4-2021

ESTABLISHING THE ROADMAP FOR THE IMPLEMENTATION OF GENOMIC MEDICINE AND PHARMACOGENOMICS IN THE UNITED ARAB EMIRATES

Azhar Talal Mahmoud Rahma

United Arab Emirates University

College of Medicine and Health Sciences

ESTABLISHING THE ROADMAP FOR THE IMPLEMENTATION OF GENOMIC MEDICINE AND PHARMACOGENOMICS IN THE UNITED ARAB EMIRATES

Azhar Talal Mahmoud Rahma

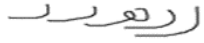
This dissertation is submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy

Under the Supervision of Professor Fatma Al-Maskari

April 2021

Declaration of Original Work

I, Azhar Talal Mahmoud Rahma, the undersigned, a graduate student at the United Arab Emirates University (UAEU), and the author of this dissertation entitled "*Establishing the Roadmap for the Implementation of Genomic Medicine and Pharmacogenomics in the United Arab Emirates*", hereby, solemnly declare that this dissertation is my own original research work that has been done and prepared by me under the supervision of Professor Fatma Al-Maskari, in the College of Medicine and Health Sciences at UAEU. This work has not previously been presented or published or formed the basis for the award of any academic degree, diploma or a similar title at this or any other university. Any materials borrowed from other sources (whether published or unpublished) and relied upon or included in my dissertation have been properly cited and acknowledged in accordance with appropriate academic conventions. I further declare that there is no potential conflict of interest with respect to the research, data collection, authorship, presentation and/or publication of this dissertation.

Student's Signature:  Date: 18/ 04/2021

Advisory Committee

1) Advisor: Fatma Al Maskari

Title: Professor

Public Health Institute

College of Medicine and Health Sciences

2) Member: Bassam Ali

Title: Professor

Department of Genetics and Genomics

College of Medicine and Health Sciences

3) Member: Luai Ahmed

Title: Associate Professor

Public Health Institute

College of Medicine and Health Sciences

4) Member: George Patrinos

Title: Professor

Department of Pharmacy

School of Health Sciences

University of Patras, Greece

Approval of the Doctorate Dissertation

This Doctorate Dissertation is approved by the following Examining Committee Members:

1) Advisor (Committee Chair): Fatma Al Maskari
   Title: Professor
   Public Health Institute
   College of Medicine and Health Sciences

   Signature  Date 18/4/2021

2) Member: Bassam Ali
   Title: Professor
   Department of Genetics and Genomics
   College of Medicine and Health Sciences

   Signature  Date 18/4/2021

3) Member: Luai Ahmed
   Title: Associate Professor
   Public Health Institute
   College of Medicine and Health Sciences

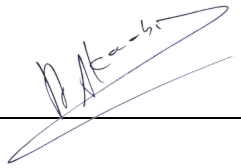
   Signature  Date 18/4/2021

4) Member (External Examiner): Vasilis Vasiliou.
   Title: Professor.
   Department of Environmental Health Sciences
   Institution: Yale School of Public Health, Yale University, USA.

   Signature  Date 18/4/2021

This Doctorate Dissertation is accepted by:

Acting Dean of the College of Medicine and Health Sciences Professor Juma AlKaabi

Signature  Date 07 July 2021

Dean of the College of Graduate Studies: Professor Ali Al-Marzouqi

Signature  Date 07 July 2021

Copy ____ of ____

Abstract

The slow clinical application of genomic medicine and Pharmacogenomics (PGx) is attributed mainly to lack of knowledge of genomic medicine and PGx and confidence among healthcare professionals, scarcity of infrastructure, and absence of stakeholders' interest. The objective of this study is to lay out a strategic plan for the implementation of genomic medicine and PGx in the United Arab Emirates (UAE) by exploring multiple areas: (1) the educational environment of genomic medicine and PGx in colleges and universities; (2) knowledge, and attitude of the medical and health sciences students, academics, and the healthcare providers; (3) the current infrastructure of genetic and genomic services; (4) the views and vision of the stakeholders. These areas were explored using a mixed method approach of qualitative and quantitative research designs besides mapping the educational environment of genomics and PGx as well as genetic and genomic services. The assessment of university curricula resulted in "genetics" being included in the majority of universities syllabus. PGx was taught in six universities but only for pharmacy majors. The mean knowledge score of the surveyed healthcare providers was 5.2 (± 2.3) out of nine, which shows a fair level of knowledge. However, 92% showed a positive attitude regarding availability of genetic testing. The top identified barrier for implementation for genomics and PGx was the cost of testing (62%), followed by lack of training or education of genomics and PGx (58%) and lack of health insurance coverage (57%). Moreover, the mean knowledge score for medical and health sciences students was 5.4 (± 2.7). Regarding genetic and genomic services, prenatal testing was the most offered genetic service among the laboratories included in the study, and blood samples was the main sample type for genetic testing followed by saliva. There was no standardization of the accreditation bodies, health insurance coverage. Most of the interviewed stakeholders emphasized the clinical demand for genomic medicine in UAE. However, many were less inclined to articulate the need for PGx at present. Most of stakeholders were in favour of building infrastructure for better genetic services in the country. However, stakeholder from health insurance sector had a contradicting stance about the cost-effectiveness of genomic medicine. The majority were concerned with the legal and ethical aspects of genomic medicine and had an opposing stance on direct-to-consumer kits. In addition, based on these findings, this

