Moving Forward

Supporting Quality in Research

BIOBANK REPORT 2018/2019

قطر بيوبنك
qatarbiobank
for medical research للبحوث الطبية
عضو في مؤسسة قطر
Member of Qatar Foundation

Supporting Quality in Research

BIOBANK REPORT 2018/2019

TABLE OF CONTENTS

Annual Report 2018/19

Table of Contents

Welcome Letters 6
Vision and Mission 10
Qatar Biobank Supporting Quality in Research 12
Our IRB Committee 14
2018/2019 Biobank Report Introduction 16
Meet the Team 18
Participant Results Feedback 20
Qatar Birth Cohort Study (QbiC) 24
Research Access Office 26
Research Projects 28
Feedback from our Researchers 31
Communications and Participant Recruitment Department 32
IT Department Updates 38
Clinic Department 40
The Laboratory Department 42
The Future 44
Key Findings and Analysis 46
Challenges 55
The Qatar Genome Project 56

Biobank Report 2018/2019

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Supporting Quality in Research

Her Excellency Dr
Hanan Al Kuwari

Minister of Public Health, Chairperson, Qatar Biobank Board of Trustees

As the largest population-based health initiative ever undertaken in Qatar, Qatar Biobank is helping improve the lives of future generations by enabling medical research on the causes of diseases that prevail in Qatar.

As a member of Qatar Foundation, Qatar Biobank works with the Ministry of Public Health, Hamad Medical Corporation, Sidra Medicine and scientists from other partner institutions in Qatar and beyond to drive Qatar's quest for a healthier tomorrow.

Over the next few years, the research enabled by Qatar Biobank will show how the health of the Qatari population is affected by their lifestyle, environment and genes.

More than 18,000 members of the community have already registered at Qatar Biobank and donated their biological samples and data, and an increasing number of volunteers are joining in every day. The depth and breadth of the information from those thousands of samples is already providing insights into key health issues facing the local population.

At the World Innovation Summit for Health (WISH) 2018, Her Highness Sheikha Moza bint Nasser was presented with the first 'Q-Chip', which highlighted a major achievement of Qatar Biobank and Qatar Genome Programme. It is the first local gene array designed and based on data from thousands of Qatari genomes sequenced over the past three years, and represents a major step in gaining insights into the health of the local population, including the prevalence of diabetes, obesity, and vitamin D deficiency.

We are hosting the 'Qatar International Biobanking Conference' in 2019 in collaboration with our international partners, including the European and Middle Eastern Society for Biopreservation and Biobanking (ESBB), and supported by BBMRI-ERIC, a European research infrastructure for biobanking, and the International Society for Biological and Environmental Repositories (ISBER). The three-day event, entitled, 'Quality Matters: A Global Discussion in Qatar,' is a unique opportunity for scientists, researchers, industry experts, and students to learn about the latest developments in the global biobanking sector and showcase their research findings.

Dr Richard O 'Kennedy

Vice President for Research, Development and Innovation (RDI), Qatar Foundation

Biomedical research forms a key part of Qatar Foundation's research agenda. At Qatar Foundation's Research, Development and Innovation, we realize the importance of our research institutions and particularly the work done by Qatar Biobank and the Qatar Genome Programme. Qatar Foundation is making it possible for researchers and scientists to support and advance research to guide healthcare strategies for the most effective prevention of disease and the development of new treatments. Researchers have access to an incredible opportunity provided by the Qatar National Research Fund's Path Towards Precision Medicine (PPM) programme. Researchers who conduct genomic research in Qatar utilizing the samples and data collected by Qatar Biobank and Qatar Genome Programme can take part and make full use of this funding opportunity. Research into the risk-factors for major health challenges for the Qatari population are vital to enhance the applications of precision medicine, enable for better and more economic healthcare and clearly establish Qatar as a world leader in this area of medical Research.

Professor
Asmaa Al Thani

Board Vice Chairperson of Qatar Biobank and Chairperson of Qatar Genome Programme Committee

Medical research has been most effective when scientists have access to quality data. Qatar Biobank, together with Qatar Genome Programme, empowers medical researchers in Qatar to carry out vital research into drivers of some of the most common health challenges. Both institutions have taken first important steps towards developing Qatar's biomedical research profile and charting a roadmap for personalized medicine in the country.

The data collected by Qatar Biobank for the Qatar Genome Programme is giving scientists a unique insight into the causes, thus enabling prevention of these diseases by way of personalized treatments in line with the genetic coding of an individual.

We are delighted to welcome more than 18,000 participants to Qatar Biobank – a milestone that represents the local population's eagerness to contribute to their improved health. The increased number of participants will play a pivotal role in advancing quality research for a healthier local population for generations to come.

Researchers have already been able to use Qatar Biobank's samples to gain important insights into the health of the local population, including the discovery of high levels of diabetes, obesity, and vitamin D deficiency. These findings will enable researchers to make recommendations to healthcare providers and policy-makers to better tailor their actions to address specific conditions.

Qatar Biobank continues to serve as a unique resource that will advance Qatar's journey towards becoming a regional hub for medical research and expertise and will help Qatar contribute to the development of biomedical knowledge globally.

Professor Dr
Nahla Afifi

Director of Qatar Biobank

Qatar Biobank serves as a large-scale biomedical research initiative that is based on population in the Arab world, thus ensuring far more accurate and effective targeted medical treatments. We encourage the people of Qatar who are eligible and have not yet been screened to participate in this vital initiative – the success of which is dependent on large-scale participation by the local population, particularly Qatari youth.

Public engagement is at the core of Qatar Biobank's unique recruitment approach. Qatar Biobank partners with the local population to understand the core causes of most health challenges we face in the country. From the onset, when participants visit us for initial screening, to when they receive their results, our experts work with them to understand the vital contributions they are making to shaping the health of the future generations.

Our participants receive a range of benefits and are impacted positively through their participation. 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.

As we enter an important phase in biomedical research in Qatar, we will continue to work with our collaborators to understand the health challenges we face, diagnose the core causes and find feasible solutions in the long-run.

Qatar Biobank

Vision and Mission

VISION

The vision of Qatar Biobank is to 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

The mission of Qatar Biobank is 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 Biobank
Supporting Quality in Research

Qatar Foundation for Education, Science and Community Development is a private non-profit organisation that serves the people of Qatar by supporting and operating programmes in 3 core mission areas: education, science and research and community development.

Qatar Biobank is a member of Qatar Foundation Research, Development and Innovation and is working towards achieving specific initiatives and priorities within the research, development and innovation national strategy. Through a range of dedicated centres and initiatives Qatar Foundation aims to achieve sustainable and tangible improvements both locally to develop a healthier future for the population of Qatar and internationally.

Qatar Biobank Institutional Review Board (IRB) Committee

All research applications involving human research subjects will require submission and approval from the Qatar Biobank IRB committee. The QBB IRB committee was founded on the 30th of September 2016.

The purpose of the Qatar Biobank IRB committee is to formalize the process of medical research work of Qatar Biobank which it is committed to and ensuring that all human subject research in which it is engaged is conducted in accordance with the ethical principles through an Institutional Review Board Committee (IRB) as stated by Ministry of Public Health in Qatar: Policies, Regulations and Guidelines for Research Involving Human.

Qatar Biobank IRB Committee will:

- Review the appropriateness of the research protocol as well as the risks and benefits to study participant information. It will ensure that clinical trial participant information is exposed to minimal risks in relation to any benefits that might result from the research.
- Review and approve all study-related materials before and during the research.
- Assist in biomedical research horizon scanning to help Qatar Biobank prepare for and adapt to emerging trends in biomedical research, new technologies and new opportunities to contribute to the advancement of medical research

Dr Ayman Shabana
Member
Associate Research Professor, Georgetown University, Qatar

Clinton Hermes
Member
General Counsel and Secretary, Sidra

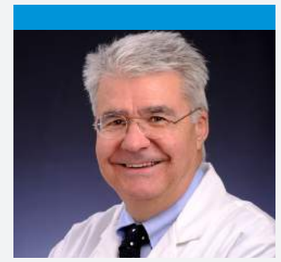
Dr Khalid Al Ansari
Chair
Director Pediatrics Emergency Center Department, Hamad Medical Corporation

Dr Khalid A. Alali
Vice Chair
Acting Assistant Undersecretary for Higher Education Affairs

Professor Nahla Afifi
Member
Director, Qatar Biobank

Dr Asma Al - Khtib
Member
Manager Oral Health Division, Operations Department, Primary Health Care Corporation

Dr Ahmed Al Kuwari
Community Member
Group Board Advisor, Qatar Islamic Bank



Dr Pablo Rodriguez
Member
Associate Professor of Medical Ethics in Medicine Weill Cornell Medical College, Qatar

2018/2019 Biobank Report

Introduction

Supporting Quality in Research

Qatar Biobank is a platform that will make vital health research possible through its collection of biological samples and information on health and lifestyle from large numbers of the Qatari population. Qatar Biobank, Qatar's long-term medical health initiative, was created to give Qatar's people better chances of avoiding serious illnesses and to promote better health for our future generations. Qatar's long term science and research initiatives are supported through the work of Qatar Biobank. Our goals remain aligned with the strategic goals of Qatar Foundation for Research, Development and Innovation to enable quality research in Qatar through the work being conducted at Qatar Biobank.

2018 has been a very busy and eventful year for Qatar Biobank and marks the 6th anniversary since our beginning.

The World Health Innovation Summit (WISH) 2018, hosted in Qatar in November saw the presentation of the 1st version of the Qatari Gene chip or Q-Chip to Her Highness Sheikha Moza Bint Nasser from Her Excellency Dr Hanan AL Kuwari, Minister of Public Health, Qatar. The first Q-chip contains over half a million of DNA mutations and variants that can be used in diagnosing various diseases as well as in national screening programmes. The Q-chip will help researchers understand the genetic heritage of the Qatari population and continue the personalised and precision medicine approach to healthcare in Qatar. New technologies such as the Q-Chip and the skilled staff to work on such projects are part of the ongoing work to reach the goals of the Qatar National Vision 2030 project.

