

**QATAR BIOBANK** REPORT 2016/2017



عضو في مؤسسة قطر Member of Qatar Foundation







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### **VISION**

Establish a research enterprise platform across Qatar to achieve extra-ordinary improvement in diagnostic and prognostic intelligence required to deliver personalized health care for the benefits of people in Qatar, the region and worldwide

### **MISSION**

To act as the Qatar National Centre for biological samples and health information to enable research towards the discovery and development of new healthcare interventions.

# QATAR FOUNDATION SUPPORTING MEDICAL RESEARCH

Qatar Foundation for Education, Science and Community development (QF) is a private, non-profit organization that serves the people of Qatar by supporting and operating programs in three core mission areas: education, science and research and community development.

Through its unique cycle of education and research, Qatar Foundation is supporting the nation on its journey towards a knowledge-based economy, while also fostering a progressive and engaged society appreciative of its heritage. Integral to the mission of Qatar Foundation and part of its commitment to creating a knowledge-based economy, is healthcare innovation. Through a range of dedicated centers and initiatives, QF aims to achieve sustainable and tangible improvements, locally regionally and internationally.

A member of Qatar Foundation and Qatar Foundation Research and Development, Qatar Biobank for medical research is a testament to this dedication. Through its collection of samples and information on health and lifestyles of large numbers of Qatar's population, Qatar Biobank makes vital medical research possible for scientists in Qatar, the region and the world. This, in-turn, is supporting QF's mission to build national innovation and technology capacity and assists in the delivery of the country's health priorities.









### QUOTE FROM HER HIGHNESS SHEIKHA MOZA BINT NASSER

In her keynote speech at the November 2016 World Innovation Summit for Health in Doha, Her Highness Sheikha Moza bint Nasser, Chairperson of Qatar Foundation for Education, Science and Community Development, discussed the role of the Qatar Biobank in advancing precision medicine. The following are excerpts from that speech:

"When medical practitioners understand a person's biological map, it will enable them to better diagnose and to treat disease individually, or as I call it, 'customized medicine.'

"Working with partners, we are seeking to find ways to develop systems that enables citizens' genome data to be accessible to all health care centers, hospitals and clinics in order to provide efficient and customized treatment, while also guaranteeing the protection and confidentiality of patients' health information.

"With all this, we must keep in mind the moral and religious responsibility when we consider the impact of research and medical innovation. We need to open and broaden our horizons when dealing with issues of health. As we pursue research and science, our culture and religion also demand that we look at these pursuits through an ethical lens. In other words, we should respect our religious and ethical values, but that should not prevent us from being both present and impactful on the global health map."



## HER EXCELLENCY DR HANAN AL KUWARI

### Chairperson, Qatar Biobank Board of Trustees

As one of the most significant research initiatives in Qatar, Qatar Biobank has a crucial role to play in the development of personalized healthcare. In 2016, we reached an important milestone toward that goal when we collected samples from our 5000th Qatari participant. The depth and breadth of the information from those thousands of samples is already providing insights into key health issues facing the local population, such as obesity and diabetes.

The last year has seen Qatar Biobank increase its role in the global biomedical community as well. Our doctors presented at a number of global symposia, including the Europe Biobank Week Congress and the Middle East Molecular Biology Congress and Exhibition. We look forward to future opportunities to exchange knowledge and share best practices.

We will host the Second Qatar Biobanking Congress, under the theme "The Impact of Biobanking on Precision Medicine Initiatives," bringing together experts on biobanking, genomics and personalized medicine.

Qatar Biobank was established by Her Highness Sheikha Mozah Bint Nasser to act as an infrastructure platform to provide invaluable resources for biomedical research projects in the country. We continue to strengthen that purpose through our partnerships with Hamad Medical Corporation and Sidra Medical and Research Center, as well as a Memorandum of Understanding signed with Weill Cornell Medicine-Qatar in 2016.

Together with our partners locally and globally, we look forward to the continued pursuit of a better and healthier future for generations to come.



### SHEIKHA PROFESSOR ASMAA AL-THANI

### Vice Chairperson, Qatar Biobank Board of Trustees

Advances in medicine have always come through collaboration. When Her Highness Sheikha Moza bint Nasser announced the launch of the Qatar Genome Programme in 2013, to be incubated under Qatar Biobank, it was a major step towards charting a roadmap for personalized medicine in Qatar. In the years since, both Qatar Biobank and the Qatar Genome Programme have played integral roles in developing the nation's biomedical research profile.

Already, we are learning a great deal about Qatar's local population; for example, the pilot phase found high overweight and obesity levels, as well as a 17 percent rate of diabetes in the adults surveyed. These are critical health issues that must be addressed, and we are enabling researchers to dig deeper into the Qatar health profile with that in mind.

The data collected by Qatar Biobank for the Qatar Genome Project will give scientists a unique insight into the causes, thus enabling prevention of these diseases by way of personalized treatments that are compatible genetic coding of an individual.

Qatar Biobank and the Qatar Genome Programme are already valuable national resources for Qatari health. As we continue to take and sequence samples generously donated by the local population, we will continue our role as a leader in developing personalized health strategies for all.



# PROFESSOR NAHLA AFIFI

Scientific & Education Manager/ Acting Director, Qatar Biobank

Since our doors opened in 2012, more than 6,000 volunteers—including more than 5,000 Qataris—have generously donated their time to enable us to begin building a comprehensive resource for geneticists, biomedical experts and other medical researchers.

Qatar Biobank does not only aim at recruiting the public to take part in biomedical research, but also wishes to partner with our public and help them become "citizen scientists" who, through their personal contributions, play an active role in the process. As such, Qatar Biobank's recruitment approach provides a model for public involvement in biomedical research and promotes Qatar's dedication to raising awareness and commitment, engaging the community in shaping better health for themselves and generations to come.

The benefits to the local population are manifold. Participants receive a comprehensive analysis of their health profile, including clinical phenotypic information. This enables us to refer visitors to doctors or specialists for previously undiagnosed conditions such as diabetes, anaemia and high blood pressure.

On a larger scale, each participant is contributing to an ambitious effort to make healthcare truly local. Until now, most medical treatments have been developed through the study of Western populations, and there has been a lack of large-scale research based on populations in Qatar and the region. Qatar Biobank, in partnership with the local population, will play a vital role in helping to prevent and improve treatment of diseases that affect our communities.



Prof Asmaa Al Thani

Prof. Asmaa Al Thani Vice Chairperson of QBB Board Chairperson Qatar Genome Program

Prof. Nahla Afifi Acting Director Qatar Biobank Scientific & Education Manager

Dr. Eleni Fthenou Scientist, QBB Scientific & Education

Ms. Linda Hannigan Research & Training Specialist, QBB Scientific & Education

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# ABOUT QATAR BIOBANK



### **ABOUT QATAR BIOBANK**

Qatar Biobank is a center under the Qatar Foundation for Education, Science and Community Development, in collaboration with Hamad Medical Corporation and the Ministry of Public Health, to aid medical research on prevalent health-related conditions in Qatar. Through its collection of samples and information pertaining to the health and lifestyle of a large part of the population of Qatar, Qatar Biobank will facilitate vital health research in Qatar.

To further Qatar Foundation's research and development goals, Qatar Biobank seeks to establish a research enterprise and platform across Qatar to achieve extra-ordinary improvement in diagnostic and prognostic intelligence required to deliver personalized health care for the benefits of people in Qatar, the region and worldwide.

As Qatar's long-term medical health initiative, Qatar Biobank aims to grant the people of Qatar a better chance of avoiding serious illnesses, while securing a healthier future for generations to come.