thesis conceptualizes a pharmacogenomics' literacy framework alongside a roadmap for the implementation of genomic medicine and PGx in UAE.

Keywords: Genomics, pharmacogenomics, framework, knowledge, attitude, stakeholders, education, healthcare providers, literacy, medical students, health sciences students, genetic and genomic services.

Title and Abstract (in Arabic)

خريطه لتطبيق طب الجينوم وعلم الجينوم الصيدلاني في دولة الامارات العربية المتحدة

الملخص

يُعزى التطبيق السريري البطيء للطب الجينومي وعلم الجينوم الصيدلاني (PGx) بشكل أساسي إلى نقص المعرفة الجينية والثقة بين المتخصصين في الرعاية الصحية، وندرة البنية التحتية، وغياب اهتمام أصحاب المصلحة. الهدف من هذه الدراسة هو وضع خطة استراتيجية لتطبيق الطب الجينومي وعلم الصيدلة الجيني في دولة الإمارات العربية المتحدة من خلال استكشاف وتحليل مجالات متعددة بما فيها: (1) البيئة التعليمية للطب الجينومي وعلم الجينوم الصيدلاني في الكليات والجامعات؛ (2) معرفة وموقف طلاب الطب والعلوم الطبية والصحية والأكاديميين ومقدمي الرعاية الصحية؛ (3) البنية التحتية الحالية للخدمات الجينية في الدولة؛ (4) وجهات نظر ورؤية أصحاب المصلحة والمسؤلين. تم استكشاف هذه المجالات باستخدام نهج مختلط من تصاميم البحوث النوعية والكمية إلى جانب رسم خرائط البيئة الحالية للتعليم والاختبار الجيني. أدى تقييم المناهج الجامعية إلى إدراج "علم الوراثة" في معظم مناهج الجامعات ولكن يتم تدريس الجينوم الصيدلاني في ست جامعات ولطلاب تخصصات الصيدلة فقط. ان متوسط درجة المعرفة الجينية لمقدمي الرعاية الصحية الذين شملهم الاستطلاع 5.2 (± 2.3) من تسعة، مما يدل على مستوى معقول من المعرفة، أظهر 92% موقفًا إيجابيًا فيما يتعلق بتوافر الاختبارات الجينية. كان العائق الأعلى الذي تم تحديده للتنفيذ هو تكلفة الاختبار (62%)، يليه نقص التدريب أو التعليم (58%) والتأمين الصحي (57%). علاوة على ذلك، كان متوسط درجة المعرفة للطلاب 5.4 (± 2.7). كانت اختبارات ما قبل الولادة هي الخدمة الجينية الأكثر عرضًا بين المختبرات المشمولة في الدراسة، وكانت عينات الدم هي نوع العينة الرئيسي للاختبار الجيني يليها اللعاب. لم يكن هناك توحيد لهيئات الاعتماد، تغطية التأمين الصحي. أكد معظم أصحاب المصلحة الذين تمت مقابلتهم على الطلب السريري على الطب الجيني في الإمارات العربية المتحدة. ومع ذلك، كان الكثيرون أقل ميلا إلى التعبير عن الحاجة إلى علم الصيدلة الجيني في الوقت الحاضر. كان معظم أصحاب المصلحة يؤيدون بناء البنية التحتية لتحسين الخدمات الجينية في البلاد. ومع ذلك، كان لأصحاب المصلحة من قطاع التأمين الصحي موقفًا متناقضًا حول فعالية تكلفة الطب الجيني. كانت الغالبية معنية بالجوانب القانونية والأخلاقية للطب الجينومي وكان لها موقف معارض من مجموعات

الأدوات الموجهة للمستهلكين. بناءً على هذه النتائج، وضعت الدراسة تصورًا لإطار محو الأمية في علم الصيدلة الجيني جنبًا إلى جنب مع خارطة طريق لتطبيق الطب الجيني وعلم الجينوم الصيدلاني في الإمارات العربية المتحدة.

مفاهيم البحث الرئيسية: الطب الجيني، علم الجينوم الصيدلاني، هيكلة، المعرفة، موقف، صناع القرار، التعليم، الكادر الصحي، محو الامية، طلبة الطب، طلبة العلوم الصحية، الخدمات الجينية والجينومية.