In November 2018, Dr Nahla Afifi was announced as the Director of Qatar Biobank. Dr Nahla had previously taken on the role of acting director as well as her role as scientific and education manager. We congratulate Dr Nahla and wish her every success as she continues to direct Qatar Biobank into exciting and innovating opportunities and collaborations.

12975

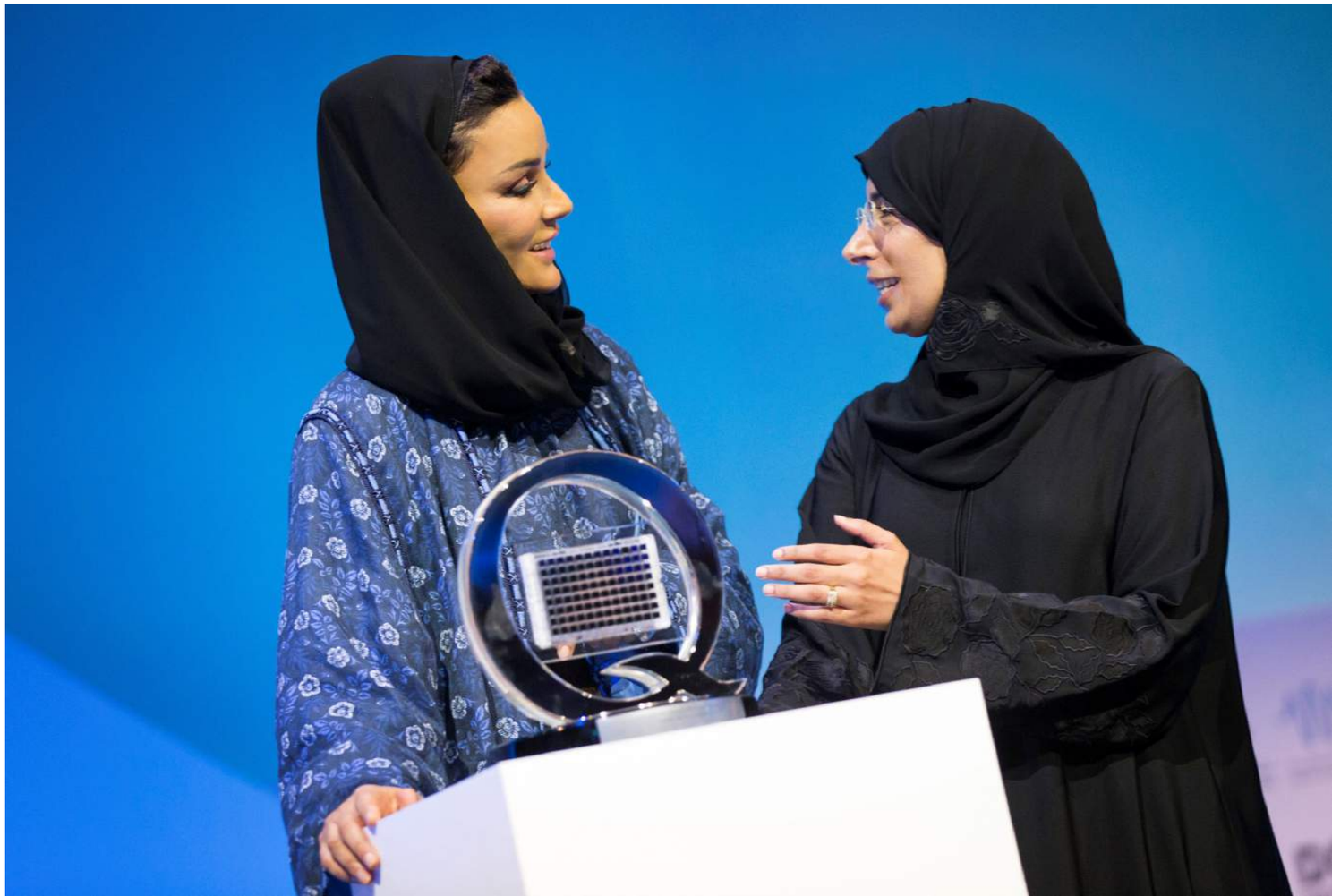
High quality DNA Samples

18,000

Participants

80 %

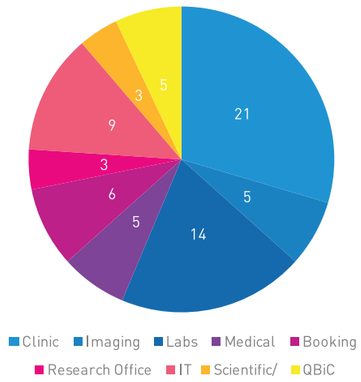
Qataris



Meet the team

Over the last 12 months, the Qatar Biobank team has grown from around 50 to over 70 members of staff which includes full time staff, temporary staff and volunteers. The growth in the staff reflects the growth in Qatar Biobank operations while working hard to ensure that the quality and expectations of our participants', customers and stakeholders are met.

Figure 1 Staffing Levels for Qatar Biobank 2018



Education and Scientific Team

2018 has seen a lot of work devoted to the revision and enhancement of the methods used for the data collected during the participant visit. The addition of the Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC) for the assessment of pain, stiffness and physical function has provided researchers with valuable information. The 36 item short form questionnaire rating quality of life measures has also been implemented. As mental health research in Qatar is an emerging topic it is hoped the addition of this questionnaire will provide researchers with much needed information.

The introduction of new biomarkers to the blood panel collected (Total IGA, Ttg, Anti-endomysial antibody, ESR, PSA, Copper, Zinc and RF Factor and PSA) now provide researchers with greater information to enhance their work but as Qatar Biobank provides participants with results feedback it helps the clinical data interpretation specialist create a comprehensive picture of health in conjunction with the other data and images collected, for the participant during their results feedback session.

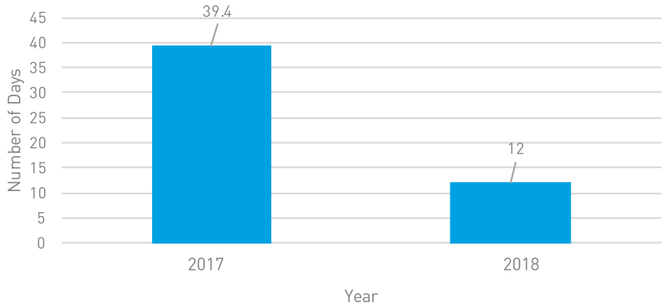
2018
/19

Participant Results Feedback

2018 saw the completion of our electronic Medical Review System (MRS). The system was designed and developed by our in house IT department in collaboration with the education and scientific department. The MRS is able to support multiple studies and multiple visits so if a participant volunteers in more than one study or has multiple visits their data will be connected by their participant clinic identification number. The MRS system draws information using the participant clinic ID from several data collection data bases, including our Clinical Information System, Laboratory information system and Picture Archiving and Communication System (PACs) to consolidate all the information for each participant in one location - the MRS system. The MRS has also been programmed to extract key information from our questionnaires including participant medical history, lifestyle, surgical, family and drug history. This information is also used by our clinical data interpretation specialists to create a picture of health for each participant and used when providing participant results feedback. The MRS has a built in management dashboard that allows the easy statistical analysis of data relating to participant visits including turnaround times for results feedback, referrals and referral feedback. The positive impact this system has had on the work of the clinical data interpretation specialist team has been vast. They are now able to review files quicker and more efficiently.

Improving the turnaround time for reviewing results has brought the next challenge which is to ensure there are enough results appointments available and participants are not waiting excessively to book an appointment to meet with the clinical data interpretation specialist staff for full results feedback and interpretation.

Turnaround Time Statistics 2017 vs 2018



The graph shows that with the introduction of the new medical review system the turnaround time statistics have greatly reduced from on average 39.4 days in 2017 to 12 days in 2018 for participant results to be reviewed and available for feedback. The definition of turnaround time is from the date of visit until the date of results reviewed by a clinical data interpretation specialist.

Figure 2 Turnaround Time Statistics 2017 vs 2018

Collection of results without feedback from a doctor

To address the wait that participants were experiencing to receive their results, we introduced the opportunity for participants to collect their results and then take them to their own physician for interpretation. This was trialed for 3 months, however it proved unpopular as most participants wanted to speak with our own in-house clinical data interpretation specialist team and so this was discontinued and we have worked hard to increase the number of appointments available to reduce the waiting times to see a member of the team to have their results explained. While results feedback may remain a controversial topic it is certainly proving very popular at Qatar Biobank.

Referrals

As part of the participant results review and feedback process we continue to work in collaboration with Hamad Medical Corporation and the Internal Medicine Clinic for management of our clinical referrals. After completion of a comprehensive review of all data and images collected from the participant visit and the biological markers, any results found to be outwith normal or expected parameters are referred to the Internal Medicine Clinic or the participants own physician for further investigation.

The figure below shows the number of referrals made in 2018

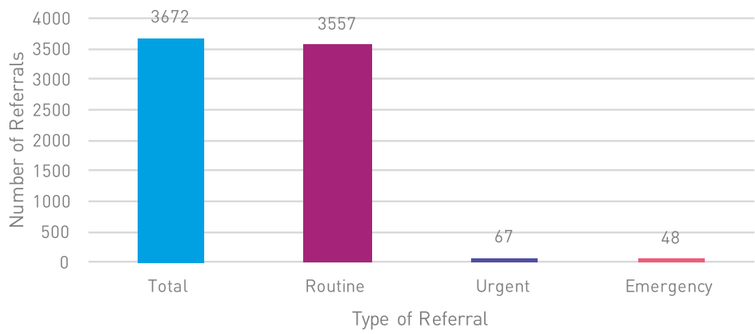


Figure 3 Number of referrals made in 2018

Participant Results Feedback ctd

In 2018, Qatar Biobank made a total of 3672 participant referrals to either their own physician or Hamad Medical City.

