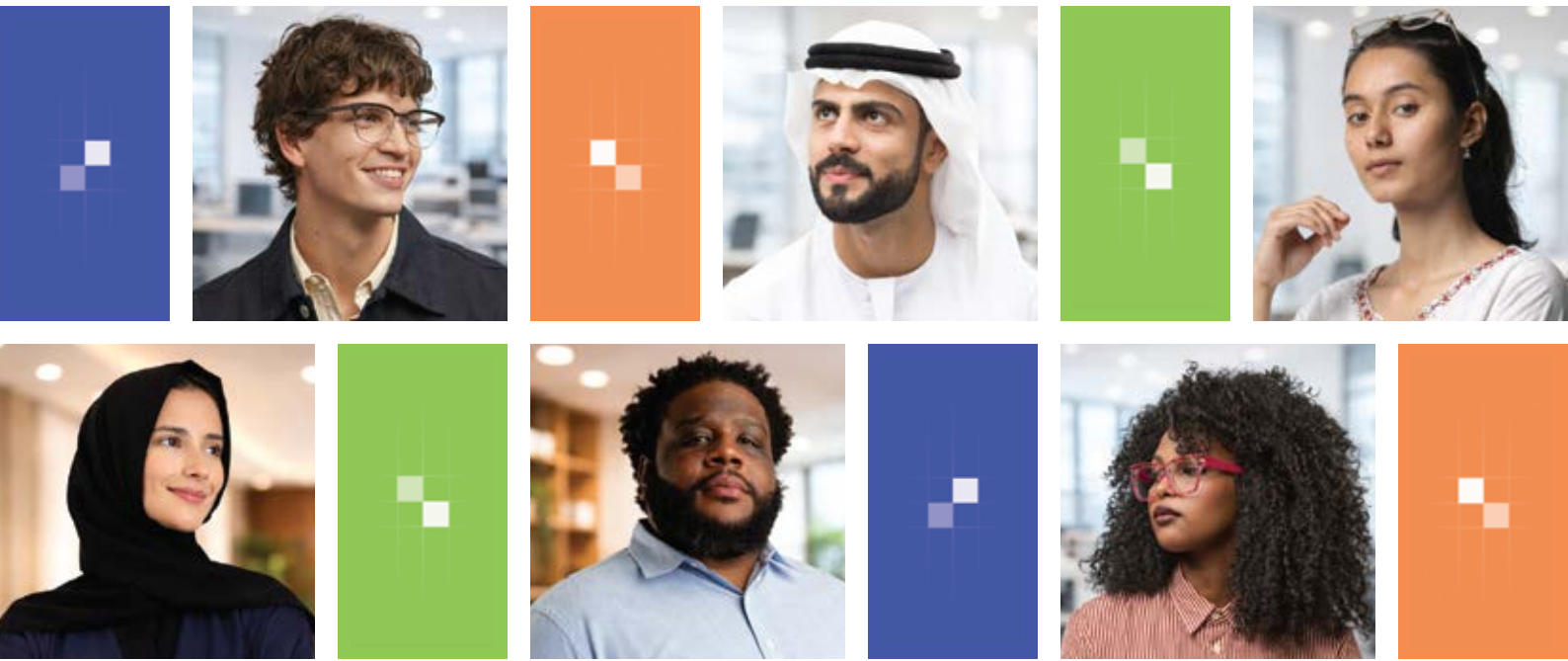


Human Phenotype Project (HPP) Abu Dhabi Participant Information Booklet



Study title

The official name of the study is “Longitudinal Observational Study for Collection of Deep Phenotype Multi-Omics Data”

We commonly refer to the study as the Human Phenotype Project (HPP) UAE

Data platform

Anonymized data is cleaned and analyzed by Pheno.ai

Study sponsor and research lead

The study is led by Mohamed bin Zayed University of Artificial Intelligence (MBZUAI)

Clinical partner

All tests will be conducted at our dedicated clinic in Abu Dhabi, by the Institute for Healthier Living Abu Dhabi (IHLAD), located at the World Trade Center (WTC)

support.hpp@hpp.mbzuai.ac.ae
+971 2 517 5994

Scan the QR code
for more information



Introduction

Thank you for your interest in the HPP! You are invited to take part in this long-term research study led by Mohamed bin Zayed University of Artificial Intelligence (MBZUAI) in partnership with the Institute for Healthier Living Abu Dhabi (IHLAD).