Acknowledgements

Whenever I watch a movie, I used to stay until the last minute of the movie that caused my friends, family and even workers in cinema get irritated with me. The reason I stay is because I like to read the names of all those who contributed. I like how everyone get thanked and appreciated. Therefore, I am happy that my acknowledgments are taking place in the beginning not the end as this is how it should be. I wrote this thesis using my brain; however, I will write this acknowledgment using my heart. This work would not be possible without the priceless contributions and support of amazing people. They say it takes a village to raise a child and I say it takes a galaxy of great people to produce a thesis, especially if you are a front liner in a pandemic era. Thanks to my beloved mother Haifa, who sacrificed endless days and nights being alone so I can study, search and write, for being my rock, for listening to all my complains and wiping my tears, for being in the first raw celebrating my achievements as if it is yours, and it is yours, I am your achievement, thank you for always preparing me food and always asking me if I eat, thank you for believing in me and strengthening my wings. I love you mama forever; you are my role model and my only love.

Thanks to my dad Talal, yes you left me and passed away in the middle of my PhD, that broke me, and I wanted to quit. But I promised when I had to say my last goodbye to you and kissed for the last time, I promised you that I will make you proud. How much I want you to be alive at this moment, I wanted you to see me honoring you. Yes, I do not have children that I can name them after you, but I have a thesis and papers that your name is on. Thank you, Prof Fatima, for adding the T. to my name "Azhar T. Rahma".

Thanks to my sister Bayrahan for being my rock and for being there for me in the focus group discussion, bringing food and greeting participants, thanks for driving me all over UAE to do interviews with stakeholders and for never complaining no matter how long it takes, for always taking care of me as if you are my big sister not my youngest. Thanks to my brother Mahmoud for being my rock and for his support and love, for taking me from laboratory to laboratory in Abu-Dhabi and always being kind, caring and protective.

I was lucky and blessed to have the best mentor in the world. My thanks go first and always to Prof. Fatima Al-Maskari whose been my rock and angel during this journey. Her support and care made this journey memorable and spectacular. Without her I would not start this journey at all. She believed in me from the first day and continued to believe in me till the end. She is the best mentor a student can get. She cares like a mother, she listens, she solves problems, she has been by my side celebrating any of my achievements, I could not ask or wish for a better mentor and supervisor. Actually, I am sad that I am about to graduate as I would not be affiliated with her and that hurts. It has been an honor to say that I am her student. Everything I accomplished or will accomplish I dedicate it to Prof. Fatima as I will be forever her student.

I am grateful to Prof. George Patrinos who introduced me to the exciting field of pharmacogenomics and whose constant encouragement led to this. His passion about pharmacogenomics led me to spend all my days and nights of isolation attending courses about pharmacogenomics from ASHP and Mayo clinic. He was always the first to congratulate me or celebrate me even on social media. One day I asked how I can thank him and he replied, “pay it forward” and that is what I have been doing

since. I am proud to say that I am his student forever. I am thankful to Prof. Bassam Ali for helping me overcome all the challenges and for pushing me to be the best. He opened doors for me, and I am forever grateful. Since day one I wanted him to be proud that I am his student. I was determined to exceed all of his expectations. I watched how his face lit up watching his students present in conferences and succeed. I want his face to light up because of me too. And I am proud to say that I am his student forever. I would like to thank Dr. Luai for his guidance, support, and patience, his actions speak loudly. Just for him being in the room was enough for me. He made me feel safe, whenever I panic with epidemiology, statistics or deadlines or anything, he gets it and in his magic way, he calms me down. His confidence is contagious. His door was always open for me, he takes care of all details and notices the invisible glitches. He is the definition of perfection and I am proud to say that I am his student forever.

How can I find words to thank Dr. Iffat Elbarazi. She is always there for me, motivating me, guiding me, opening doors for me and being there for me every step of the way. She is a friend, a sister, a role model, and a mentor. I will never forget how she gave up her weekend to drive from Sharjah on Saturday to be there for me during focus group discussions. She made me fall in love with qualitative studies. She is a blessing. She is always there 24/7 and treated me as a peer or friend not a student. When watching other students' defense, she cried imagining me be next. I wish I can really find words to thank her. I am proud to say that I am her student forever.

I would like to thank my family in the Institute of Public Health at the United Arab Emirates University for teaching me, assisting me, celebrating me. Since my first day

of MPH, I knew I was among my family.