Figure 4 The table below shows the most common conditions being detected and referred

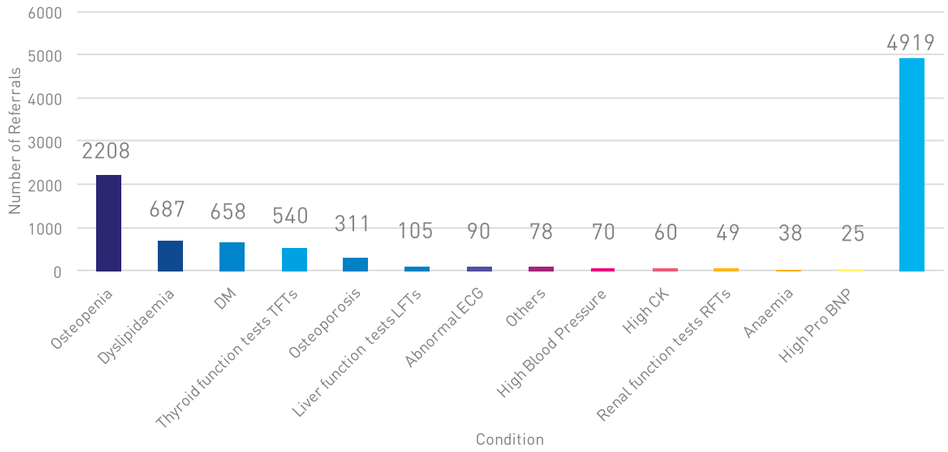


Figure 4 2018 Referrals by Condition

In 2018 at total of 4919 condition referrals were made, with the most commonly referred conditions being osteopenia (2208 referrals), Dyslipidaemia (687 referrals), Diabetes Mellitus (658 referrals) and abnormal thyroid function tests (540 referrals).

Figure 5 Referrals for preexisting conditions v's potential new diagnosis

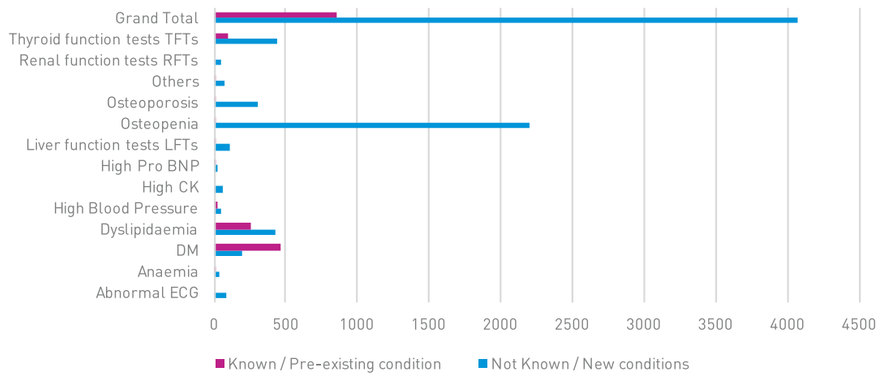


Figure 5 Referrals for preexisting conditions v's potential new diagnosis

Introduction of the new medical review system the turnaround time statistics have greatly reduced from on average 39.4 days in 2017 to 12 days in 2018 for participant results to be reviewed and available for feedback.

The analysis shows that in 2018, of the 2208 referrals for osteopenia, 2199 were new or not known conditions to the referred participant. 460 referrals were made for known or preexisting DM and a further 198 were made for new or not known potential DM conditions.

Another project started in 2018 is the creation of participant education literature which will be used to support the results feedback process. Participant education literature is being used to provide our participants with accurate information to help prevent anxiety and misunderstanding about a potentially new diagnosis or to support a known condition.

Qatar Biobank is also working in collaboration with the Diabetes Association to refer participants to the association and access their wealth of patient education literature.

Qatar Birth Cohort Study (QbiC)

The Qatar Birth Cohort Study was developed in 2018 and the pilot phase commenced in July. This study is the first mother child cohort study of its kind in the Middle East and aims to assess the synergetic role of environmental exposure and genetic factors in the development of chronic disease and monitor woman and child health and/or obstetric characteristics with high prevalence. The study is developed and funded by the Ministry of Public Health Qatar in collaboration with many national and international research institutions and is embedded within Qatar Biobank. The pilot phase saw 50 pregnant females join the study, with their husbands joining the Qatar Biobank cohort study. The project has now been renewed and is now recruiting 3,000 pregnant females their children born into the study and their husbands.

The study will initially comprise of 4 visits for the pregnant female with the 1st visit at approximately 12 weeks, the second at 30 weeks, the third at the point of delivery and the 4th visit 2 days post-delivery.

The participants after the initial consent process are interviewed on several topics including sociodemographic characteristics, dietary habits and occupational/environmental exposure. Maternal characteristics are assessed based on anthropometric measurements, spirometry and blood pressure.

Biological samples will be collected during the study and these include:

- Urine
- Saliva
- Semen
- Placenta
- Cord Blood
- Cord Tissue
- Meconium
- Stool Samples
- Colostrum and Breast milk
- Hair

Research Access Office

The research access office is a new addition to the Qatar Biobank. The aim of the office is to enable and assist researchers with access to the Qatar Biobank catalogue of data and biological samples to help facilitate vital research on the local population and ultimately enhance medical knowledge through a personalised medicine approach. This small team works closely with the local research community and the Qatar Biobank Institutional Review Board to ensure that all research access applications involving human research subjects are conducted in accordance with the required ethical principles and guidelines.

Mid 2018, the tender process began for the development of a Research Collaboration Management Solution and online researcher portal that would facilitate researcher activities from data query and data catalogue access, research access application through to IRB application to data extraction and delivery. The requirements have been identified in collaboration with the research team and our IT department. This is currently in the technical evaluation stage and hopefully in 2019 we will have a permanent system. However, at the end of 2018 a temporary online researcher portal was launched which is a data query and research access application portal.

The work of the research access office has enabled many undergraduate and graduate students to complete their final year research projects and help to develop the researchers of the future here in Qatar.

Research Projects

Qatar Biobank first released data to the research community in 2014 with 12 project applications. As the biobank has grown and developed the number of research applications has increased. Qatar Biobank continues to accept research application proposals.

Figure 6 QBB Research Collaboration Projects

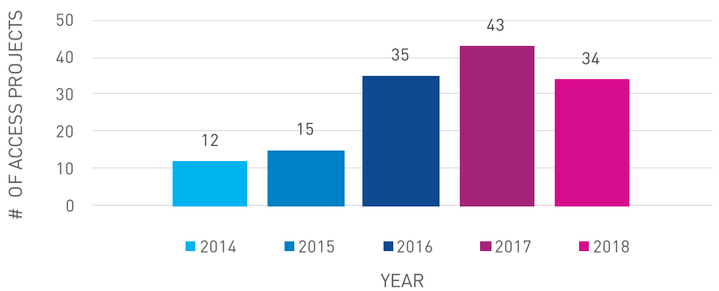


Figure 6 QBB Research Collaboration Projects

Figure 7 QBB Access Project Status

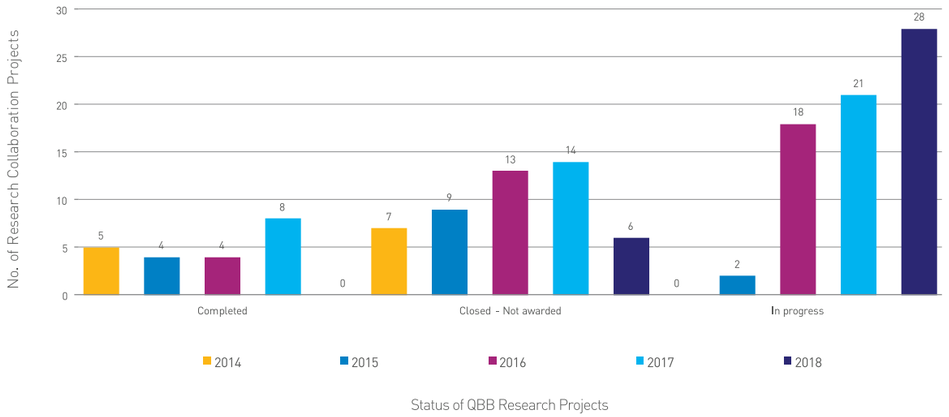


Figure 7 QBB Access Project Status

Definitions: Completed: the research is complete and the Principle Investigator (PI) has submitted the publication or poster and feedback form.

Closed: The project has not been awarded, so the PI does not have the fund to start the project.

In progress: the project is active/ongoing and the PI is working on it.

Figure 8 Category Distribution of Access Projects in Qatar Biobank

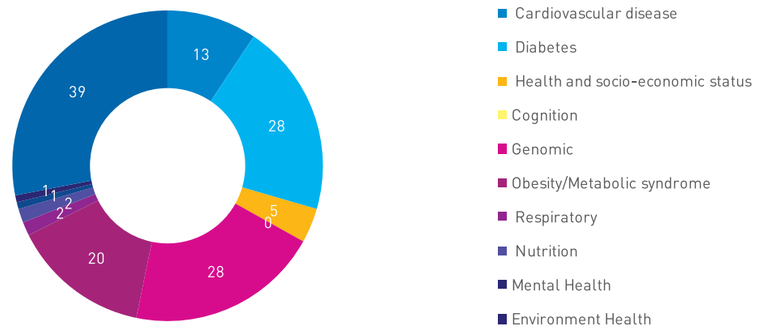


Figure 8 Category Distribution of Access Projects in Qatar Biobank

Figure 8 shows that from the 139 access application projects received by Qatar Biobank research access office, 28 focus on Diabetes Melitus, a further 28 will use genomic data to complete their research.

