (EBTIC), Zayed Military Hospital, Cleveland Clinic Abu Dhabi, Healthpoint Hospital, Daman and NYU Medical Center.

The study has been reviewed and approved by the Research Ethics Committees of the institution from which you are being recruited.

WHAT DOES TAKING PART IN THE UAE HEALTHY FUTURE STUDY INVOLVE?

You can participate in this study by reading this leaflet and signing a consent form during the assessment visit. By signing the consent form, you would be confirming your willingness to:



As detailed below, the whole process should take less than 1 hour.

Participation in the study is entirely voluntary.

1. Questionnaire:

- Personal Details (Name, Email Address, Mobile Number, Date of Birth and Emirates ID number)
- Education, Employment, Home and Living Arrangements
- Smoking / Tobacco use
- Personal Health and Medical History
- Early Life and Family History
- Psychological State
- Driving Behaviour

Your personal information will immediately be separated from your responses to all other questions so they cannot be linked to you and all your information is kept confidential. Further details are given below.

2. Physical Measurements:

- Blood pressure
- Sitting and standing height
- Waist, hip and neck circumference
- Weight and body fat composition
- Wearing a tracker to measure physical activity

3. Biological Samples:

- **Blood sample:** you will be asked to give a small sample of blood (4 tubes, about 4 teaspoons) for analysis.
- **Urine sample:** you will be asked to give a urine sample for analysis (10ml).
- **Mouthwash sample:** you will be asked to give an oral mouthwash sample for analysis (10ml).

A number of research tests will be done on your samples in the coming years looking for associations between biomarkers (things we can measure in the blood or urine, for example, Glucose, Vitamin D, Protein) and obesity, diabetes and cardiovascular disease. Additionally, the mouthwash sample will allow us to look at whether the types of bacteria in your mouth are associated with these diseases.

4. Follow-up:

For many years after the assessment visit, we will follow the health of everyone who agrees to take part by re-contacting you by email or phone.

You will be asked to answer some more questions, for example, on diet and physical activity although giving such additional information would be entirely optional.

You will also be asked to attend another assessment visit to have further tests done (for example, an ultrasound of the arteries in your neck) but again attendance at such visits would be optional and additional consent will be taken.

At the time you consent to take part in the study, you will be asked for permission to collect your Emirates ID number which will only be shared with the Department of Health – Abu Dhabi (DOH), for the purposes of collecting follow-up data from their databases on an annual basis on a limited number of health conditions. Specifically, the DOH will inform us if you are diagnosed with obesity, diabetes, high blood pressure, high cholesterol or heart disease. It is very important for us to know which participants develop these diseases in the future so we can understand their causes.

DO I NEED TO AGREE TO EVERYTHING?

You will not be able to take part in the study unless you are happy to be re-contacted by us and share your Emirates ID number with the DOH as detailed above. We would also like you, and everyone who agrees to take part in the study, to complete all parts of the assessment visit. This will give us the best opportunity to answer the research questions mentioned above.

However, if you feel uncomfortable about answering certain questions then you do not need to answer them. Similarly, if you do not want to have certain physical measurements taken, or to give a blood, urine or mouthwash sample, then tell the staff.

In this study we look at the overall results of the 20,000 participants for research purposes, therefore, we will not give back your results after analysis. By agreeing to take part in this study, you are confirming your understanding that your results will not be shared with you. If you are interested to obtain a health check, please join the Weqaya Program.

WHAT RESEARCH WILL BE DONE ON MY DATA AND SAMPLES?

Researchers can ask to study the data stored in the database. This includes researchers from NYU Abu Dhabi and NYU New York as well as other universities and research organizations in the United Arab Emirates and internationally. The scientific committee of the UAE Healthy Future study will review each request, and there will be an ethics review for any new studies. This kind of review is to ensure that any risks are minimized and that your rights, and welfare, are fully protected. If a study is approved, we might give a part of your sample and information to the researchers, along with samples and information from many other people. We will not notify you every time your samples and information are used. **We will not give researchers any information that could identify you, but we will share your Emirates ID number, with the DOH for the purposes of follow-up as detailed above.**

Individual results of research:

Researchers must study samples and information from many people over many years before they can know if the results have meaning. The genetic and other tests we are doing are for research only and are not designed for use in diagnosis or treatment of disease. Therefore, these results will not be shared with you or any other individuals, to the full extent allowed by the UAE law. We will not give the results to your doctor, and we will not put them in your medical record.

There is a small chance that researchers could discover something that might be very important for your health or medical care right now. Although unlikely, if this happens, we will contact you to see if you want to learn more.