Deepest thanks to UAEU for the fellowship and for the privilege of being her student and ALUMNI forever. Thanks to the Zayed Center for Health Sciences for awarding the grant to support my research; I love Sheikh Zayed Al-Nahyan; he was an iconic man and to be affiliated to his name in anyway makes my heart melts. I am grateful to Prof. Ali Al Marzouqi, Dr. Rami Beiram and Prof. Grivna for their continuous and unlimited support, and for always motivating me to reach the sky. Thanks to Dr. Mohamad Yousif Hassan Baniyas for opening doors for me and for being down to earth. Thanks to Mr. Mahmoud Mahmoud for his support. Thanks to Dr. Mouza Al Ameri for all her support.

Special thanks extended to the National Medical Library especially Miss Linda, Miss Mona and Mr. Khalid as well as Mr. Sajir and Mr. Zeeshan, and Miss Mahanna, and Dania for being my heroes.

Heartfelt thanks to my peers in the PhD program. You are great peers, supporting each other, helping each other, and celebrating each other. You are evidence that still there is goodness in the world.

Special thanks to those who tried to break me, who tried to stop my research and made me cry, without your darkness I would not been able to see and appreciate the shining stars in my life.

Thanks to my friends who were cheering for me from the start line and waiting for me at the end line. Thanks to the Male and Female Medical students Association for distributing my survey and thank you for the students who helped me and for the participants who participated in this research.

Dedication

To United Arab Emirates, to my beloved mother Haifa, to my late father Talal, to my rocks, sister Bayrahan and brother Mahmoud, to my joy in life my nephew Mohamad, to my angel Prof. Fatima, to my friends, and to myself for never quitting and for pursuing the dream.

Table of Contents

List of Tables

List of Figures

List of Abbreviations

CAA	Commission for Academic Accreditation
CME	Continuing Medical Education
COREQ	Consolidated Criteria for Reporting Qualitative Research
COVID-19	Coronavirus Disease
CPIC	The Clinical Pharmacogenetics Implementation Consortium
CSM	Common-Sense Model of Self-Regulation
CVD	Cardiovascular Disease
CYP2D6	Cytochrome P450 2D6
DNA	Deoxyribonucleic Acid
DOH	The Department of Health
FDA	Food and Drug Administration
FGD	Focus Group Discussions
G6PD	Glucose-6-Phosphate Dehydrogenase Deficiency
GCC	Gulf Cooperation Council
GTEx	Genotype-Tissue Expression
IBM SPSS	International Business Machines Corporation Statistical Package for the Social Sciences
IGNITE	The Implementing GeNomics In PracTicE
ISO	International Organization for Standardization
ISONG	The International Society of Nurses in Genetics
ISP	The International Society of Pharmacogenomics

MENA	Middle East and North Africa
NAT2	N-Acetyltransferase 2
PGx	Pharmacogenomics
PGLP	Pharmacogenomics Genomics Literacy Framework for Pharmacists
PUGGS	Public Understanding and Attitudes towards Genetics and Genomics
SD	Standard Deviation
UAE	United Arab Emirates
WHO	World Health Organization

Chapter 1: Introduction

1.1 Overview

The overall aim of this research is to evaluate the current status of applying genomic medicine and pharmacogenomics in the United Arab Emirates and construct a roadmap for fully implementing these modern disciplines in the healthcare systems.

1.2 Statement of the Problem

The United Arab Emirates (UAE) is a rapidly developing cosmopolitan country consisting of a mixture of multinational populations with varying educational backgrounds, religious beliefs, and cultural practices. Although it has not been accurately measured, it is believed that the health burden imposed by genetic and genomic variations on the UAE national population is very high. For example, according to the 2006 March of Dimes report, the UAE is ranked sixth out of 193 countries in terms of prevalence of birth defects, mainly caused by genetic disorders (Christianson et al., 2006). In addition, at least 400 genetic diseases have been reported among the UAE national population with over 250 of these disorders are caused by mutations in single genes (Al-Gazali & Ali, 2010). In fact, the majority (> 60%) of the reported single gene disorders are caused by homozygous mutations in recessive genes due to the high rates of inbreeding and consanguinity (Al-Gazali & Ali, 2010). Furthermore, the incidence of multifactorial diseases that are partly caused by genetic predisposition variations and interactions with the environment are very common. This include diseases such as type 2 diabetes, obesity, hypertension, cancer, neurodegenerative and cardiovascular diseases, and they have been steadily rising in

the UAE over the past few decades. This is mainly due to the rapid socioeconomic growth and a significant rise in life expectancy because of improved health care systems (Al-Gazali & Ali, 2010). However, the rapid increase in the prevalence of these multifactorial diseases also suggest genetic predisposition to those diseases revealed by rapid changes in lifestyle including diet. In addition, it has been extensively documented that responses to medications used for the treatments of various conditions such as diabetes, cancer, cardiovascular etc. are largely influenced by genetic variation. These responses include therapy failure and/or adverse drug reactions and negative side effects. Scholars in UAE have made major advances in the understanding of the genetic causes of single genes disorders (Al-Gazali & Ali, 2010) and are currently active in identifying genetic biomarkers that influence response to some of the most commonly used medications (Al-Mahayri et al., 2020). This was hugely facilitated by significant and recent advances in genotyping technologies such as the advent of next generation sequencing technologies and bioinformatics tools (Knaup et al., 2004). Despite these advances, the burden of genetic aberrations and side effects or therapy failure is still high in UAE and therefore efforts (including public health efforts) should be made to reduce them.