The IRB committee has reviewed in total 72 projects since its creation in 2016. The breakdown of the projects is in figure 9

Figure 9 Qatar Biobank Institutional Review Board Number of Reviews

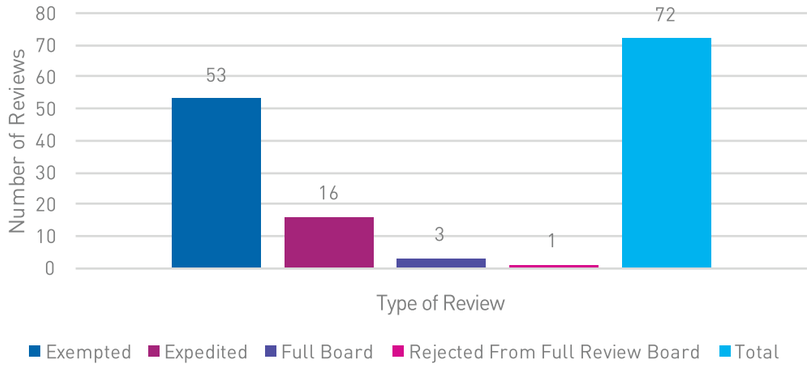


Figure 9 Qatar Biobank Institutional Review Board Number of Reviews

Research Projects ctd

Collaborations/Partnerships

Qatar Biobank is supporting research from over 20 institutions across the country.

Figure 10 Institutional Distribution of QBB Access Projects

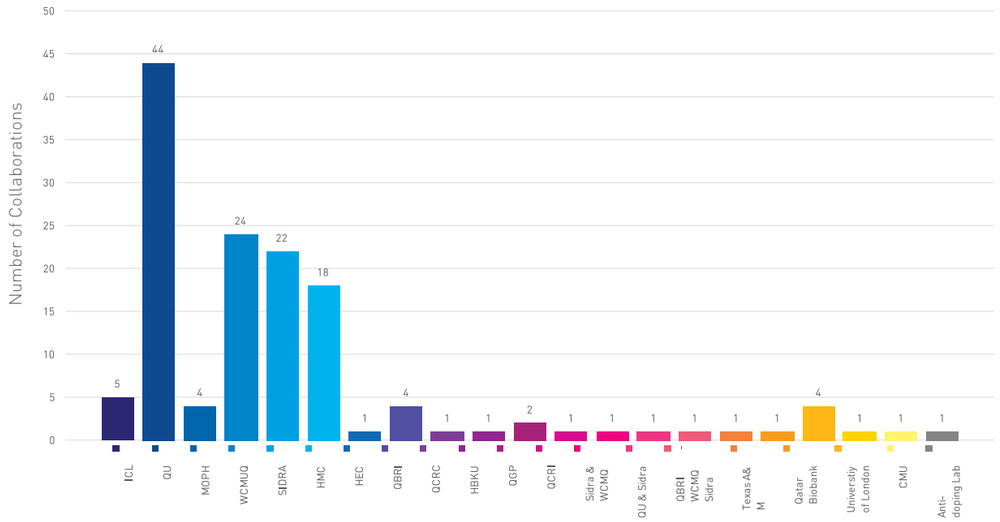


Figure 10 nstituational Distribution of QBB Access Projects

All researchers granted access to QBB data and samples must make reasonable efforts to publish their findings and also provide their final results to Qatar Biobank. The information may be made available to other researchers for use in public interest healthcare research.

Figure 11 QBB access projects completed: publication/ presentation

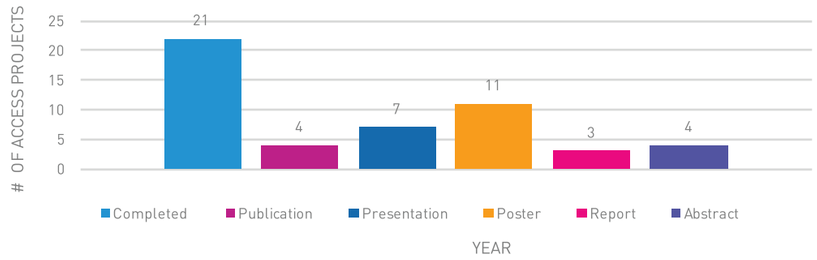


Figure 11 shows the publication status of the 21 completed research projects, with to date 11 poster presentations, 7 publications and 4 publications.

Feedback from our Researchers

Feedback from our researchers

Ensuring the data and information provided to the research community is very important to Qatar Biobank and their feedback is very important to us.

Qatar Biobank is effectively shaping the future of health and medical research in Qatar. It provides an incredible opportunity for researchers and scientists in Qatar and beyond to carry out thorough research into the drivers of some of the most of common health challenges that the country currently faces. It offers high quality data and biological samples, which has truly enriched our research and made the entire process efficient. Thanks to Qatar Biobank's research endeavor and highly supportive team, we have two completed two publications and the remaining two are in the process of being published.

Professor Stephen Atkin, Professor of Medicine at Weil Cornell Medicine Qatar.

As a unique national health research project, Qatar Biobank is making it implausibly easier for researchers in Qatar to conduct high-quality research into some of the most pressing health problems in Qatar. The research made possible as a result of Qatar Biobank's continuous support are being published in high-impact journals and publications worldwide, which is helping Qatar cement its position as a leader in the global biobanking and genomics industry. I along with my researchers will be delighted to take part in another round of research with Qatar Biobank and contribute to the nation's quest for an even healthier population.

Dr. Hiba Ahmad Abed Bawadi, Section Head of Clinical Education – College of Health Sciences, Qatar University.

I would like to extend my sincerest gratitude to Qatar Biobank's leadership and support team for helping us conduct impactful research over the recent past. As the first of its kind research project in Qatar, Qatar Biobank has surpassed researchers' expectations and has made its mark visible to everyone. In the long-term, the research outcomes will ensure that the people of Qatar gain access to customized healthcare and the level of the common diseases in the country is reduced dramatically.

Dr. Ammira-Sarah Akil, Staff Scientist, Human Genetics Department at Sidra Medical and Research Centre.

Communications and Participant Recruitment Department

+18,000

Participants recruited

The Qatar Biobank Communications Department achieved numerous milestones and completed a series of important assignments over the course of 2018 in line with the institution's broader strategic objectives. In 2018, Qatar Biobank went through an important phase as it endeavoured to recruit at least 18,000 participants.

Our communications activities throughout the year were also aimed at further strengthening Qatar Biobank's relations with key stakeholders in Qatar and beyond, and most importantly, raising the profile of its research activities as a step to ensure people of Qatar get the correct understanding of personalized medicine in the context of Qatar's healthcare and medical sector.

A multi-pronged participant outreach strategy, powered with proactive public relations activities, has been set and utilized throughout the year to ensure the above targets were achieved in a timely manner.

The core pillars of the participants outreach strategy included participation in industry events, awareness programs (i.e., World Diabetes Day), and national events (i.e., Qatar National Day, National Sports Day, Garangao), sustained media outreach, and continued social media activities.

Enhancing Registration through Participation in Industry Events

Qatar Biobank attended a wide range of industry events in 2018, introducing its underlying mission and vision as well as its research and achievements to a broader audience in Qatar and beyond. The participation proved helpful in increasing registration for Qatar Biobank through raising awareness about the benefits the work can bring to the people of Qatar in the long-term.

The following Table 1 highlights the various events throughout the year and the relevant impact in terms of participation:

Event Title	Date	Location	Participants Registered
Qatar National Day	12 – 20 Dec	Darb Al Saai	**840**
Functional Genomics 2018 Symposium	1-10 Dec	Qatar National Convention Centre	**10**
PHCC Scientific Research Conference	1-2 Dec	Hilton Qatar	**5**
3rd Qatar Diabetes, Endocrinology and Metabolic Conference	29 Nov – 1 Dec	Sheraton Grand Doha Resort & Convention Hotel	**12**
World Diabetes Day	14 Nov	Oxygen Park (QF)	**35**
Information Session at Mshiereb Museums: Journey to the Heart of Life	30 Oct	Mshiereb Museums, Bin Jelmood House	**15**
Conference on Understanding Molecular Mechanisms in Cardiovascular Biology, Diabetes, obesity and Stroke(CUDOS-2018)	22-25 September, 2018	Qatar National Convention Centre (QNCC)	**22**
European Biobank Week 2018	4-7 Sep	Antwerp, Belgium	**NA**
Qatar Foundation Garangao	2 June	Al Shaqab	**NA**
Qatar Genome Symposium	29 April	Qatar National Convention Centre	**12**
6th Middle East Forum on Quality and Safety in Healthcare	23 – 25 March	Qatar National Convention Centre	**20**
Qatar Foundation Annual Research Conference (QFARC)	19-20 March,	Qatar National Convention Centre	**2**
Kidney & Women's Health by HMC	9 March	Corniche – beside Costa Coffee	**12**
National Sports Day 2018	13 Feb	Qatar Army- National Service (Meqdam)	**30**
14th Gulf Heart Association Conference	11 - 13 Jan	Sheraton Grand Doha Resort & Convention Hotel	**4**

Communications and Participant Recruitment Department ctd

Recruiting more than 18,000 Participants

Qatar Biobank's participant outreach team has achieved an important milestone by reaching a record number of participants over the past years and in 2018 in particular. The inclusive outreach strategy resulted in recruiting more 18,766 participant from across Qatar of which over 80% were Qatari nationals.