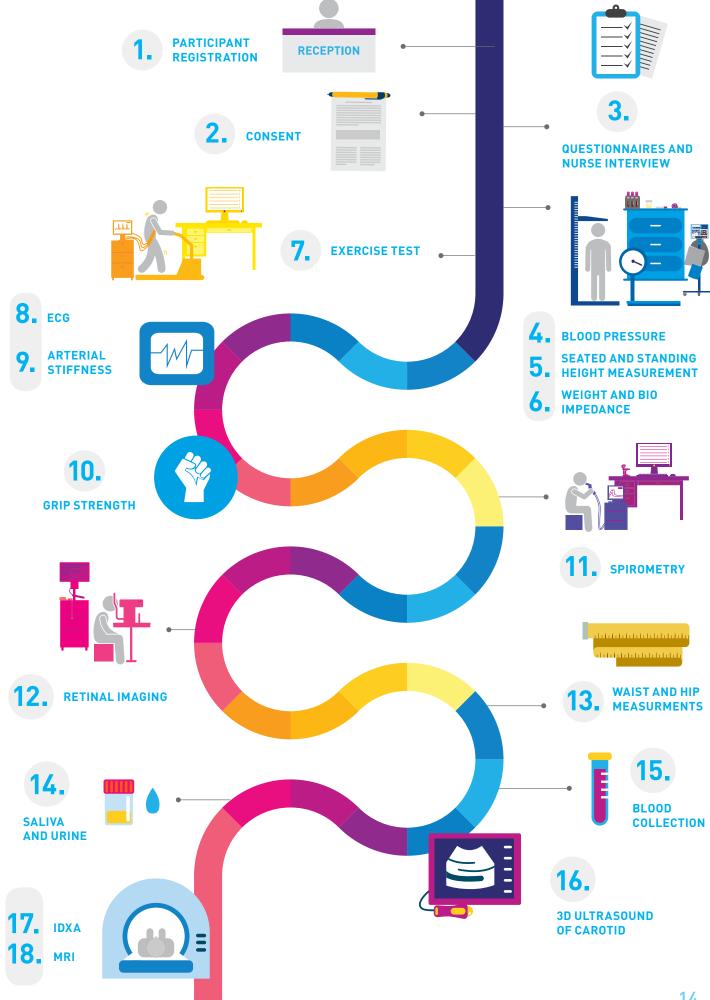
Qatar Biobank is a globally unique resource that is raising Qatar's profile within the path to precision medicine and biomedical research environment both within the Gulf region and internationally.



# WALKTHROUGH OF PARTICIPANT'S VISIT

Anybody who is an adult (at least 18 years old) and is either a Qatari national or long-term resident (lived in Qatar for at least 15 years) can contribute to Qatar Biobank by offering approximately 3 hours of their time. The visit is broken down into stages, reception and registration, questionnaire, measurements and fitness and imaging stages (Figure 1). After registering into the study and completing the consent procedure, the participant will be asked to answer a series of questions which will ask about their lifestyle and family, their dietary habits, their medical history and medication. The questions are separated into 4 different questionnaires with the main and dietary questionnaires designed to be self-administered while the nurse interview and the contraindication questionnaire are designed to be completed in an interview format by the nursing staff (Table 1).

Figure 1: The visit flow of a Qatar Biobank participant



### WALKTHROUGH OF PARTICIPANT'S VISIT (CTD)

Table 1: Questionnaires completed by Qatar Biobank participants

Questionnaire	Content
Main Questionnaire	The main questionnaire asks detailed questions about the participant current and past health conditions, smoking history both tobacco and shisha, occupation, socio-demographic factors, sleep patterns, activity levels, mobile phone use and cognitive and psychological state
Dietary Questionnaire	The dietary questionnaire asks participants to reflect on their dietary habits including dietary modifications, the frequency they consumed various foods and beverages over previous year.
Nurse Interview	Participants are asked about previous or prevalent health conditions they or their family members may have suffered from. Information about their medication use is asked and for females questions about reproductive factors.
Contraindication Questionnaire	The contraindication questionnaire is designed to ask specific questions to ensure the safety for the participant of the measurements that are conducted during the clinical visit and the reliability of the results that are collected.

The participant will complete a series of measurements after completing the contraindication questionnaire. Any measurements that are contraindicated may be completed during a revisit or may be permanently excluded (Table 2).

Table 2: Measurements performed and equipment used during Qatar Biobank clinical visit

Measurement	Instrument
Anthropometry and Body Composition	Sitting and Standing Height and Weight and waist and hip circumference Bio Impedance Analysis (Seca) Full Body iDXA (GE) scan
Bone Health	Full Body iDXA (GE) scan
Strength	Grip Strength was measured using a Jamar J00105 hydraulic hand dynamometer.

### WALKTHROUGH OF PARTICIPANT'S VISIT (CTD)

Vision	Microscopic features of the optic nerve and macula assessed using a Topcon TRC-NW6S retinal camera.					
Cardiovascular system	Blood pressure measured 3 times Electrocardiogram (ECG using the Mortara Eli 350 automated system) Arterial Stiffness assessed using a Vicorder device Bilateral Carotid Artery scan using Phillips iU22 device					
Respiratory Function	The Pneumotrac Vitalograph spirometry test					
Cardiorespiratory fitness	Treadmill fitness test with heart rate monitoring (H/P/Cosmos)					
Biological Samples Collected	Blood Urine Saliva					





# BIOLOGICAL SAMPLE COLLECTION, PROCESSING, STORAGE AND LABORATORY ANALYSIS

During the clinic visit the participant consents to donating biological samples:

- Urine
- Saliva
- Blood

Whole blood (approximately 60 ml similar to a pocket sized hand sanitizer), a urine and a saliva sample are collected and processed at Qatar Biobank for clinical analysis and storage. The blood samples for Hematology and Biochemistry analysis are transferred to Hamad Medical Corporation and returned for clinical interpretation by the Qatar Biobank medical review office. These results are provided to the participant during a feedback session.

65 biomarkers (Table 3) are assessed adding increased value to the data available to researchers and offering participants an accurate overview of their biology at the time of the clinic visit. The biomarkers assessed during the visit have been chosen because of their association with disease development risk factors.

Table 3: 65 Clinical biomarkers were routinely measured as part of the Qatar Biobank visit

Group	Variable
Bone and Joint Markers	Calcium Phosphorus Uric Acid Vitamin D
Coagulation Tests	Activated Partial Thromboplastin Time Fibrinogen Level International Normalized Ratio Prothrombin Time
Diabetes Related Tests	C-Peptide Glucose Glycated Hemoglobin A1C % Insulin
Differential White Cell Count	Basophils Basophils % Eosinophils Eosinophils % Lymphocytes Lymphocytes % Monocyte Monocyte Monocyte % Neutrophils Neutrophils % White Blood Cell
Electrolytes and Renal Function Tests	Chloride Serum Creatinine Bicarbonate Potassium Sodium Urea Nitrogen



# BIOLOGICAL SAMPLE COLLECTION, PROCESSING, STORAGE AND LABORATORY ANALYSIS (CTD)

•	
Group	Variable
Full Blood Count	Hematocrit Haemoglobin Mean Corpuscular Haemoglobin Mean Corpuscular HGB Concentration Mean Corpuscular Volume Mean Platelet Volume Platelets Red Blood Cell
Sex Hormones	Estradiol Sex Hormone Binding Globulin Testosterone
Inflammation / Autoimmune	C-Reactive Protein
Lipid Profile	Cholesterol High Density Lipoprotein Low Density Lipoprotein Triglycerides
Liver Function Tests	Albumin Alkaline Phosphatase Alanine Transaminase Asparate Transaminase Gamma Glutamyl Transferase Total Bilirubin Total Protein
Minerals	Iron Ferritin Magnesium Total Iron Binding Capacity
Muscle Markers	Creatine Kinase Myoglobin
Thyroid Function Tests	Free Triiodothyronine Free Thyroxine Thyroid Stimulating Hormone
Vitamins	Vitamin B12 Folate Serum
Other Tests	Homocysteine N-Terminal Brain-Type Natriuretic Peptide