In recent years, translation of genomic discoveries into mainstream medical practice and public health has gained significant attention and importance. However, there are often major discrepancies in the pace of implementation of genomic medicine and pharmacogenomics between different countries. The main reason does not only lie in the limitation of resources but also in the slow pace of adoption of the new findings and the poor understanding of the potential that this new discipline offers to rationalize medical treatment and diagnosis. There are several examples from the successful

implementation of genomic medicine in resource-limited and or developing countries, particularly in the field of public health genomics, emphasizing in the latter case in genomic education, stakeholder analysis and economics in pharmacogenomics (Zgheib et al., 2020). These examples can be considered as model cases and be readily replicated for the wide implementation of pharmacogenomics and genomic medicine in other countries such as the UAE.

The researcher believes that in order to advance genomic medicine utility into the UAE healthcare system, the public health aspects of genomics medicine and pharmacogenomics has to be addressed. In other words, the investigator must understand the current state-of-the-art healthcare environment for implementing genomic medicine and pharmacogenomics in the clinic, including the available genetic and genomic provisions, the educational and knowledge environments, and the stance of stakeholders. This will set the scene for mapping the roadmap for the full implementation of genomics medicine and pharmacogenomics in UAE with possible adoption by other countries in the gulf or MENA region.

1.3 Relevant Literature

In the UAE, pharmacogenomics research started in 1996, initially involving erythrocyte Glucose-6-Phosphate Dehydrogenase Deficiency (G6PD) related with drug induced hemolytic anemia (Bayoumi, 1996), and later N-Acetyltransferase 2 (NAT2) (Woolhouse et al., 1997). In addition, the Cytochrome P450 2D6 (CYP2D6) pharmacogenomic biomarker allele frequencies were investigated in the Emirati population, including reporting of four novel CYP2D6 variants (Qumsieh et al., 2011), and warfarin pharmacogenomics for the Emirati population (Al-Mahayri et al., 2019),

as well as the pharmacogenomics of cancer in UAE (Al-Jaibeji et al., 2016). In addition, significant advances had been made in understanding the molecular and cellular basis of single disorders in the UAE (Akawi et al., 2016; Al-Gazali & Ali, 2010; Kizhakkedath et al., 2014; Komara et al., 2016).

Public Health Genomics: As defined in a review by Roberts et al. (2014), is a comprehensive interdisciplinary initiative that defies succinct description or definition. It includes within its purview many longstanding disciplines, such as genetic epidemiology, biostatistics, health policy, and health education, as well as state-funded programs focused on surveillance and prevention of birth defects and heritable disorders. A study by Mitropoulou and co-workers undertook an initiative to assess the level of support or opposition to pharmacogenomics and genomic medicine in Greece (Mitropoulou et al., 2014). This survey indicated that the majority of the key stakeholders, namely academic institutions and research organizations, the bioethics council, private genetic laboratories, citizens, pharmaceutical and biotechnology companies, genetics and genomics professional associations, the private health insurance industry, pharmacists, and physicians (both geneticists and other specialties), are highly supportive of pharmacogenomics and genomic medicine in Greece. On the contrary, the Ministry of Health and the public health insurance funds are opposed to the implementation of genomic medicine, while the Greek National Medicines Organization displays a neutral stance, possibly since the cost-effectiveness of a pharmacogenomics approach is not yet fully proven, the proper legislation to oversee the operation of private genetic testing laboratories is not yet in place or simply because they fear that reimbursement of genetic testing could increase rather than decrease the overall healthcare expenditure. These latter stakeholders have high

intervention potential against the implementation of pharmacogenomics and genomic medicine into mainstream clinical practice. Subsequently, several opportunities and obstacles in the pharmacogenomics and genomic medicine policymaking in Greece derived from this analysis, based on the current position and intervention potential of the key stakeholders. Similar analysis could also be conducted in the Gulf Cooperation Council (GCC) countries particularly in the UAE, which will positively impact on the pace of implementation of genomic medicine.