Figure 12 Breakdown of Qatar Biobank Participants

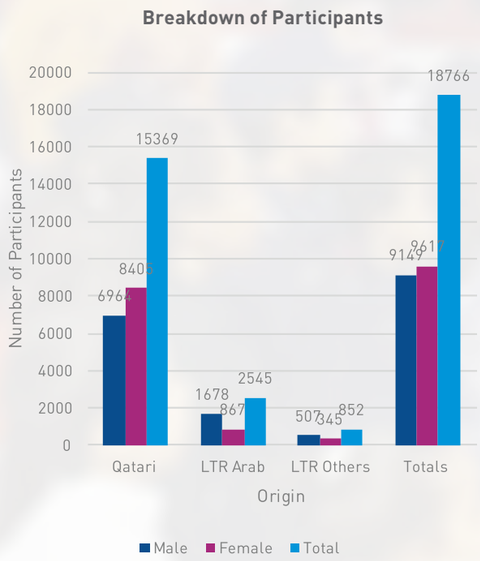
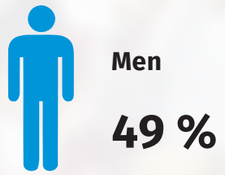
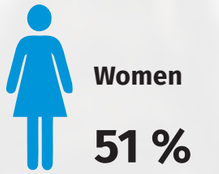


Figure 12 Breakdown of Participants



Men

49 %



Women

51 %

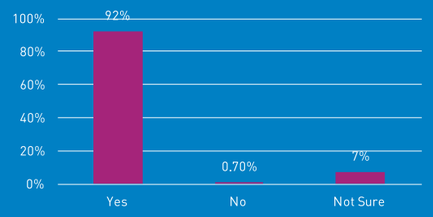
Participant Feedback about Qatar Biobank

The overall feedback survey also provided very positive results with 91% of participants rating the services as excellent and a further 7% found the services to be very good.

Figure 13 How would you rate the quality of services?

Figure 14 Given the opportunity, would you take part in Qatar Biobank again? When participants' were asked if they would take part again 92% said yes.

Figure 14 Given the opportunity, would you take part in Qatar Biobank again?



Over 2,281 participants registered online, 5,762 in total came through the pre-registration form (1696) and call centre (4066) and 1,107 of the participants registered at the various events.

Figure 15 Qatar Biobank participant recruitment methods

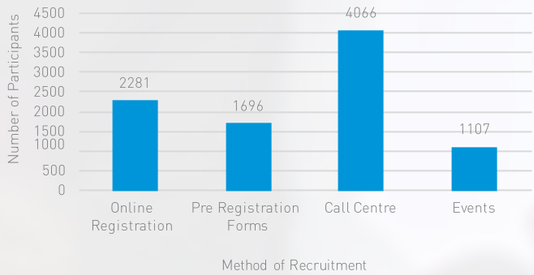


Figure 15 Qatar Biobank participant recruitment methods

Communications and Participant Recruitment Department ctd

Participant Feedback about Qatar Biobank ctd.

The participant is asked to complete a feedback form at the end of the participant visit and then again once they have received their results which is an overall feedback survey. The feedback is very important to us to continually improve and enhance the services we provide.

From the survey completed at the end of the participant visit the analysis shows that 76% of respondents took part in Qatar Biobank to have a health check.

Figure 16 What were your reasons for participating in Qatar Biobank Study?

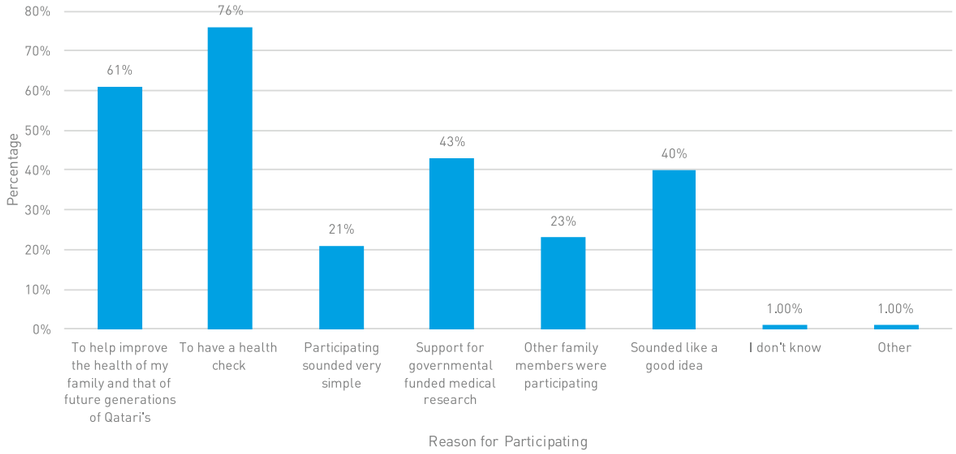


Figure 16 What were your reasons for participating in Qatar Biobank Study?

61% of people participated to contribute to improving the health of their family and the health of future generations of Qatari's.

Additional Key Highlights

01 In 2018, 110 articles were published in Arabic and English media about Qatar Biobank, its activities, achievements and programs. The articles were generated by the public relations content (i.e., press releases and feature stories), which were shared with the media on a regular basis.

02 All types of media including newspapers, TVs and Radios, were engaged throughout the year to disseminate the relevant messages to the people of Qatar. Qatar Biobank management and key spokespersons took part in 17 interviews with the media over this period.

03 Social media has been widely used over this period to share updates and news with the main target audience. Qatar Biobank's Twitter followers reached 2,624 and Instagram reached 796. Qatar Biobank's social media platforms have served as important channels to reach out to potential participants.

04 Qatar Biobank participated in the Qatar Genome Programme's second symposium, held under the theme 'Ethics, Regulations, and Best Practices in Genomic Medicine' in collaboration with the Ministry of the Public Health and the Research Center for Islamic Legislation and Ethics.

05 Her Excellency Sheikha Hind bint Hamad Al Thani, Vice Chairperson and CEO of Qatar Foundation (QF), visited Qatar Biobank to receive an update on the organization's current projects and tour the state-of-the-art facilities. During the meeting, H.E. Sheikha Hind met with senior representatives including H.E. Dr. Hanan Mohamed Al Kuwari, the Minister of Public Health; Dr. Asmaa Al Thani, Chairperson of Qatar Genome Programme Committee and Board Vice Chairperson of Qatar Biobank; and Dr. Nahla Maher Afifi, Scientific and Education Manager and Acting Director of Qatar Biobank.

06 Qatar Biobank and Qatar Genome Programme worked closely with Mshiereb Museums to highlight the permanent DNA Exhibition as an important tool to educate the public about the important and the value of biobanking and genomics. Collaborative programs, such as seminars and educational tours, were held in the last quarter of the year.

07 Qatar Biobank participated in key industry events throughout the year including: the World Innovation Summit for Health, Qatar National Day activities, 6th Middle East Forum on Quality and Safety in Healthcare, Qatar Foundation Annual Research Conference, 14th Gulf Heart Association Conference, Qatar Foundation Tent at Darb Al Saai, Qatar Clasico: Al Sadd vs. Al Rayan Football Match, Qatar Foundation Garangao Event, and the 2nd Conference on Understanding Molecular Mechanisms in Cardiovascular Biology, Diabetes, Obesity and Stroke.

IT Department Updates

The IT infrastructure is at the core of Qatar Biobank connecting different departments and systems/databases while enabling the safe collection, management and storage of the data and biological samples collected from participants during their visit. Many demands have been placed on the IT department and the systems under their management as the biobank continues to grow and develop with the introduction of additional studies, multiple participant visits and taking on more requirements to meet the needs and expectations of our stakeholders and customers both internally and externally. Demands on the work of the IT department seem to be ever present and the last couple of years have seen major changes to the IT systems and infrastructure being used within Qatar Biobank.

Since the deployment of the Clinic Information System in 2016 many enhancements to the system have been introduced which have made the collection and retrieval of information more streamlined. In 2018, all legacy systems have been removed and replaced by in-house designed systems, the transition involved a complicated data migration and consolidation activity, bringing data from all legacy systems in line with new ones. The advantages of the new systems included the data extraction processes for data delivery are more streamlined and less time consuming, this also helps to improve quality checks, thus improving the quality of the products provided to researchers. With the introduction of the Clinic Information System all clinic devices have successfully been integrated to this system to ensure data capture and transfer to our storage facilities.

The clinical information system has been extended and developed to include the Birth Cohort Study, the Magnetic Resonance Imaging and Cognitive function study and the 5 year revisit. With the new visits the blood data base has been developed to support multiple visits.

The IT department are involved in the tender and technical evaluation process for our research management system and our participant management system. We hope to have identified suppliers and start the development and installation process for both systems early in 2019.

The creation of an online data catalogue has helped to transform the way researchers can gain visibility of the information being held within Qatar Biobank, this has helped to reduce query time and improve the application experience as researchers can clearly see what information is held.

Another exciting project that the IT team is working on is the linking of diagnosis data from Hamad Medical Corporation Cerner records system with QBB. This information will provide researchers with often needed background information to participants to aid their research.

2019 continues to promise further developments and enhancements to our information technology systems with the next phase of the laboratory management system, the next phase of our researcher online platform and the implementation of our booking system management system. The vision and goal of the IT system continues to be a stable infrastructure and network that supports the operations of Qatar Biobank and meets the needs of our stakeholders and customers both internally and externally. Ultimately offering an IT system that is suitable for now and the next generation of biobanking operations and requirements.

Clinic Department

At the end of 2017 Qatar Biobank commenced their ramp up procedure to increase participant numbers with the initial stage seeing 36 participants visit the clinic each day through 3 shifts of 12. With the increase in operations this required an increase in staff to support this with more nurses, radiographers, laboratory technologists and clinical data interpretation specialists joining the team.

As well as increasing the number of participants each day, changes to the information collected were made with an emphasis on mental health data so a short questionnaire about mental health was included as well as a questionnaire inquiring about participant pain levels. Mental health research is an important and emerging topic in Qatar and Qatar Biobank is happy to contribute to this by including this topic in our study protocol.

November 2018 saw the completion of the installation and validation of the Magnetic Resonance Imaging (MRI) equipment. Participants who have returned for a 5 year Qatar Biobank cohort 2nd visit will be offered the opportunity to participate in an MRI and Cognitive function visit. A new safety questionnaire has been developed to ensure that the participants safety remains paramount at all times. A brain and whole body protocol has been developed in partnership with Hamad Medical Corporation and Sidra Medicine. The cognitive function testing will use a battery of tests that can assess memory, executive function, attention and processing speed, cognitive assessment and rapid visual processing.