# BIOLOGICAL SAMPLE COLLECTION, PROCESSING, STORAGE AND LABORATORY ANALYSIS (CTD)

#### Storage of Biological Samples

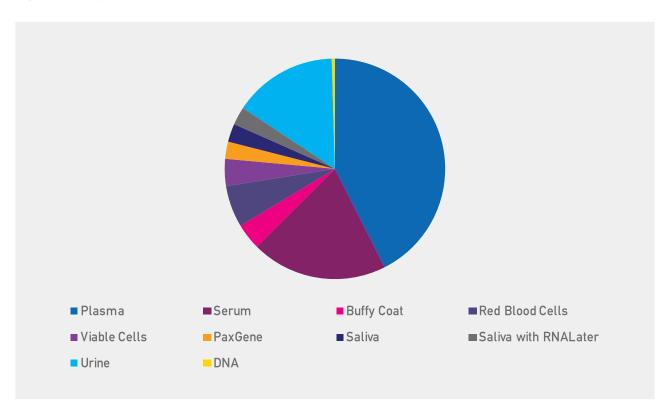
Qatar Biobank expanded laboratories in 2016 with the addition of the automated DNA extraction using advanced integrated technologies. This process has allowed Qatar Biobank to process a high throughput of DNA samples (n=2320) to the Qatar Genome Program pilot phase.

Table 4: Table Biological Samples (research samples) collected during the Qatar Biobank visit.

Sample Type	Plasma	Serum	Buffy Coat	Red Blood Cells	Viable Cells	PaxGene	Saliva	Saliva with RNALater	Urine	DNA	Total Number of samples
Number of Samples	213108	100048	19246	30650	19929	12594	13372	13299	76354	2320	500920

Qatar Biobank stores processed samples onsite at -80°C and in Liquid Nitrogen. As an ongoing commitment to Qatar Biobank's biosecurity plan, a complete set of backup samples are stored at an offsite location. To date more than half a million biological samples are stored across Qatar Biobank facilities (Figure 2).

Figure 2 Samples stored across Qatar Biobank



### QATAR BIOBANK PARTICIPANT RATES AND PERCEPTIONS

Participant rates continued to increase with a marked increase expected moving into 2017. Qatar Biobank continues to expand and work efficiently to increase participant throughput. By the end of December 2016, Qatar Biobank had reached 6475 participants, out of that figure almost 80% (5136) were Qatari. (Figure 3).

Total Number of Participants vs. Number of Participants at 2016

7000

6000

4000

3000

1000

Dec -15 Jan-16 Feb-16 Mar-16 Apr-16 May-16 Jun-16 Jul-16 Aug-16 Sep-16 Oct-16 Nov-16 Dec-16

QatariParticipantsForTheYear TotalParticipantsSinceInception QatariParticipantsSinceInception

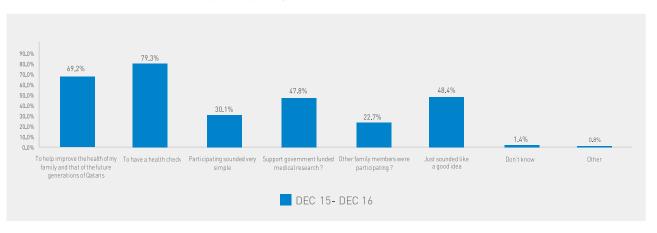
Figure 3: Total Number of Participants vs. Number of Participants at 2016.

Qatar Biobank obtained participant evaluation at 2 key time points in the biobank process. The first time point was at the end of the initial clinic visit and the second, after the results feedback, where each participant was asked to complete an evaluation feedback questionnaire.

From a sample of the questions asked and a breakdown of the results, it shows that more participants were taking a positive interest in their own health and would be happy to take part again in Qatar Biobank (Figure 4).

Figure 4 Reasons for Participating in Qatar Biobank

#### Q1. What were your reasons for participating in Qatar Biobank study?



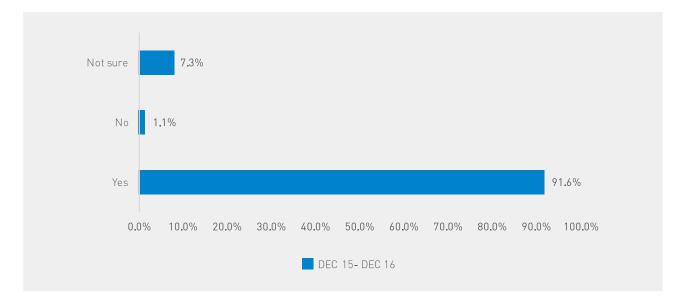
### QATAR BIOBANK PARTICIPANT RATES AND PERCEPTIONS (CTD)

### As shown in the graph, the main reasons for participants to join in the study were:

- i) to have a health checkup (79.3%)
- ii) to help improve the health of their families and of future generations of Qataris (69.2%)
- iii) just sounded like a good idea (48.4%)
- iv) to support government funded research (47.8 %)
- v) participating sounded very simple (30.1%)
- vi) their family member was participating (22.7%)

#### Figure 5 Engagement of Participants

#### Q2. Given the opportunity would you take part in Qatar Biobank again?



### 91.6 %

of participants said that they would participate again in the study if they were given the opportunity.



### **ANALYSIS**

The demographic data obtained from the registration process shows that an almost even number of men (51%) and women (49%) registering with the highest number of both registering in the 25-34 age group. The mean age of participants was 39 years with the minimum age registered being 18 years old and the maximum registered 85 years (Figure 6)

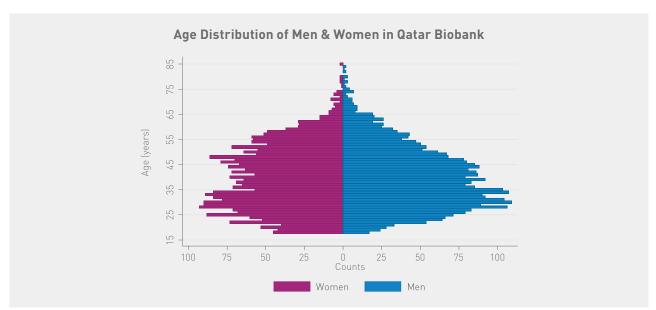


Figure 6 Age distribution of men and women recruited in Qatar Biobank

The data from the socio demographic questions showed that the majority of participants have high education levels attending university (men 46%, women 47%) or technical school (men 25%, women 19%). Furthermore, the socio demographic data showed 98% of men and 76% of women were employed. 82% of men and 65% of women were married (Figure 7 A and B).

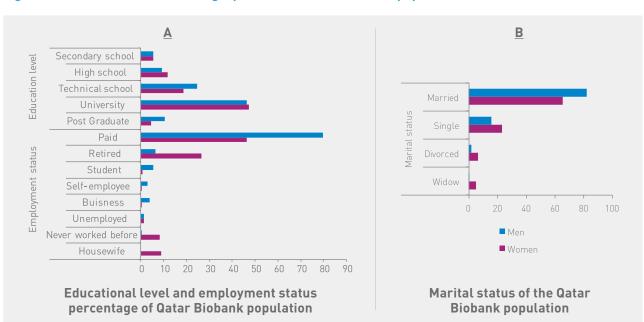


Figure 7 A and B Main Socio-demographic data of Qatar Biobank population

During their clinical visit, participants underwent a series of anthropometric measurements. Table 5 shows that men had an average height of 1.72m, weight 85.9Kg and BMI 28.6 Kg/m2, mean height was 1.58m, weight 74Kg, and had a higher BMI (29.6 Kg/m2) than men, their blood pressure was within the normal ranges.