Moreover, insufficient genomics education and lack of genomics awareness among healthcare professionals and the general public are two perspectives of the same issue, which hinders the smooth incorporation of genomic medicine into clinical practice (Mai et al., 2014; Reydon et al., 2012; Syurina et al., 2011). On one hand, the vast majority of healthcare professionals declare that they feel insufficiently trained in genomics to be able to engage with the delivery of genomics services, while on the other hand, patients and the broader public tend to have low genomic literacy, which impairs their capacity to meaningfully integrate genomic-based information into their lifestyle decision-making, which is a challenge for public health genomics. On top of this, pharmacogenomics education is not uniformly provided in the various academic institutions worldwide, with the United States and Western European countries leading the way and the Southeastern European countries lagging behind. A survey in 175 departments from 98 universities from 11 Southeastern European countries indicated that for a significant number of universities the topic of pharmacogenetics/pharmacogenomics is not included at all in their undergraduate and postgraduate curricula in health sciences (Pisanu et al., 2014). Additionally, studies that surveyed Greek and Italian physicians indicated that only a small fraction of those

feel competent enough either to propose a genetic test for their patients and/or to interpret the results from such a test. These findings are in sharp contrast with the current reality of pharmacogenomics education in North European countries, where pharmacogenomics is more uniformly and extensively taught and highlight the need for a more in-depth genomics education, either with the incorporation of pharmacogenomics and genomic medicine in their undergraduate or graduate training, or in the form of continuous medical education seminars. These studies might provide the basis to harmonize pharmacogenomics education in Southeast European countries with those of Northwestern European countries, such that it would directly impact on a smoother integration of pharmacogenomics into mainstream medical practice.

As in other resource-limited regions, in Latin America for example, there are very few postgraduate programs focused on genomics (Palacios & Collado-Vides, 2007). In Africa, the high cost of genomics and low private investment is compounded by a relatively low level of medical professionals with understanding of genomics (Wonkam et al., 2006). In addition, another attempt in sub-Saharan Africa to triangulate the views of multiple stakeholders related to Sickle-Cell Disease (SCD) (doctors, parents with SCD-affected children and adult SCD patients) towards prenatal diagnosis of SCD showed several discrepancies. The majority accepted the principle of prenatal genetic diagnosis for SCD (78.7%, 89.8%, and 89.2% respectively); however, parents (62.5%) were more in favor of termination of SCD-affected pregnancy, than doctors and adults' patients (36.1% and 40.9% acceptance, respectively). These differential attitudes signal potential value-based conflicts on the horizon and can usefully inform the future policy actions on the African continent, as

OMICS technologies are increasingly employed in global health (Wonkam & Hurst, 2014).

1.3.1 The Educational Environment of Genomics

Pharmacogenomics (PGx) is the study of the impact genetic variation has on a person's drug response (Aneesh et al., 2009). PGx can play an important role in the future of personalized medicine (Pisanu et al., 2014). PGx aims to minimize drug toxicity and improve drug efficacy (Gurwitz et al., 2003; Pisanu et al., 2014).

The slow clinical application of PGx is mainly attributed to the lack of genomic knowledge and lack of confidence among healthcare professionals (Pisanu et al., 2014). Therefore, PGx education is essential, especially for pharmacists, in order to support the delivery of PGx services (Talwar et al., 2019). Pharmacists have a unique role due to their extensive knowledge in pharmacokinetics and pharmacodynamics of drugs placing them in an integral position in which they can accelerate the implementation of PGx (Elewa & Awaisu, 2019).

Several studies demonstrate that, despite their belief in the PGx importance in pharmacy, pharmacists and healthcare providers perceive themselves to have low confidence in their knowledge and application of PGx testing, indicating the need for extensive PGx education in order to optimally guide patients (Formea et al., 2013; McCullough et al., 2011; Pisanu et al., 2014). A survey by Formea et al. (2013) assessed the pharmacist's educational exposure to PGx pointed out that 67.1% reported that PGx should be a focal point in school education yet 80.1% reported that it was not an integral part of their education. In a larger context, a survey evaluating PGx education in Southeast Europe reported that 85% of students and residents and 95% of

specialized physicians believe PGx should be taught more extensively during medical and surgery curriculums (Pisanu et al., 2014).

In 2005, The International Society of Pharmacogenomics (ISP) published recommendations directed to the deans of Education at medical, pharmaceutical and health schools worldwide (Gurwitz et al., 2005). It included a recommendation with an urgency to implement PGx in core pharmacology curricula. Therefore, many studies conducted evaluations and assessments of PGx education using the ISP's recommendations as the reference point (Green et al., 2010; Higgs et al., 2008; Karas Kuželički et al., 2019).

The ISP recognized PGx to be crucial in integrating personalized medicine into clinical practice and recommended that curricula of medical, health and pharmaceutical schools include at least 4 hours, ideally 8 hours, of PGx teaching (Gurwitz et al., 2005). A survey conducted on PGx education in British medical schools found that only 4 out of the 14 respondents (29%) adhered to the ISP's recommendation of the minimum 4 hours of teaching with the majority teaching for 1-2 hours during the degree's curriculum. However, the majority of respondents (84%) did teach the main elements recommended by the ISP addressing the core elements of PGx (Higgs et al., 2008) . A survey completed in 2010 showed that 74.4% of respondents of US and Canadian medical schools have incorporated PGx into the degree's curriculums but still less than the 89.3% of US pharmacy schools and the 84% of British medical schools (Green et al., 2010).