The Laboratory Department

The laboratory department has seen many changes through 2018 from the automation of more of their processes to the introduction of new technologies such as the Qatari Chip (Qchip).

A new laboratory integrated management system (LIMS) is being developed and the finished system will manage and track biological samples from the biological sample kit creation, to the collection of biological samples in the clinic, through to laboratory registration and processing to storage, data request and delivery to researchers.

The quality of biological specimens collected and processed in our labs are of paramount importance to us as this can affect the quality of research performed. The automation of procedures can help to improve quality and consistency as well as increasing the throughput. The automation of buffy coat extraction from our whole blood samples for DNA and RNA extraction has increased the throughput of samples to support our partners such as the Qatar Genome Project and the requests of our local research community. The next phase was the installation of the of the spectrophometric equipment for purity estimation and integrity check. All new devices have gone through a rigorous installation and validation process to ensure the correct setup has been achieved.

Within the cryopreservation laboratory a further liquid nitrogen storage tank will be installed offering storage for a further 250,000 biological samples, bringing the total to 5 tanks

Currently across our different storage facilities we have nearly 2,000,000 samples available.

Table 2 shows the breakdown of the different biological samples stored within QBB and at off site storage facility

Storage Location	Buffy Coat	DNA	Eryth-ro-cytes	PAXgene Whole Blood	Plasma	RNA	Saliva	Saliva + RNA Later	Serum	Urine	Viable Cells	Grand Total
LN2			16903		83818		8293	8372	109334	84258		310978
- 80 Offsite			10389		56582	have	3265	4144	79403	42462		196245
- 80 Onsite	62711	11326	62711	30991	494696	4218	31800	33919	331513	272849	43438	1345633
Grand Total	62711	11326	90003	30991	635096	4218	43358	46435	520250	399569	43438	1852856

As part of the ongoing work with the Qatar Genome Project the QBB laboratories have provided 12975 DNA samples to this project and a total of 21760 samples were provided to researchers in 2018.

The Future

2019 is already shaping up to be another busy and exciting year. In March 2019 we will host in collaboration with the European, Middle East and Africa Society for Biopreservation and Biobanking (ESBB) an international conference to the vibrant city of Doha. The 3 day conference titled ‘‘Quality Matters: A global Discussion in Qatar – will see many local and international experts in the field of research, biobanking and biopreservation speak. We are excited to welcome familiar faces and meet new ones here in Doha and share our Arabian hospitality. Marhaban Birkum!

2019 will see the continued overhaul of the IT infrastructure and systems with a new participant management system for our communications team, the completion and full integration of our Laboratory Information Management System, the research management portal and ongoing developments to our existing clinical information systems and medical review systems.

2019 will also focus on the quality of our biosamples with the labs commencing proficiency testing starting with testing for RNA and DNA samples

Key Findings and Analysis

This section will introduce some of the results of the internal data analysis performed in 2018. The results are based on almost 14,000 participants.

Figure 17 Age distribution of Men and Women in Qatar Biobank

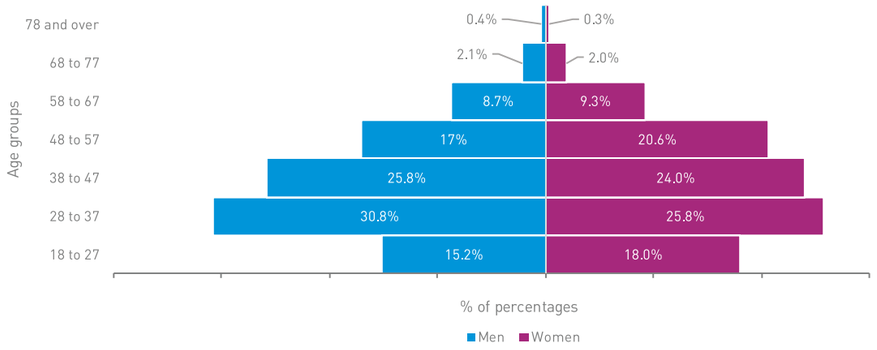


Figure 17 Age distribution of Men and Women in Qatar Biobank

The demographic data shows that from the registration process almost an even number of men (49%) and women (51%) registered with the highest numbers being in the 28-37 year old age group

Figure 18 Nationality Distribution of Qatar Biobank Participants

The analysis shows that the majority of participants in Qatar Biobank registered as Qatari nationals at 82.5%.

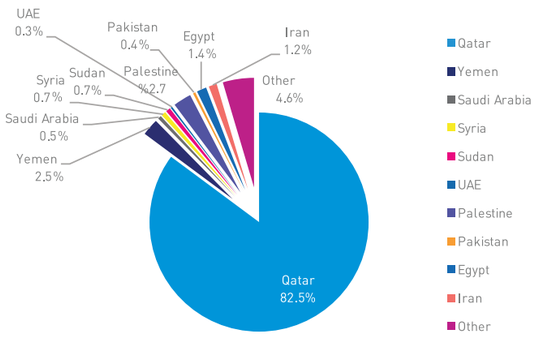


Figure 18 Nationality Distribution of Qatar Biobank Participants

The data from the socio demographic questionnaires showed that the majority of participants 41.3% of women and 41.7% of males have completed university.

78.7% of men and 46.4% of women were in paid employment and a further 5.2% of men and 1% of women were self-employed or owned their own business.

Figure 19 Educational Level and Employment Status percentage of Qatar Biobank population

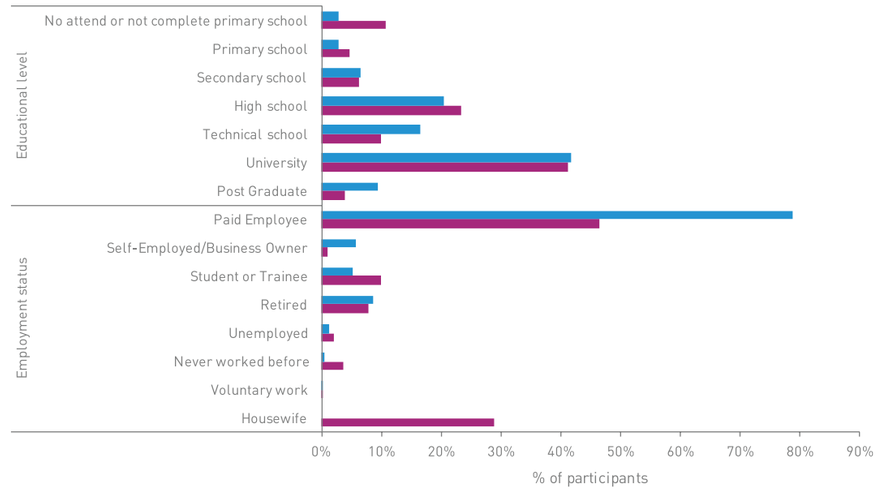


Figure 19 Educational Level and Employment Status percentage of Qatar Biobank population

Figure 20 Marital Status of Qatar Biobank Population

The analysis shows that 81.9% of men and 64.6% of women are married with 16% of men and 22.5% of women reporting as single

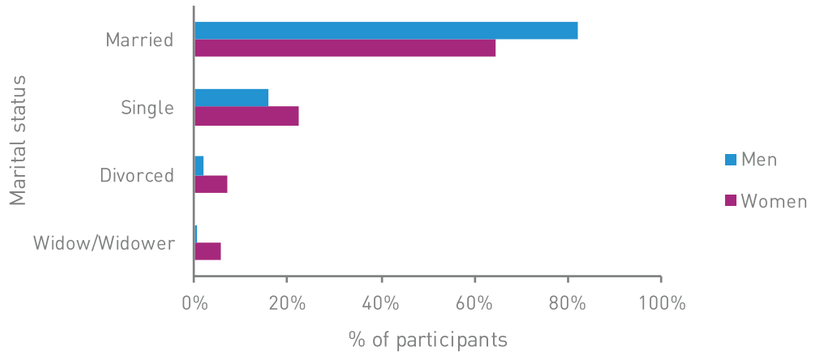


Figure 20 Marital Status of Qatar Biobank Population

Key Findings and Analysis ctd

Anthropometric Data Analysis

A series of anthropometric measurements are completed during the participant clinic visit. Table 3 shows the breakdown of results for men and women. The results show that men have an average height of 172.3m, weight 86.1kg and BMI 29.0kg/m2. For women the average height is 157.7m, weight 74.9kg and BMI 30.1 kg/m2. The results showed that blood pressure results for both men and women were within normal ranges.

Table 3 Anthropometric measurements of Qatar Biobank population

Men	Number	Mean	SD	Min	Max
Height (cm)	6653	172.3	6.6	126.2	203.4
Weigh (Kg)	6652	86.1	17.8	36.3	199.7
Waist Circumference (cm)	6646	94.8	13.5	55.0	192.0
Hip Circumference (cm)	6646	105.3	10.7	72.0	189.0
Systolic Blood Pressure (mmHg)	6657	118.4	13.7	85.0	210.0
Diastolic Blood Pressure (mmHg)	6657	72.4	10.4	33.0	124.0
BMI (kg/m2)	6652	29.0	5.6	13.4	68.3

Women	Number	Mean	SD	Min	Max
Height (cm)	7203	157.7	6.0	120.3	187.1
Weigh (Kg)	7197	74.9	16.5	30.1	168.6
Waist Circumference (cm)	7191	85.6	13.9	51.0	158.0
Hip Circumference (cm)	7191	109.0	12.2	65.0	186.0
Systolic Blood Pressure (mmHg)	7203	112.8	16.7	63.0	209.0
Diastolic Blood Pressure (mmHg)	7203	65.9	10.1	34.0	128.0
BMI (kg/m2)	7196	30.1	6.6	14.1	70.2

During the participant visit approximately 60mls of blood is collected for the biochemical profile analysis and the participant will receive feedback on approximately 75 different biomarkers.