Table 5 Anthropometric measurements of Qatar Biobank population

Table 5 Antili opolinetric measurements of datar blobank population							
Male	Number	Mean	SD	Min	Max		
Height (cm)	3119	172.6	6.6	146.1	199.4		
Weight (Kg)	3087	85.9	17.7	38.9	199.7		
Waist Circumference (cm)	3116	95.1	13.5	55.0	180.0		
Hip Circumference (cm)	3116	105.6	10.8	11.0	170.0		
BMI (Kg/m3)	2854	28.6	5.1	15.1	53.2		
Systolic Blood Pressure (mmHg)	3120	119.4	13.4	87.0	203.0		
Diastolic Blood Pressure (mmHg)	3120	74.7	10.2	33.0	124.0		
Female	Number	Mean	SD	Min	Max		
Height (cm)	2959	158.0	6.1	86.3	176.6		
Weight (Kg)	2929	73.9	16.5	35.3	165.2		
Waist Circumference (cm)	2950	85.4	14.0	55.0	158.0		
Hip Circumference (cm)	2950	108.6	12.4	75.0	186.0		
BMI (Kg/m3)	2828	29.6	6.5	14.8	55.6		
Systolic Blood Pressure (mmHg)	2958	111.6	16.3	63.0	206.0		
		68.7	10.6	38.0	128.0		

Following the anthropometric results, the biochemical profile of the Qatar Biobank participants was shown in Table 6. The table shows diabetes related tests for women's HbA1C% levels were at the higher end of normal with the mean being 5.7 (SD 1.1) and fasting glucose levels exceeded the normal levels at 5.6 mmol/L (SD 2.4). For men the same tests showed HbA1C% levels were at the higher end of normal with the mean being 5.6% (SD 1.2) and similarly the fasting glucose levels for men exceeded the higher end of the normal range at 6.0 mmol/L (SD 2.6).

Table 6 Biomarkers Profile of Qatar Biobank Participants Associated with Different Biological Systems

		Male			Female	
Lipid profile	Number	Mean	SD	Number	Mean	SD
Cholesterol (mmol/L)	3113	5.0	1.0	2949	4.9	0.9
High Density Lipoprotein- HDL (mmol/L)	3110	1.2	0.3	2949	1.5	0.4
Low Density Lipoprotein - LDL (mmol/L)	3065	3.1	0.9	2949	2.9	0.8
Triglycerides (mmol/L)	3113	1.6	1.1	2949	1.2	0.7
Thyroid Function						
Free Triiodothyronine -FT3 (pmol/L)	2712	4.5	0.6	2681	4.2	0.6
Free Thyroxine- FT4 (pmol/L)	3064	13.1	1.5	2918	13.3	1.9
Thyroid Stimulating Hormone- TSH (mlU/L)	3060	1.7	2.4	2910	2.0	3.8
Diabetes Related						
Glycated Hemoglobin A1C %	3041	5.8	1.2	2859	5.7	1.1
Fasting Glucose(mmol/L)	1786	6.0	2.6	1599	5.6	2.4
Fasting Insulin (mcunit/mL)	1746	22.0	30.4	1574	16.3	23.3
Liver Function						
Alkaline Phosphatase-Alk Phos (U/L)	3107	71.1	18.6	2943	69.4	21.7
Alanine Transaminase-ALT (U/L)	3113	29.7	19.6	2948	17.6	12.5
Aspartate Transaminase-AST (U/L)	3113	22.0	10.8	2949	17.8	8.3

The liver function results showed that for both men and women the mean results lay within the normal reference ranges. The lipid profile for men showed a mean total cholesterol level at 5 (SD 1), mean HDL 1.2 (SD 0.3), LDL 3.1 (SD 0.9) and triglycerides 1.6 (SD 1.1) all results were within the expected normal reference ranges. The lipid profile results for women showed mean total cholesterol levels at 4.9 (SD 0.9), HDL 1.5 (SD 0.4), LDL 2.9 (SD 0.8) and triglycerides 1.2 (SD 0.2) also within the normal reference range. The thyroid hormone profile mean results for men and women showed all results were within expected normal reference ranges.

#### **Lifestyle Characteristics**

Qatar as a nation has some of the highest levels of metabolic disorders such as obesity and diabetes mellitus within the region. A series of questionnaires were deployed to examine the lifestyle characteristics including dietary habits and physical activity levels of the Qatar Biobank population.

The dietary questionnaire results showed that both men and women were consuming more poultry (19% and 20%, respectively), than meat or fish. The results showed that the most commonly consumed foods in both men and women were milk (men 26% and women 29%), fruits (men 20% and women 30%), vegetables (men 26% and women 35%) and rice (men 30% and women 31%.

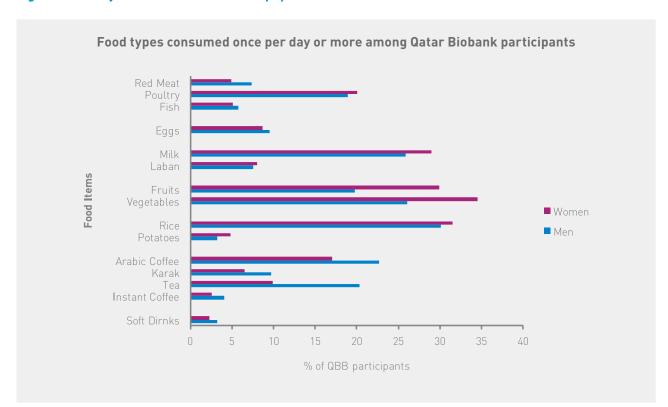
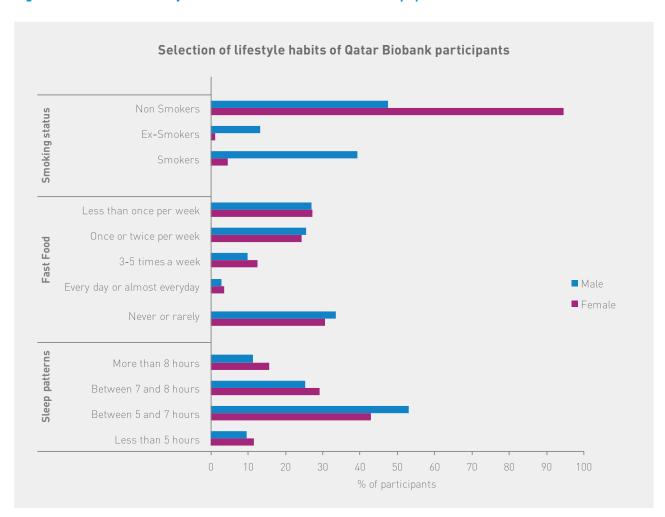


Figure 8 Dietary habits of Qatar Biobank population

Another characteristic of the population was the high consumption of fast food (Figure 9). More than 45% of both men and women consumed fast food more than 3 times per week. A unique characteristic of Qatar Biobank population was the low rate of smokers, almost all the women (94%) and half of the men (47%) had never smoked, while in the smokers category men played a dominant role with a percentage of 39% versus 4% for women. The majority of the population were having between 5 to 8 hours sleep.