A study in 2014 concluded that PGx educational programs were not uniformly provided. The study contrasted survey results from Northern and Southern European

countries. It showed that Northern European countries, such as the United Kingdom, Germany and Netherlands's PGx education at undergraduate and postgraduate studies level is more uniform than South Eastern countries where PGx is either not at all included (Bosnia and Herzegovina, Cyprus and Malta), or included in some (Bulgaria, Albania, Croatia, Serbia and Turkey), or extensively taught (Greece and Italy) (Pisanu et al., 2014).

Little is known and studied regarding PGx educational environment and healthcare professionals' knowledge and attitudes towards the practice in the Gulf Cooperation Council (GCC) countries. Nevertheless, two studies have been conducted in Qatar and Kuwait and presented similar findings to the above-mentioned studies (Albassam et al., 2018; Elewa et al., 2015). Lack of knowledge was highlighted as a top barrier in both Qatar and Kuwait respondents despite their positive attitudes towards PGx. Pharmacists exhibited more positive overall perceptions than doctors or physicians in Qatar and Kuwait, respectively. This supports the importance and advocating of pharmacists' roles in pharmacogenetic services. In both studies, the majority of survey respondents were aware of the importance of PGx in individualized medicine. Moreover, both Qatar and Kuwait, pharmacists' felt a higher sense of responsibility and a more positive attitude than physicians in regard to PGx's relevance in their practice. Lack of confidence in applying PGx testing in practice was also evident in Kuwait's study with only 16% of respondents claiming high confidence. The high self-confidence was significantly common in those with 10 or more years of experience and previous exposure to PGx. Altogether, these findings contribute to the urgency needed to offer effective PGx teaching programs.

Another presented viewpoint in several studies is the provision of continuing educating to interested pharmacists and healthcare providers (Green et al., 2010; Karas Kuželički et al., 2019; Tsermpini et al., 2019). It can be deemed essential for the healthcare professionals with insufficient genomic education and knowledge to implement PGx into practice. There have been efforts to bridge this knowledge gap with providing online e-learning and training courses (Tsermpini et al., 2019). In addition, low genetic literacy of the public has been noted to be a problem that should be explored so as to facilitate lifestyle decision-making based on genomic information (Karas Kuželički et al., 2019; Pisanu et al., 2014; Tsermpini et al., 2019).

There is necessity to map the educational environment of genomics and PGx in the UAE and to assess the readiness and willingness of the higher education system in UAE to move forward with the implementation of genomic medicine and PGx.

1.3.2 The Knowledge and Attitude of the Healthcare Providers

There has been a substantial amount of investigation on genes and medications detailing variations in drug response in individuals. An individual's genetic makeup significantly influences their reaction to the medication, accounting for an estimated 20 – 95% of variations in drug response (Bush et al., 2016; Chanfreau-Coffinier et al., 2019a). These results give the premise to PGx and pharmacogenetics testing. The utilization of genetic tests to determine the ideal pharmaceutical therapy for a patient will enhance drug efficacy and will lower adverse drug responses (Haga et al., 2012; Muzoriana et al., 2017; Pisanu et al., 2014). The expressions PGx and pharmacogenetics are often used interchangeably; however, PGx has a greater emphasis on the entire genome's influence on drug response (Jarrar et al., 2019).

Amongst 193 countries, the UAE is positioned sixth in the prevalence of birth defects, predominantly due to genetic roots (Al-Gazali & Ali, 2010; Christianson et al., 2006). PGx and genetic testing can act as a vital tool in comprehending genetic makeup, diagnosing disease-causing genes, and delivering protective and supportive measures to these diseases. The prospect of PGx implementation in medical practice is vastly reliant on healthcare workers' acceptance and the application of pharmacogenetics tests (Mai et al., 2014; Pisanu et al., 2014; Rogausch et al., 2006). Pharmacists are proposed to be at the heart of PGx implementation due to their integral and unique roles as educators to healthcare workers and patients (Formea et al., 2013; Jarrar et al., 2019; McCullough et al., 2011; Muzoriana et al., 2017). In fact, pharmacists expressed more positive perceptions than physicians toward PGx, as stated in two previous studies in Qatar and Kuwait (Albassam et al., 2018; Elewa et al., 2015). In these studies, the majority of survey respondents were aware of the significance of PGx in individualized medicine. As the largest group in the healthcare workforce, nurses also assume a central role in patient advocacy as defined by the American Nursing Association. Therefore, they are anticipated to be acquainted on this type of genetic testing to assume responsibility in incorporating it in clinical setting (Dodson, 2011). The laborious implementation of genetic testing and PGx can be associated to many reasons, including but not limited to, a lack of evidence in clinical use, costing, and ethical concerns (Dodson, 2011; Muzoriana et al., 2017). Despite the limited widespread implementation of PGx testing, it is currently being applied and used to model treatments for certain cancers, diabetes, and cardiovascular diseases (Nishant et al., 2012). Cardiovascular Disease (CVD) represents one of the foremost health threats in the UAE. According to the World Health Organization (WHO) report on the UAE,