Before deciding whether to participate, it is important that you understand why

the study is being carried out, what participation involves, the possible benefits and risks, and how your information and samples will be handled safely and securely, to the highest standards.

Participation is entirely voluntary, and you may withdraw at any time. Withdrawing from the study will not have any negative affect on you in any way.

What is the Human Phenotype Project?



The Human Phenotype Project is a longitudinal observational research study designed to follow participants over many years. The study aims to better understand how biological, lifestyle, environmental, and social factors interact to influence health and disease over time.



I've heard of genes, but what is a phenotype?



A phenotype refers to how your genetic information is expressed in real life. This includes your physical traits, biological measurements, health status, and how your body responds to lifestyle and environmental factors.

Using AI to spot patterns across phenotypes can help scientists and clinicians to better understand and predict disease, as well as make advancements in the fields of human health and personalized medicine.

Who can take part?



Participation is open to UAE citizens and residents aged 18 to 70 years. We ask that you complete a screening questionnaire to assess your suitability, and that you understand the commitment involved in a longitudinal study.



Do I have to take part?



Participation is completely voluntary. You may choose not to take part or to withdraw from the study at any time, without giving a reason. Your decision will not affect your medical care or legal rights.

What does participation involve?



Your participation includes registration through the study portal, completion of a screening questionnaire, informed consent, and a baseline clinic visit. This is followed by a short home monitoring period of two weeks, and long-term follow-up of up to 25 years, with periodic check-ins (visits or calls) conducted on an annual or biennial basis.



The baseline clinic tests – your first visit



Your first visit will take place at the IHLAD clinic in Abu Dhabi and will last approximately two to three hours. During this visit, trained clinic staff will carry out measurements, tests, and sample collection for research purposes.

Measurements and tests may include:



- Body measurements including height, weight, circumference, blood pressure, and heart rate
- Physical examination of hand grip strength
- Ankle-brachial index (ABI) test to compare blood flow between the legs and arms
- Electrocardiogram (ECG) – a quick test that tracks the heart's rhythm by measuring its electrical activity
- Fundus imaging to capture images of the retina, blood vessels, and optic nerve
- Ultrasound imaging of the liver
- Ultrasound imaging of the carotid arteries (neck) to measure thickness
- Bone density and body composition using a DXA scan (low-dose X-ray)
- Voice recording to analyze sound patterns and help predict potential health risks

Samples collected may include:



- Blood samples for standard markers (e.g. blood count), as well as advanced molecular testing such as metabolomics, proteomics, and DNA sequencing. Some samples will be stored for future research purposes
- Stool sample (self-collected at home) to analyze the gut microbiome – the natural community of beneficial microorganisms in the digestive system that support overall health
- Vaginal sample (for female participants, self-collected at the clinic) to analyze the vaginal microbiome – the natural balance of beneficial microorganisms that help maintain a healthy environment and support well-being



Home monitoring period



Following the clinic visit, you will wear a continuous glucose monitor (CGM) for approximately two weeks and record meals, physical activity, sleep, and medications using the study mobile application.

Long-term follow-up



Follow-up will involve clinic visits every other year, with questionnaires and phone interviews every other year (clinic visits and questionnaire interviews take place on alternating years), for up to 25 years.



Will I receive medical insights and advice?



This study is conducted for research purposes only and does not replace medical care or advice. The tests are not intended to diagnose disease, and results / insights that are shared should not be used as clinical advice.

What are the possible benefits?



As well as contributing to research that may benefit future generations, you will be given personal insights based on the collected data which you will be able to track over time. We encourage you to share your personal insights from the study, with your professional healthcare provider. In due course, we hope to provide cohort information via the participant app, but this is under development.



Are there any risks?



Risks are considered low and may include mild discomfort from blood draws, temporary skin irritation from monitoring devices, or very low-dose radiation exposure from DXA scans.



What happens to my data and samples?



Your data and samples will be securely stored within the UAE. Personal identifiers are stored separately from research data, and all information is handled in accordance with applicable UAE laws. Department of Health approvals, along with ethical approvals from MBZUAI and IHLAD are in place.

Confidentiality



Your identity will remain confidential. Secondary, anonymous data may be accessed by both academia and private companies for further research and development purposes, but you will never be identified in publications, datasets, or reports arising from this study.



Questions



If you have any questions about the study or your rights as a participant, please feel free to reach out to our support team.