Table 4 Biochemical Profile

	Male			Female		
Lipid profile	**Number**	**Mean**	**SD**	**Number**	**Mean**	**SD**
Cholesterol (mmol/L)	6636	5.0	1.0	7150	4.9	0.9
High Density Lipoprotein- HDL (mmol/L)	6629	1.2	0.3	7150	1.5	0.4
Low Density Lipoprotein - LDL (mmol/L)	6556	3.1	0.9	7131	2.9	0.8
Triglycerides (mmol/L)	6634	1.5	1.1	7150	1.2	0.7
Thyroid Function						
Free Triiodothyronine -FT3 (pmol/L)	6208	4.1	0.7	6816	3.9	0.7
Free Thyroxine- FT4 (pmol/L)	6585	13.2	1.6	7111	13.1	1.8
Thyroid Stimulating Hormone- TSH (mlU/L)	6573	1.8	2.5	7089	2.0	3.0
Diabetes Related						
Glycated Hemoglobin A1C %	6557	5.8	1.3	7056	5.7	1.2
Fasting Glucose(mmol/L)	3804	5.8	2.2	4537	5.6	2.0
Fasting Insulin (mcunit/mL)	3777	12.1	14.3	4511	11.4	12.3
Liver Function						
Alkaline Phosphatase-Alk Phos (U/L)	6628	71.8	19.6	7144	70.9	22.0
Alanine Transaminase-ALT (U/L)	6631	29.5	20.1	7138	17.5	12.9
Aspartate Transaminase-AST (U/L)	6636	22.2	16.4	7148	17.6	7.9
Bilirubin Total (umol/L)	6516	9.6	5.6	6696	7.1	3.7
Total Protein (gm/L)	6635	73.8	4.0	7150	73.2	3.9
Albumin (gm/L)	6636	45.2	3.3	7151	43.2	3.3
Gamma-Glutamyl Transferase (U/L)	6320	37.4	50.3	6979	23.2	25.1
Renal Function						
Urea (mmol/L)	6636	4.9	1.4	7150	4.0	1.3
Creatinine (umol/L)	6635	78.5	19.3	7150	58.0	17.6
eGFR (Ml/min)	Number	(%)		Number	(%)	
(>60 Ml/min)	4710	98.2		5481	98.7	
(≤60 Ml/min)	85	1.8		75	1.3	

Key Findings and Analysis ctd

Qatar continues to have some of the highest levels of metabolic disorders such as obesity and diabetes mellitus. The laboratory analysis shows that the number of Qatar Biobank participants with HbA1C levels ≥ 6.5% is 14.8% of men and 13.9% of women and a further 18% of men and 17.4% of women fall into the prediabetes level with hbA1c levels between 5.7 – 6.4%

Table 5 Biochemical Profiles

	Total		Men		Women	
Qatar Biobank Screening – HbA1c Levels	**Number**	**%**	**Number**	**%**	**Number**	**%**
Diabetes (HbA1c ≥ 6.5%)	1888	13.9	971	14.8	917	13.0
Pre-Diabetes (HbA1c: 5.7 - 6.4%)	2409	17.7	1183	18.0	1226	17.4
Normal (HbA1c < 5.7%)	9323	68.5	4409	67.2	4914	69.6
Medical History - Self-Reported Status						
Self-Reported Diabetic	2414	17.5	1068	16.2	1346	18.8
Self-Reported Diabetic (No) & HbA1c≥6.5	258	1.9	173	2.7	85	1.2
Self-Reported Diabetic (Yes) & HbA1c≥6.5	1601	11.8	775	12.0	826	11.7
Family History At Diabetes Mellitus						
Diabetic Father	5762	41.5	2762	41.4	3000	41.6
Diabetic Mother	6527	47.4	3010	45.6	3517	49.1
At Least One Of The Siblings Diabetic	3251	32.0	1456	31.2	1795	32.7

Dietary Habits of Qatar Biobank Population

The dietary questionnaire results show that both men 20.4% and women 19.70% are eating more poultry than meat and fish. Women eat more fruits 29.70% and vegetables 33.30% than men who eat 20.60% fruits and 26.90% vegetables. Tea is most often drunk by both men 57.8% and women 49.50% with Arabic coffee being drunk (men 52.40% and women 47.10%) more than instant coffee, with the sweet tea drink Karak, favoured by both men 36.1% and women 37.7%

Figure 21 Food Types Consumed once per day or more among Qatar Biobank participants

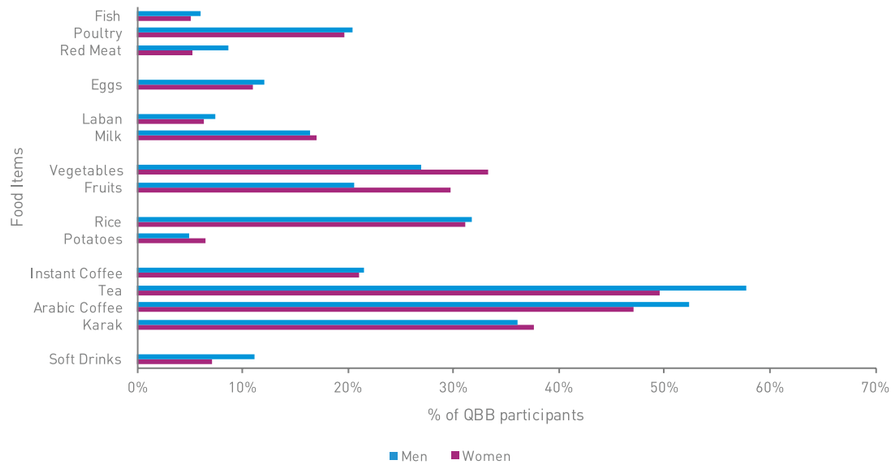


Figure 21 Food Types Consumed once per day or more among Qatar Biobank participants

During the questionnaire process participants are asked questions about bariatric surgery. 12.6% of the Qatar Biobank population reported having bariatric surgery with sleeve gastrectomy being the most popular type of bariatric surgery with 82.4% of men and 75% of women reporting to have this surgery. The most popular location to have this surgery is Qatar with 47.3% of men and 62.8% of women having the surgery locally.

Table 6 Bariatric Surgery

	Total		Men		Women	
Bariatric Surgery	**Number**	**%**	**Number**	**%**	**Number**	**%**
	1226	12.6	433	9.7	793	15.1
Bariatric Surgery Types						
Gastric Band	69	5.6	17	3.9	52	6.6
Gastric Bypass	33	2.7	8	1.8	25	3.2
Sleeve Gastrectomy	952	77.7	357	82.4	595	75.0
Duodenal Switch	44	3.6	8	1.8	36	4.5
Other	128	10.4	43	9.9	85	10.7
Location (bariatric surgery performed)						
Qatar	703	57.4	205	47.3	498	62.8
Other Gulf State	108	8.8	36	8.3	72	9.1
Other Arabic Country	376	30.6	171	39.5	205	25.8
Europe	18	1.5	8	1.8	10	1.3
North America	10	0.8	5	1.2	5	0.6
Other	11	0.9	8	1.8	3	0.4

Key Findings and Analysis ctd

The self-reported lifestyle habits of the Qatar Biobank participants show that many chronic diseases can be prevented through an active lifestyle, information collected during the questionnaire stages of the Qatar Biobank visit show that slightly more men 28% than women 25% watched TV or used their mobile phones or tablets for between 2-4 hours per day.

Figure 22 Sedentary lifestyle habits measured by hour/day in reference to TV, mobile phones and tablets

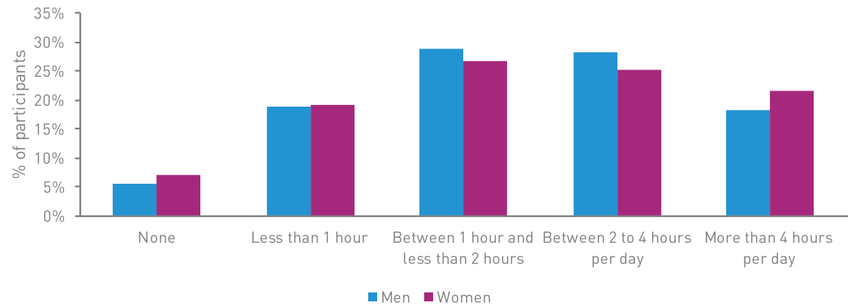


Figure 22 Sedentary lifestyle habits measured by hour/day in reference to TV, mobile phones and tablets

The questionnaire stages of the participant visit gathers data about participants' physical activity and body mass index (BMI) levels. The results show that almost 38% of the Qatar Biobank population reported doing no physical activity and 43% were recorded as obese with a BMI of ⩾ 30kg/m2. The MET/h definition for the purposes of these results is one MET is the 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.

Figure 23 Physical Activity & BMI levels of Qatar Biobank population

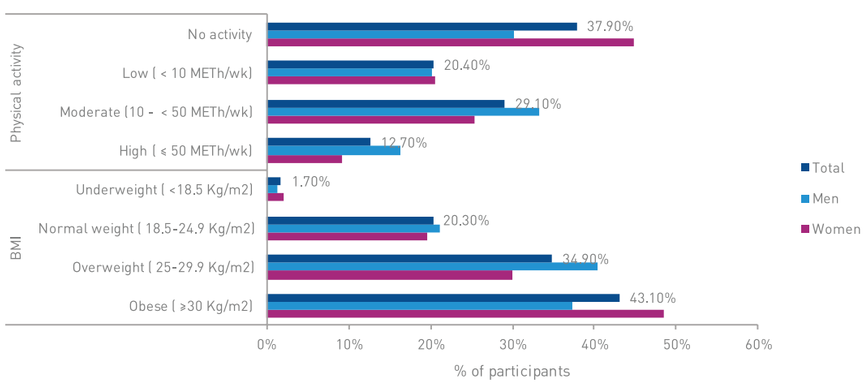


Figure 23 Sedentary lifestyle habits measured by hour/day in reference to TV, mobile phones and tablet

Figure 24 shows the most commonly self-reported medical conditions from the participant visit data collected during the questionnaire stage. Almost 30% of participants reported having high cholesterol with men recording slightly higher at 31.4% and women 28.10%. Self-reported high blood pressure was reported in 16.5% of participants. Thyroid disease was reported by 10.4% of participants with women 16.6% reporting significantly higher than men at 3.1%.