Summary results of research from the UAE Healthy Future study will be made available to the participants, and others who might be interested, through our website www.UAEHealthyFuture.ae.

HOW IS PRIVACY AND CONFIDENTIALITY MAINTAINED IN THE UAE HEALTHY FUTURE STUDY?

We will not give information, that identifies you, to anyone without your permission, except as required by the UAE law. Insurance companies, and employers, will not be given any individual's information, samples or test results. The UAE Healthy Future study takes many steps to protect the privacy of people who take part.

We will remove your name, and any other information that could directly identify you, from your samples and other data we have collected from you. We will replace this information with a code number. We will create a master list linking your code number to

your name. We keep this list separate from your coded sample and research data.

Your personal information will be kept in Abu Dhabi and is subject to UAE and Abu Dhabi governmental personal privacy protections.

We will keep the de-identified samples in locked freezers in locked buildings. We will keep the health information and research data on secure computers. These computers have many levels of protection.

Researchers who study your sample and information will not know who you are. We will give them only the code number, and not any information that directly identifies you. The researchers must sign an agreement that they will not try to find out who you are.

Protected Health Information:

We will be collecting health information that could be linked to you (protected health information). Your signature on the consent form (V 2.5 2nd Aug 2018) means that you give us permission to use your protected health information for this research study.

If you decide to take part in the study, your protected health information will not be given out except as allowed by the UAE law. Everyone, working with your protected health information, will work to keep this information strictly private.

The results of the data from the study may be published but you will never be identified by name.

ARE THERE ANY RISKS FOR ME IN JOINING THE UAE HEALTHY FUTURE STUDY?

Taking part in the study should not cause you any physical harm. Drawing blood may cause some people to feel brief pain or have some bruising from the needle. Infection, light-headedness, and fainting are also possible, but are very unlikely. Collection of urine and a mouthwash sample, and the physical measurements should not cause any discomfort.

As described above, the protection of your privacy, and the confidentiality of your health information, are our highest priority. We will make every effort to protect them. As with all electronically stored information, there is a theoretical risk that someone could get access to the data we have stored about you. However, all appropriate security measures are in place and the chance of this happening is extremely small.

HOW DO I WITHDRAW IF I WANT TO DO SO?

You have the right to withdraw from this study at any time without giving any reason. If you want to leave the study, you can do so by contacting the **Study Coordinating Center**:

Toll-free: 800 2327
Email: info@uaehealthyfuture.ae
Address: New York University Abu Dhabi
Saadiyat Campus
P.O. Box 129188
Abu Dhabi

WHO DO I CONTACT IF I HAVE ANY CONCERNS?

If you have any concerns or complaints about anything to do with the study then you can contact the Study Coordinating Center.

Study Coordinating Center

Toll-free: 800 2327
Email: info@uaehealthyfuture.ae
Address: New York University Abu Dhabi
Saadiyat Campus
P.O. Box 129188
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For questions about your rights as a research participant, you may also contact the Institutional Review Board, New York University Abu Dhabi, **(+971) 2 6284313** or IRBnyuad@nyu.edu.



UAE Healthy Future

Telephone: 800 2327

Email: info@uaehealthyfuture.ae

New York University Abu Dhabi

Saadiyat Island

P.O. Box 129188

Abu Dhabi

CONSENT FORM: UAE HEALTHY FUTURE STUDY

Center: _____

Participant Identifier: _____

If you would like to participate, you need to agree to each of the following statements and then sign.

	I Agree	
I confirm that I am over 18 years old.	Yes	No
I confirm that I have read and understand the Information Leaflet (Version No. 2.5, 2 August 2018), and have had the opportunity to ask questions.	Yes	No
I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and that this withdrawal will not adversely affect my healthcare or employment.	Yes	No
I understand that I will be re-contacted by the UAE Healthy Future Study team to answer some more questions and to attend another assessment visit.	Yes	No
I understand that all my data will be kept confidential and in a safe place.	Yes	No
I understand that none of the results on my samples will be given to me except for some measurements during this visit.	Yes	No
I give permission for collection of my Emirates ID number and associated demographic data (including date of birth and gender).	Yes	No
I understand my Emirates ID will only be shared with the Abu Dhabi Department of Health for the purposes of follow-up to enable them to inform the UAEHFS if I am diagnosed with obesity, diabetes, high blood pressure, high cholesterol or heart disease.	Yes	No
I agree to take part in the UAE Healthy Future Study.	Yes	No

Name of participant	Date	Signature

Name of staff member	Date	Signature