Within the QBB population 39% of men and 4% of women smoked

Figure 9 Selection of lifestyle characteristics of Qatar Biobank population







An active lifestyle can help to prevent the development of many chronic diseases TV, mobile and tablet usage are major factors contributing to a sedentary lifestyle. The results from the main questionnaire showed that around 40% of both men and women watched TV or used their phones or tablets for more than 2 hours per day (Figure 10).

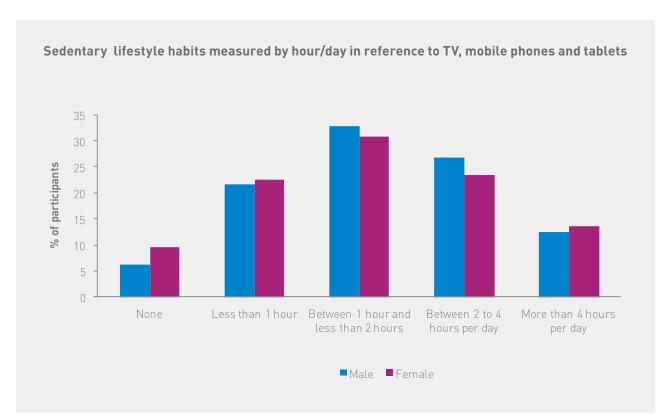


Figure 10 Sedentary lifestyle characteristics of Qatar Biobank population

Examining the results further showed that the level of physical activity reported by Qatar Biobank participants MET/h per week. The MET/h definition for the purpose of these results is one MET is the energy equivalent used by an individual while seated at rest. While exercising, the MET equivalent is the energy used compared to rest so MET values indicate the intensity of the activity. An activity with a MET value of 5 means you are using 5 times more energy (number of calories) than you would at rest.

The graph in Figure 11 shows the levels of physical activity reported by Qatar Biobank participants. More than 70% of the population belonged to the overweight and obese categories. The interesting finding was that the percentage of men (48%) was more pronounced in the obese category comparing to the women (40%). The incidence of obesity was being verified from the low levels of physical activity where 83% of the total population had low or no activity levels, while almost half of the population (41%) did not participate in any activity during the week.

Physical Activity & BMI levels of Qatar Biobank Population Low (<1 0excess METh/wk) Moderate (10 - <50 excess METh/wk) High (≤50 excess METh/wk) Total Men Underweight (<18.5Kg/m2) ■ Women Normal weight [18.5-24.9 Kg/m2] Overweight (25-29.9Kg/m2) Obese(>30Kg/m2) 50 10 15 45 30 % of participants

Figure 11 Physical Activity and BMI levels of Qatar Biobank participants

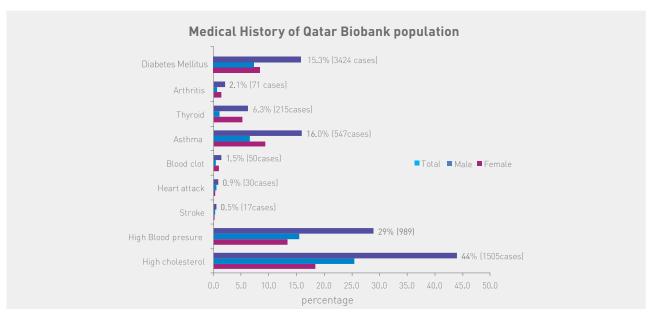
#### **General Health of the Qatar Biobank Participant**

In an effort to gain a general picture of health of the Qatar Biobank participant a series of questions were asked to identify their past medical history and their family health history.

#### Figure 12 shows the main chronic diseases reported were:

- i) 44% of all participants showed high cholesterol (men 26% and women 18%)
- ii) High Blood Pressure 29% of all participants showed high blood pressure (men 16% and women 13%)
- iii) Asthma 16% of all participants had previous diagnosis of asthma (men 7% and women 9%)
- iv) Diabetes Mellitus 15.5% of all participants had previous diagnosis of diabetes mellitus (men 7% and women 8.5%)
- v) Thyroid disease 6% of all participants had a previous diagnosis of thyroid disease (men 1% and women 5%)

Figure 12 Medical history Qatar biobank population



Other findings included the most prominent types of cancers within Qatar Biobank population (Figure 13), were for women breast, cervical followed by thyroid cancers. For men the findings showed that prostate and bladder cancers were the most prominent.

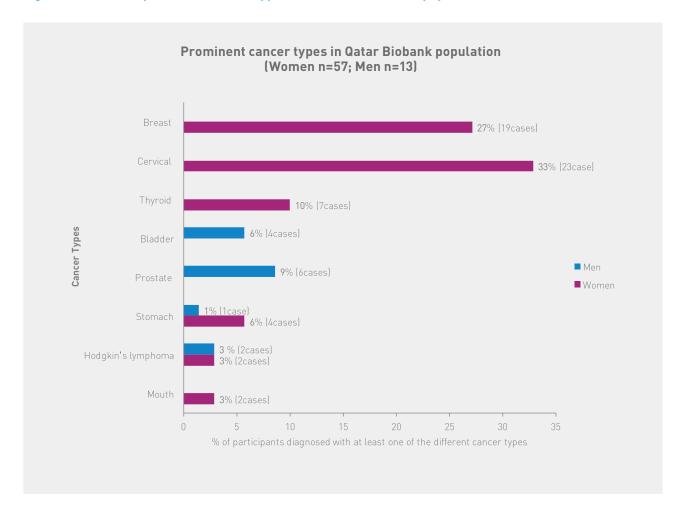
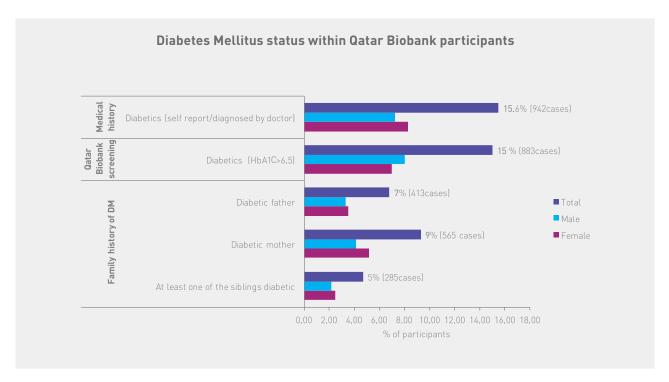


Figure 13 The most prominent cancer types within Qatar biobank population

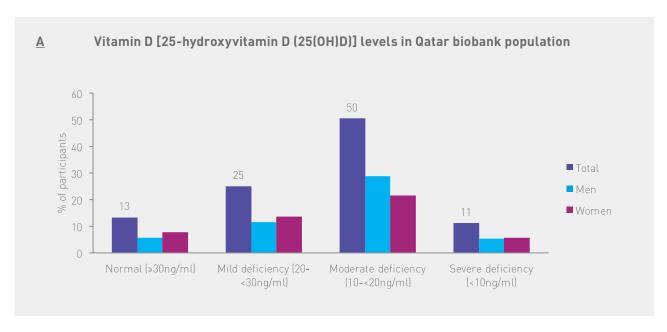
Examples of additional findings include the high incidence of Diabetes Mellitus and low levels of Vitamin D in both men and women, within Qatar Biobank population.