Figure 24 Medical History (Self Reported) of Qatar Biobank Population

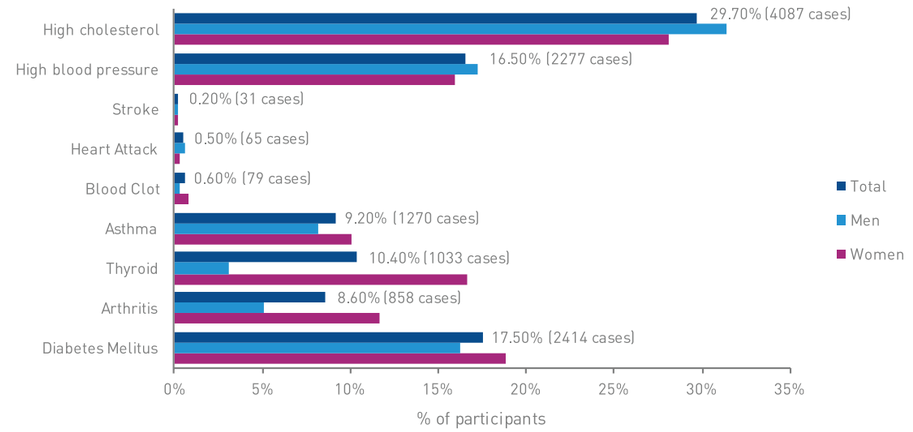


Figure 24 Medical History (Self Reported) of Qatar Biobank Population

The most prominent cancer types reported during the clinic visit shown in figure 25 below. For women the most prominent cancer types were breast (45.8%) cervical (17.8%) and thyroid (23%). For men prostrate (38%) Hodgkin's Lymphoma (16%) and bowel cancer (13.5%).

Figure 25 Prominent cancer types in Qatar Biobank Population

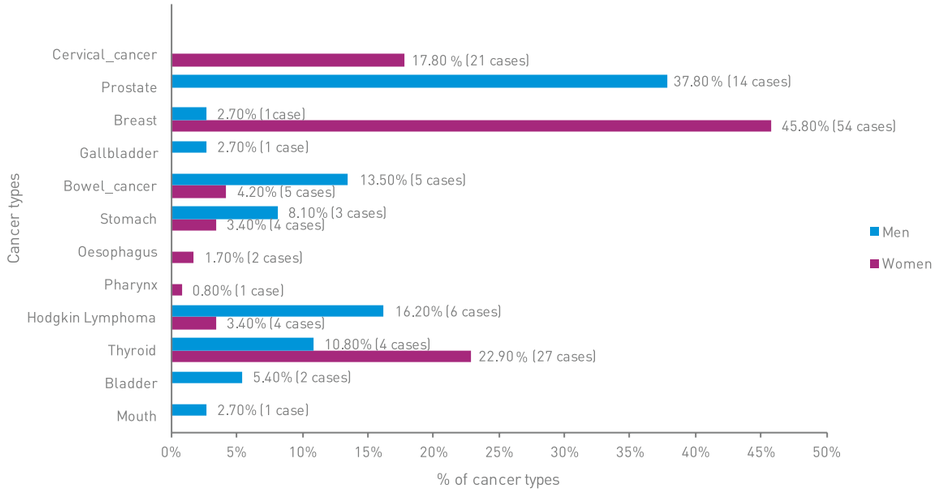


Figure 25 Prominent cancer types in Qatar Biobank Population

Key Findings and Analysis ctd

The laboratory analysis showed that almost 90% of the Qatar Biobank population are Vitamin deficient. 53% of men and 46% of women were moderately deficient and a further 28% of women and 22% of men were mildly deficient. Only 12% of participants from laboratory analysis were within normal Vitamin D levels.

Figure 26 Vitamin D (25 Hydroxyvitamin D (25(OH)) D) levels in Qatar Biobank Population

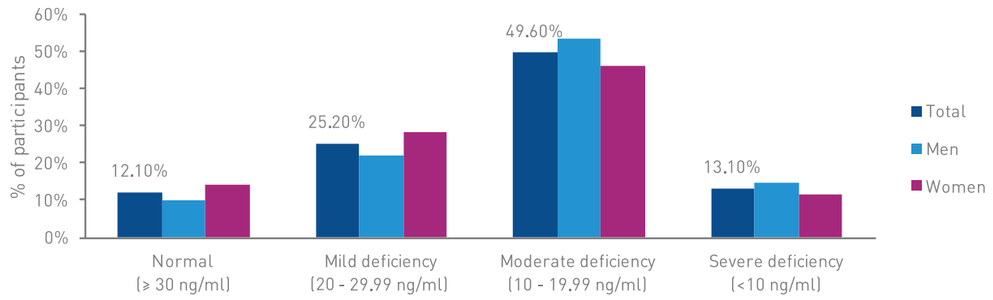


Figure 26 Vitamin D (25 Hydroxyvitamin D (25(OH)) D) levels in Qatar Biobank Population

Information collected on the use of vitamin D supplements and vitamin D deficiency, showed that 40% of women and 31% men reported taking vitamin D supplements, however despite this 25% of men and 32% of women remain deficient.

Figure 27 Vitamin D Deficiency and Vitamin D supplements intake within Qatar Biobank Population

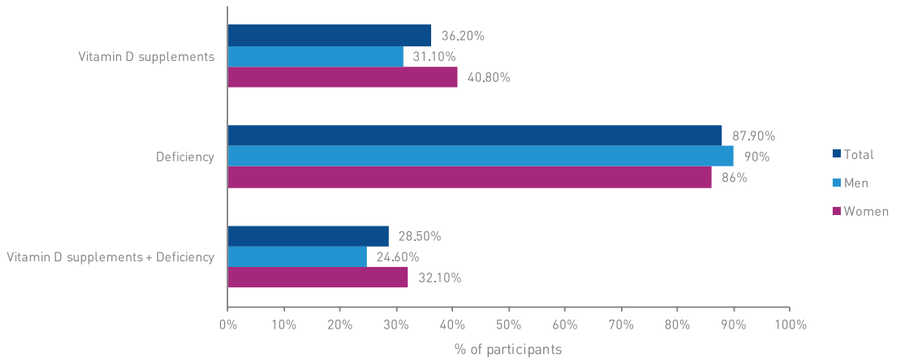


Figure 27 Vitamin D Deficiency and Vitamin D supplements intake within Qatar Biobank Population

Challenges

At the end of 2017 and into 2018 the business continuing plan was tested as a result of facing many challenges that mirror those of the nation as a result of the ongoing political situation. The immediate effect of having to find new suppliers, new delivery routes for equipment and the personal impact to many members of the team who found themselves separated from their families did not dampen the spirit or hinder the work of QBB. In true Qatari style and determination the outcome is a stronger and more self-sufficient country and for the Biobank a robust tried and tested business continuity plan ready to face the challenges of 2019 whatever they may be. Many challenges experienced by the different departments include a lack of personnel.

The Qatar Genome Project

The Qatar Genome Programme (QGP) is an ambitious population-based project that aims to position Qatar among the pioneering countries in the implementation of precision medicine.

The programme is in the process of generating a large database combining whole genome sequencing and other omics data with the comprehensive phenotypic data and samples collected at Qatar Biobank for Medical Research. Through the wealth of data collected, researchers will be able to make breakthrough discoveries and help policymakers map out the future healthcare system in Qatar.

In 2018, and having achieved the goals outlined in the pilot phase, the QGP pursued initiatives directed at national impact. The impact started to realize with one of QGP main pillars, building human potential, in March 2018, Qatar University launched it MSc program in Genetic Counselling, which will provide Qatar with the specialized workforce it needs.

Furthermore, and realizing that each genomic breakthrough comes with corresponding moral, ethical and legal issues, QGP held its second international symposium in April 2018 under the theme 'Ethics, Regulations, and Best Practices in Genomic Medicine, and proving that the issues discussed and presented were of the utmost interest to the local and international audience, more than 1200 healthcare professionals participated on each day of the symposium. The first day featured three sessions, including presentations and panel discussions, on three broad topics: National Genome Projects: Governance, Policies and Regulations; Genomic Data Ownership, Sharing and Integration into the Health System; and Delivery of Genomic Data, and the second day concluded with discussions about genetic counselling and genomics in the context of Islamic ethics.

Another important milestone was the completion of 10000 Qatari whole genomes, this wealth of data that constitutes the basis for the future of precision medicine, to allow medical care to be tailored at the preventative, diagnostic, and therapeutic levels.

Continuing on QGP's mission to work with various local institutions on improving the future of healthcare in Qatar, a research collaboration with the Qatar Cardiovascular Biorepository (QCBio) at the Heart Hospital of Hamad Medical Corporation (HMC), and Qatar Biobank, for around 1,000 Qatari patients and their families, involving whole genome sequencing of a large cohort of Qatari patients, to analyse the underlying genetic determinants related to heart problems in the Qatari population, and aims to lead to the discovery of protein biomarkers, and effective prevention and treatment measures.

Leaning more on spearheading efforts to create national impact, Qatar Genome and Qatar Biobank have partnered with the Department of Genetic Medicine at Weill Cornell Medicine-Qatar to facilitate the development of the first Qatari gene chip, known as the 'Q-Chip'. The partnership also includes the Diagnostic Genomic Division at Hamad Medical Corporation as well as the Sidra research team at Sidra Medicine. The national working group aims to translate the outcomes of basic genomic research into high impact deliverables at the clinical care end, in the form of the Q-Chip product.

The first version of the Q-chip was announced in November 2018, and it contains gene variants specific to the Qatari population, identified through the sequencing and genetic screening of thousands of Qatari citizens. The partnership will act as a platform open for inclusion of gene mutations identified by local research groups.

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