The Abu Dhabi Cohort study
PARTICIPANT INFORMATION LEAFLET

Invitation to join a medical research study on the causes and prevention of obesity, diabetes and heart disease among the Emirati population of Abu Dhabi.

Dear Participant,

You are being invited to take part in a major medical research study called the Abu Dhabi Cohort Study (ADCS). The study is being led by investigators from New York University Abu Dhabi in collaboration with Zayed Military Hospital, Abu Dhabi Blood bank, UAE University and Zayed University. Before you decide whether to join, it is important for you to understand why the research is being done and what is involved. Please take the time to read the following information carefully.

If there is anything that is not clear, or if you would like more information, please telephone (800 2327) to talk to a member of the study team. More information about ADCS is also available at nyuad.nyu.edu/phrc

At the study assessment visit, there will be a further opportunity to ask any questions about the study that you might have.

Thank you for taking the time to consider participation in this study.

Contact details:

ADCS Coordinating Centre
Telephone: 800 2327
Email: info-adcs@nyu.edu
Abdishakur Abdulle, PhD
Associate Director, Public Health Research Center
New York University Abu Dhabi
Saadiyat Campus
P.O. Box 129188
Abu Dhabi.
What is the purpose of the Abu Dhabi cohort study?

The 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 in the UAE have come together to find out why by setting up the Abu Dhabi Cohort Study (ADCS)

ADCS is a medical research study which seeks to determine how the health of 20,000 UAE national men and women, currently aged 18 and above from Abu Dhabi is affected by their lifestyle, environment and genes.

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?

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 the participant directly, the study will show how peoples' lifestyles, genes and environment affect the health of the people of the UAE and 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.

What does taking part in the Abu Dhabi cohort study involve?

You can participate in this study by:

- Signing a consent form during the assessment visit.
- Attending a local study assessment centre for about 1 hour to answer some simple questions, to have some standard measurements taken, and to give small samples of blood, urine and a mouth rinse sample.
• Being re-contacted by the research team to answer some additional questions and/or to attend a repeat assessment visit (which would be optional).

Do I have to take part in the Abu Dhabi cohort study?

No; it is entirely up to you to decide whether or not to help with this study. If you do decide to take part you will be asked to sign a consent form during the assessment visit.

Why do you need my written consent?

Your participation in the study is entirely voluntary. By signing the consent form, you would be confirming your willingness to take part. In particular, you would be agreeing to:
• Answer questions on your health, lifestyle, work and family.
• Have measurements of blood pressure, pulse rate, height, weight, waist, hip and neck circumference, body fat, grip strength.
• Give small samples of blood (2 tubes, about 2 teaspoons), urine and mouth rinse for analysis (including genetic studies).
• Be contacted again in the future for this study.

The whole process should take less than 1 hour.

Do I need to agree to everything?

No. 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 health measures, or to give a blood, urine or mouth rinse sample, then tell the staff.

We also need your agreement to contact you in the future to update information about your health-related activities and to request your permission to obtain information about your health status from your physicians, health care facilities and Abu Dhabi government agencies. These requests for information will not be made without your permission.

What happens AFTER the assessment visit?

For many years after the assessment visit, we would like to follow the health of everyone who agrees to take part, initially by re-contacting you and in the future, after taking an additional consent from you and getting approval from the Health Authority of Abu Dhabi (HAAD), directly through your medical and other relevant records.
Some participants might be re-contacted by us and asked some more questions, although giving such additional information would be entirely optional. Similarly, some participants might be asked to attend a similar assessment visit in later years, although again attendance at such visits would be optional.

**What research will be done on my blood, urine and mouth wash samples?**

**Research on your samples.**

Researchers can ask to study the data stored in the database. This includes researchers from NYU in New York and Abu Dhabi and Zayed Military Hospital as well as other universities and research organizations in the United Arab Emirates. The scientific committee of the Abu Dhabi Cohort Study will review each request and there will be an ethics review. 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 give researchers any information that could directly identify you. We will not notify you every time your sample and information are used.

**Sharing the results of this research with other research groups.**

To do more powerful research, it is helpful for researchers to share information they receive from studying human samples. They do this by putting the research results into one or more scientific databases, where it is stored along with information from other studies. Researchers can then study the combined information to learn even more about health and disease. If you agree to take part in the Abu Dhabi Cohort Study, some of your genetic and health information might be placed into one or more scientific databases. A researcher who wants to study the information must apply to the database. Researchers with an approved study may be able to see and use your information, along with that from many other people.

**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 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 Abu Dhabi cohort study will be made available to participants, and others who might be interested, through our website at www.nyuad.nyu.edu/phrc.

How is Privacy and Confidentiality maintained in the Abu Dhabi cohort study?

We will not give information that identifies you to anyone without your permission, except as required by law. Insurance companies and employers will not be given any individual's information, samples or test results. The Abu Dhabi Cohort 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. This 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 this form 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 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 Abu Dhabi cohort 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 mouth wash 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 and 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.

**Who is organising and funding the Abu Dhabi Cohort study?**

The study is being led by investigators from NYU Medical Centre (NYUMC), New York University Abu Dhabi (NYUAD) working in collaboration with a number of partners: Zayed Military Hospital, The Abu Dhabi Health Services Company (SEHA), Sheikh Khalifa Medical City (SKMC), the Blood Bank, UAE University and Zayed University.

The study has been reviewed and approved by the Research Ethics Committees of all these institutions.

**How do I withdraw if I want to do so?**

You have the right to leave the project at any time without giving any reason. If you want to leave the project, you can do so by contacting us in the below address.

**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 telephone us on 800 2327 or email: info-adcs@nyu.edu

For questions about your rights as a research participant, you may also contact the Institutional Review Board, NYUAD, (+971) 2 6284313 or IRBnyuad@nyu.edu.

Contact details:

**ADCS Coordinating Centre**

**Telephone:**  800 2327  
**Email:** info-adcs@nyu.edu

Abdishakur Abdulle, PhD  
Associate Director, Public Health Research Center  
New York University Abu Dhabi  
Saadiyat Campus  
P.O. Box 129188  
Abu Dhabi.
Consent Form: The Abu Dhabi Cohort study

Centre Number: __________________________________________
Participant Identifier: ________________________________________

If you would like to participate, please respond to each of the following questions and then sign.

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<tr>
<th>Statement</th>
<th>I Agree</th>
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<tr>
<td>I confirm that I have read and understand the Information Leaflet [(Version No. 3.7, 28th December 2014), and have had the opportunity to ask questions.</td>
<td>Yes No</td>
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<td>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.</td>
<td>Yes No</td>
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<td>I understand that I will be re-contacted by the ADCS team to answer some more questions and/or attend another assessment visit.</td>
<td>Yes No</td>
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<td>I understand that I may be re-contacted by the ADCS team to take further consent for access to my medical and other health-related records, but this will be optional.</td>
<td>Yes No</td>
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<td>I understand that all my data will be kept confidential and in a safe place.</td>
<td>Yes No</td>
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<td>I understand that none of the results on my samples will be given to me except for some measurements during this visit.</td>
<td>Yes No</td>
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<td>I agree to take part in the Abu Dhabi cohort study</td>
<td>Yes No</td>
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