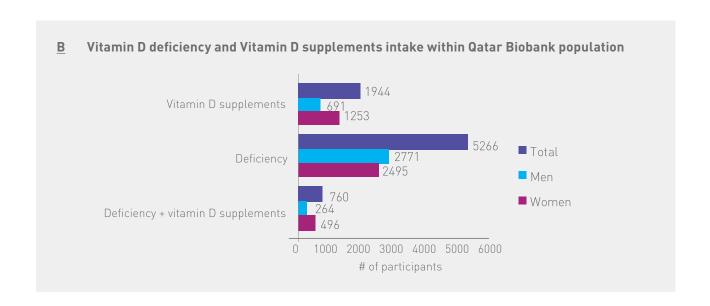
Figure 14 shows participants who have reported being previously diagnosed with diabetes mellitus (DM). Almost 16% of the total Qatar Biobank population had been diagnosed with DM while 7% of participants had a diabetic father and 9% had reported having a diabetic mother and 5% had at least one sibling also being diagnosed with DM. Through Qatar Biobank laboratory analysis results we have identified that 15% of the participants had elevated HbA1C% levels out with the normal reference ranges.

Figure 14 Diabetes Mellitus status within Qatar Biobank participants



Qatar Biobank laboratory analysis also showed that 86% of the total Qatar Biobank population were Vitamin D deficient (Figure 15 A) and 32% (n=1944) indicated taking Vitamin D supplements. Further analysis of the Vitamin D deficient population showed that 14% (n=760) despite taking Vitamin D supplements remained deficient (Figure 15 B). From that number 65% (n=496) were women and 35% (N=264) were men (Figure 15 B).









## QATAR BIOBANK MEDICAL OFFICE REFERRAL RESULTS

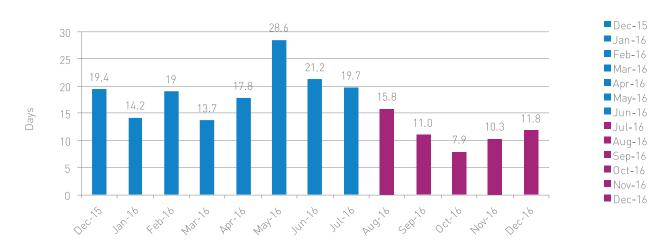
During the clinical visit the participant was offered the opportunity to return in approximately 3 weeks for results feedback (clinical and biological). The results feedback session was completed by the medical review office and includes interpretation of results, appropriate lifestyle advice and referrals for any results (clinic or biological) that lie out with recognized normal parameters. Referrals were made either to the participants own physician or to the Internal Medicine clinic building 310 at Hamad Medical Corporation.

#### **Turnaround Time (TAT) Statistics**

Figure 16 showed the average turnaround time (TAT) from the date of clinic visit (DOV) to the date of results review by the medical review office from the time period December 2015 to December 2016. Qatar Biobank aimed to ensure that all results were reviewed within 21 days of clinic visit. In July 2016, access to Cerner PowerChart medical software system had been established in Qatar Biobank which markedly improved the results turnaround time.

Figure 16 Average Turnaround Tine from Date of Visit to Date of Results Review.





#### **Newly Diagnosed Participants**

Through the Qatar Biobank visit and the results feedback session, participants with no existing diagnosis were found to have at least one new diagnosis. Between December 2015 and December 2016,1192 participants were referred and out of them 789 (66%) were referred for Osteopenia, followed by newly diagnosed dyslipidemia (33%). Figure 17.

# QATAR BIOBANK MEDICAL OFFICE REFERRAL RESULTS (CTD)

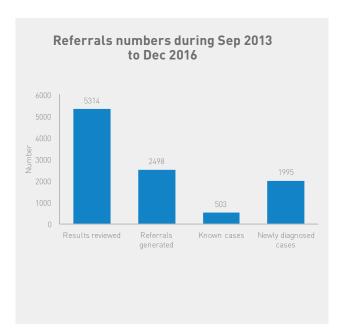
Total Number and Percentage of Newly Diagnosed Conditions (Nov-15 to Dec-16) 1400 1192 1200 789 (66%) 800 600 400 76 (6%) 62 (5%) 30 (3%) 23 (2%) High Blood Osteopenia Osteoporosis Newly Newly Newly Insulin Diagnosed Pressure Diagnosed Resistance Diagnosed Conditions DM Dyslipidemia

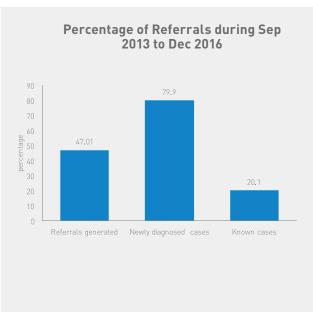
Figure 17 Total Number and Percentage of Newly Diagnosed Conditions (Dec-15-Dec16.

One of the major findings of Qatar Biobank cohort was that almost 80% of the referred population prior to attending the clinic had an undiagnosed condition which was identified through the Qatar Biobank medical review office and referred for further investigations and treatment.

The graph in Figure 18 showed that between September 2013 and December 2016, 2498 out of 5314 participants (47%) were clinically referred.

Figure 18 Referrals by numbers and percentage September 2013-December 2016





# QATAR BIOBANK MEDICAL OFFICE REFERRAL RESULTS (CTD)

% of Referred Conditions from Total reviewed (Sep-13 to Dec-16) 25 15 **%** 6 6 5 5 0 Abnormal Dyslipidemia DM HTN Anemia Abnormal Abnormal LFTs bone density

Figure 19 Percentage of Referred Conditions from Total Reviewed (Sep-13-Dec 16)

Most of the referrals were for Abnormal bone density (22%), followed by Dyslipidemia (18%) and Diabetes (13%).

From the findings, the Qatar Biobank data repository can be used as a resource for policy makers to design future evidence based strategic health programs within Qatar and the wider region.





## **QATAR BIOBANK RESEARCH IMPACT**

#### **About Qatar Genome Programme**

The Qatar Genome Project (QGP) is a national initiative aiming to map the genome of the local population. Announced by Her Highness Sheikha Moza bint Nasser, Chairperson of Qatar Foundation and Vice Chairperson of the Ministry of Public Health during the World Innovation Summit on Health (WISH) 2013, the Qatar Genome Program has recently concluded its pilot phase.

Managed by the Qatar Genome Committee, and incubated by Qatar Biobank, QGP uses a collection of samples and data from Qatar Biobank participants to identify genotype-phenotype associations relevant to the Qatari population. The medical data obtained through this initiative will provide unique insights that will enable the development of personalized healthcare in Qatar.

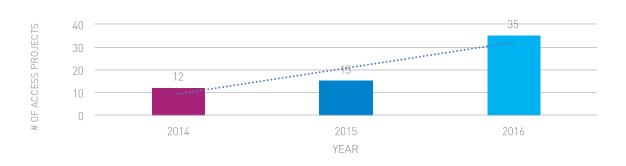
#### Qatar Biobank 'Research Access Projects'

Qatar Biobank recognizes the importance of data and biosample sharing, publications and presentations at scientific meetings. Researchers granted access to QBB data and biosamples must make all reasonable efforts to publish their findings and must provide their results to QBB. This information may be made available to other researchers for use in public interest healthcare research. Accordingly, Access Policy has been developed and implemented in order to enable informed and efficient collaboration; to encourage fair, timely and transparent access to Qatar Biobank's Research Data for high-quality research; and, to ensure that Qatar Biobank's Research Data and/or Biosamples are used in a scientifically and ethically acceptable manner. The Policy is implemented through approved Qatar Biobank's access procedures to ensure that the resource is optimally used in accordance with long-term research goals.

Research application proposals are currently being accepted and the following figure shows a breakdown of the proposals received to date to access the Qatar Biobank data. As Qatar Biobank expands the number of proposals increases.

Figure 20 QBB Access Projects Yearly Spread

#### **QBB ACCESS - PROJECTS YEARLY SPREAD**



## **QATAR BIOBANK RESEARCH IMPACT (CTD)**

Figure 20: This graph shows the total number of access project requests received by Qatar Biobank. As the graph shows the number of requests are steadily increasing as Qatar Biobank continues to develop.

Figure 21 Institutional Distribution of QBB Access Projects

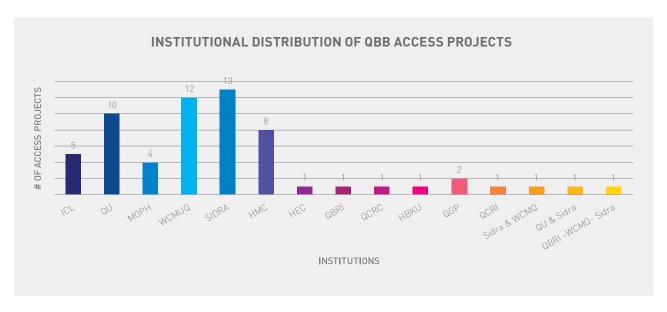


Figure 21: This graph shows the Institutional breakdown of access requests. While not all requests have been awarded access, the majority of the requests have been received from organizations within Qatar.



## **QATAR BIOBANK RESEARCH IMPACT (CTD)**

Figure 22 Status of QBB Access Projects Percentage

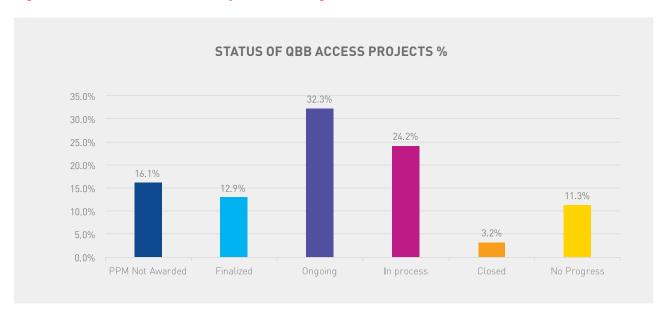


Figure 22: This graph shows the status in percentage of the access project requests received. From the graph it shows that the highest number of requests are ongoing which for the definition of this graph means that access has been awarded and the project is running.



## **QATAR BIOBANK ACHIEVEMENTS 2016**

**2016** QATAR BIOBANK HIGHLIGHTS





4797 Qataris





## ISO 9001:2008 QMS ISO 27001:2013

Maintaining second surveillance of ISO 9001:2008 QMS and ISO 27001:2013 without non-conformance



19 new research collaboration projects



4 international publications

5 conference presentations



developing & implementing new QBB owned Clinical Information System



Organizing a summer training program

- Recruiting 6081 participants 4797 Qatari with satisfaction rate 97%
- 3017 samples were successfully sequenced in collaboration with Sidra Medical and Research Centre
- Providing 1085 high quality DNA samples to QGP before target time
- Maintaining second surveillance of ISO 9001:2008 QMS and ISO 27001:2013 without non-conformance
- Approving 19 new research collaboration projects with different research institutes in Qatar
- Successfully developing and implementing new QBB owned Clinical Information System which replace the ICL system by March first with average weekly throughput 50.2 compared with ICL 36.4
- Successful connection to HMC laboratory (Power chart/ Cerner) which is reflected on the turnaround time of lab results from 3 weeks to one-week average
- Organizing a summer training program from 28th of July to 27th of August
- Presenting QBB in the scientific community: Four international publications, one published and 3 in process, 5 conference presentations 2 International and 3 local

## **QATAR BIOBANK ACHIEVEMENTS 2016 (CTD)**

#### Qatar Biobank IT Achievements 2016

2016 is marked with several milestone accomplishments for the QBB IT team. While the previous year saw the gradual establishment of this team, in preparation for an operational hand-over from the historic ICL IT team. The year 2016 was primarily about establishing the operational systems, which would enable the Biobank to continue to achieve its targets and provide services, seamlessly during this transition. The challenge was tripled. On one aspect there was the operational handover to a recently established team. Secondly, new systems were required to replace outmoded pilot systems. Finally, the strategy for selecting the new systems, needed to ensure a robust design and architecture to support the Biobank's continually expanding scope and future vision.

By far, the landmark of achievements for the QBB IT team is the deployment of a new clinic information system (CIS), and the development of an intermediate laboratory information management solution (LIMS). The first week of March 2016, signaled the live transition to Onyx, the newly selected open-source CIS system from OBiBa. Onyx a web-based application covered the clinical assessment interview for the Biobank's cohort study, including participant registration, e-consenting, health questionnaires, physical measurements and participant reports. The robust design, and well-defined scope of the system, ensured that the control and capture of research-critical data with minimal compromise to configurability, accommodating swift changes to the research protocol. Since deployment Onyx accommodated enhancements to Qatar Biobank's cohort including consent and questionnaires, integration of new stages and clinical devices to support operational needs. Onyx was integrated with the open-source Dcm4che PACS; used to operate all imaging devices at the Biobank, as well as the existing LIMS solution, to accommodate sample collection. Onyx continues to operate successfully, supporting the Biobank to achieve its current 6000+ participants accomplishment.

Inside the Laboratory, the Qatar Biobank IT team worked diligently to alleviate many of the challenges faced by our lab staff, chiefly due to legacy systems. In June 2016, Qatar Biobank was provided access to HMC's Cerner PowerChart module. Utilizing the same system as HMC lab staff, entitled improved visibility into HMC Lab operations, and hence swifter problem resolution. This caused significant enhancements in the overall turnaround time of delivery of the lab result reports to QBB participants. November 2016 saw the second major landmark for the team with the introduction of an intermediate laboratory information management system (iLIMS). iLIMS was developed entirely from scratch at the Biobank, to serve the QBB lab intermediately while awaiting the deployment of a fully-fledged LIMS solution. iLIMS entitled the realization of 3 major achievements at the QBB LIMS. Primarily the replacement of the rigid legacy system, allowing the specimen processes and storage plans to be restructured and enhanced entirely. Additionally, the lab was able to immediately retire the use of unstructured spreadsheets, as temporary stores of information, which originally compromised traceability on specimen chain-of-custody. Finally, and most notably it enabled, for the first time, the introduction of automation into the specimen processing pipeline at Qatar Biobank. Significantly enhancing the optimization of lab staff resources, and allowing the introduction of further specimen processing variations including DNA extraction.

Many other achievements mark the 2016 timeline for the QBB IT team, including finalizing the selection of a number of business-crucial technologies including a LIMS and a cognitive assessment platform amongst several others. We look forward to 2017 as the year where the fruit of such achievements will become notably visible, as well as further enhancements to operational systems at QBB. Nonetheless, we strive to focus and dedicate efforts to enhancing the quality, and enriching the QBB data catalogue. All in an effort to gradually shift toward a data-driven decision making model at Qatar Biobank.



## **CHALLENGES**

In 2016 while celebrating many great achievements Qatar Biobank faced some difficult challenges. The vision and strategic objectives for Qatar Biobank have been hindered by the global economic downturn and Qatar has experienced first-hand the effects of this with the drastic cut in oil prices.

Understanding the role of information technology (IT) in the continued vital operations with the Biobank was a priority. The IT system is the heartbeat of the biobank and the responsibilities include protecting the privacy and confidentiality of our participants data and specimen samples through delinking of personal information. Maintaining and monitoring the chain of custody of this information and ensuring the accessibility of data and samples to our approved researchers. The requirements of a robust IT system as well as the need to be ever developing in line with the ongoing requirements of Qatar Biobank continue to be priority.

Other challenges faced included an increase in the number of female members of the Qatari population registering to participate and take a more active interest in their health. However, a reduction in male participants was noticed. Keeping the male population interested in their own health and agreeing to participate is vital to reach a balanced sample of Qatari society. With the increased number of participants there was a need to increase manpower within all departments of Qatar Biobank. The challenges of finding experienced, skilled and professional manpower needs to be overcome so Qatar Biobank can continue to grow and develop with a strong team offering an exciting future into 2017.







## **KEY EVENTS AND ENGAGEMENTS IN 2016**

#### Qatar Biobank Signs Memorandum of Understanding (MoU) with Weil Cornell Medicine Qatar and VITO

In January 2016, Qatar Biobank signed a Memorandum of Understanding (MoU) with Weill Cornell Medicine - Qatar (WCM-Q) and Vlaamse Instelling voor Technologisch Onderzoek in Belgium (VITO). Aimed at strengthening the scientific collaboration between Qatar Biobank, WCM-Q and VITO, the partnership includes sharing knowledge in order to further research in the field of retinal image analysis and help develop non-invasive and convenient health monitoring and early disease identification.

#### Singapore Medical Delegation Visits Qatar Biobank

In February 2016, Qatar Biobank welcomed a senior delegation from the Lee Kong Chian School of Medicine (LKC Medicine) from the Nanyang Technological University and the school's primary clinical partner, National Healthcare Group, based in Singapore. During the visit, the delegation was able to attain valuable insights into the world-class information technology systems and efficient approaches to data collection and processing of samples currently housed at Qatar Biobank. The delegation studied how Qatar Biobank collects and measures its biometric data in addition to how it delivers results to participants.

#### Qatar Biobank Attends Europe Biobank Week

Dr Nahla Afifi, Managing Director of Qatar Biobank, delivered an informative presentation entitled, "Cohort Profile: The Qatar Biobank. Study design and First Results" during a panel discussion at the European and Middle Eastern Society for Biopreservation and Biobanking (ESBB) Conference in September 2016 in Vienna, Austria. The presentation served to highlight the key research findings from the significant biomedical research being conducted by Qatar Biobank.

#### **Qatar Metabolic Institute Conference 2016**

Dr Nahla Afifi presented the findings of diabetes discovered during the pilot phase at Qatar Biobank.

#### Qatar Biobank and Qatar Genome Programme Participate in Regional Molecular Biology Conference

Doctors and researchers from Qatar Biobank and the Qatar Genome Programme presented their findings on collecting and profiling genome samples of the Qatari population at the third Middle East Molecular Biology Congress and Exhibition held in October 2016 at Qatar University. The four-day congress, organised by Middle East Molecular Biology Sources (MEMBS), was attended by leading doctors, healthcare policy-makers, researchers and students from Qatar and around the world.

Dr Nahla Afifi, Managing Director of Qatar Biobank, and Dr Said Ismail, Manager of the Qatar Genome Programme, discussed their efforts to collect and profile genome samples of the Qatari population, with the goal of moving towards more personalised and efficient medicine.

Dr Ismail opened the presentations with a look at the Qatar Genome Programme's ongoing efforts to create a reference map of the Qatari genome using samples provided by the population. By doing so, the Qatar Genome Programme is already offering valuable opportunities for local researchers to study various diseases within the population.

Dr Afifi detailed how Qatar Biobank collects samples from the volunteer participants, a three-hour process that focuses on maintaining the visitors' privacy and dignity. She also shared some findings from the study of the first 3,000 samples collected by Qatar Biobank.

## **KEY EVENTS AND ENGAGEMENTS IN 2016 (CTD)**

#### **Additional Engagements:**

- Poster Presentation at ISBER 2016 Berlin on "Qatar Biobank: Benefits of International Organization for Standardization (ISO) Accreditation."
- Poster Presentation at ISBER 2016 Berlin on "Qatar Biobank: Overall Visit Participants' Feedback."
- Presentation at Qatar Genome Symposium 2016 on "Qatar Biobank sample and data collection process and access."
- Presentation at Qatar University's BRC seminar on "Qatar Biobank's milestones in building a successful biobank & public health Issues revealed."
- Presentation at First Annual Qatar Metabolic Institute Conference on "Diabetes discovered during Bio-Bank's pilot phase: 3000 Qatar genome samples."
- Panel discussion on "Precision Medicine: A Global Action Plan for Impact." at World Innovation Summit for Education (WISH) 2016 attended by Dr Asmaa Al Thani.
- Panel discussion on "Genomics in the Gulf Region and Islamic Ethics" at World Innovation Summit for Education (WISH) 2016 attended by Dr. Said Ismail and Dr. Nahla Afifi.
- UC Davies delegates visit Qatar Biobank.
- Qatar Biobank welcomes delegates from Saudi Arabia
- US Bilateral Arab Chamber of Commerce visits Qatar Biobank

## **NEXT STEPS**

- The Qatar Biobank will hold its 2nd International Conference titled 'The Impact of Biobanking on Precision Medicine Initiatives' in early 2017
- The creation of the Qatar Human Tissue Bank. Qatar Biobank will work towards supporting the creation of the first Human Tissue bank in Qatar, further enhancing Qatar's position as a leader within the region of biomedical research.
- Collaborative Projects Qatar Biobank is working in collaboration with other research and medical organisations including:
  - Diabetic studies with Hamad Medical Corporation
  - Stroke study
  - Birth Cohort study
- The next phase of Qatar Biobank will be to introduce Magnetic Resonance Imaging (MRI) scanning as part of the participant visit in early 2017.
- Qatar Biobank having successfully gained ISO accreditation for 9001 Quality Management Systems and 27001 Information Security Management Systems in 2015, will continue to strive to achieve the standards required to maintain these accreditations during the auditing process in 2017.

# QATAR BIOBANK PARTICIPANTS' TESTIMONIALS



## MS. SARAH SAAD

Ms. Sarah Saad, head of the Research Output department at Qatar Foundation, decided to take part in Qatar Biobank's health initiative because the program presented her with the opportunity to undergo a full medical checkup. Al-Quershi noted that cancer, diabetes and blood pressure disorders pose major health challenges for Qatar.



#### ENGINEER LAHDAN AL MOHANNADI

After learning about Qatar Biobank's initiative and its vital contribution to the promotion of better health for future generations, Engineer Lahdan Al-Mohannadi, Director of Buildings Affairs and Manager of the Buildings Design Department at the Public Works Authority, decided to join the program. Al-Mohannadi recalled the special reception and thrilling experience at Qatar Biobank, praising the work team behind the initiative and the advanced technology used in the program.

Al Mohannadi said he was impressed with the high level of professionalism and quality medical tests offered by Qatar Biobank. AL Mohannadi believes that the failure to regularly exercise represents one of the major health challenges in Qatar, noting that Qatar Biobank gives people a chance to avoid illness by undergoing regular medical checkups.



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#### MR. ABDULWALI AJI

Mr. Abdulwali Aji, Director of Public Relations at Qatar Airways, signed up to undergo medical checkups at Qatar Biobank. Aji praised the nursing team and the wide-range of high quality tests offered by Qatar Biobank within the same facility.

#### **DR. JASSIM AL-OBAIDLY**

Seeking a better understanding of his health condition, Jassim Al-Obaidly, a major and faculty member of Qatar's Police College, decided to join the Qatar Biobank initiative.

Al-Obaidy praised the "unique and excellent" health initiative, which he said "proved to be the best" compared to previous medical checkups he had undergone in numerous other countries.

Al-Obaidy added that the attention dedicated to participants, the accuracy of the tests and the advanced medical equipment used at Qatar Biobank caught his attention, noting that he was impressed by the accuracy of the medical imaging technique.

Reflecting on the major health challenges facing Qatar, Al-Obaidy cited consanguinity, a lack of health awareness and regular fitness exercise as key issues, noting that Qatar Biobank's medical checkups can help Qatar's population lead a healthy life.