40% of all deaths were due to cardiovascular diseases. The Department of Health in the emirate of Abu Dhabi (DOH) reported that 71% of the population has at least 1 CVD risk factor, foreseeing a rapid increase in future CVD events. Moreover, 12% of all deaths were due to cancers and 5% to diabetes (Department of Health, 2018; World Health Organization, 2018). Many hurdles to PGx application have also been reported; however, lack of genomic knowledge and lack of healthcare professionals' confidence in decision-making are widely prominent factors affecting the practice of PGx (Abdela et al., 2017; Muzoriana et al., 2017; Pisanu et al., 2014). Therefore, it has been underscored that more concentrated and advance PGx education and training is crucial for healthcare professionals, especially pharmacists, for better the delivery of PGx and personalized medicine services (Abdela et al., 2017; Kudzi et al., 2015; Muzoriana et al., 2017; Talwar et al., 2019). Moreover, to successfully translate the discipline of PGx into clinical practice, all members of the healthcare workforce need to be knowledgeable and educated on the subject. There are no current research studies, to date, in the UAE assessing health professionals' stance and attitudes towards PGx and genomic medicine.

1.3.3 The Knowledge and Attitudes of Health Science Students

The accomplishment of the Human Genome Project in 2003 boosted personalized medicine and made the concept more prevalent between clinicians, and it encouraged the implementation of genomics education (Giri et al., 2018; Karas Kuželički et al., 2019; McCullough et al., 2011). This was presented in a global survey performed to gauge the education progress of PGx, showing that 82.1% of the programs began the implementation of PGx topics after the completion of the Human Genome project (Karas Kuželički et al., 2019). In 2007, four years after the Human Genome Project

was completed, the Food and Drug Administration (FDA) executed pharmacogenetics, labeling changes to warfarin to indicate that genetic makeup can affect dosage requirements and risks (Formea et al., 2013; McCullough et al., 2011). This change, among several others, was deemed an important tangible step in PGx and personalized medicine (AlEjielat et al., 2016; Formea et al., 2013; McCullough et al., 2011). Future advances in genomic medicine and PGx will require health professionals to be equipped with the knowledge and tools in order to fully apply and implement PGx in clinical practice as best as possible (Green et al., 2010; Gurwitz et al., 2005; Higgs et al., 2008; Tsermpini et al., 2019). In spite of the emphasis and evidence on the importance of genomic medicine and PGx in clinical practice, many healthcare professionals articulate a lack of confidence in the implementation of PGx in practice (Abdela et al., 2017; McCullough et al., 2011). This is fairly attributed to lack of education, a widely highlighted barrier, which can lead to knowledge gaps and difficulty in interpreting and communicating PGx results (Abdela et al., 2017). Medical and health science students represent future health professionals, and their perceptions are essential to expanding awareness on personalized medicine and PGx (Abdela et al., 2017; Green et al., 2010; Gurwitz et al., 2005; Gurwitz et al., 2003). Particularly, pharmacists, as drug experts, are considered fundamental in the clinical implementation of PGx due to the nature of their education and background (AlEjielat et al., 2016; McCullough et al., 2011; McMahon & Tucci, 2011; Muzoriana et al., 2017). In order to increase genomic medicine and PGx awareness and competency among medical and health science students, their knowledge, attitudes, and practice towards genomic medicine and PGx should be evaluated. Very little is known and studied regarding the genomic medicine and PGx educational environment and

medical and health science students' perceptions towards the practice in Middle Eastern and, more specifically, Gulf Cooperation Council (GCC) countries. Three studies have been conducted in Saudi Arabia, Qatar, and Kuwait. Synonymous with other studies, respondents identified lack of knowledge to be one of the challenges, despite the positive attitudes in PGx clinical implications (Albassam et al., 2018; Algahtani, 2020; El Shanti et al., 2015). Assessment of the knowledge and attitudes regarding genomic medicine and PGx among medical and health science students is key. They are the future adopters of this field, therefore an attempt to assess and bridge the knowledge gap and gain insight on their opinions and views on the practice of personalized medicine and PGx will guide the stakeholders.

1.3.4 The Current State of Genetics Testing Services in UAE

The UAE is a federation of seven emirates situated in the southeast of the Arabian Peninsula. It enjoys a unique strategic location that has made it a world-class and a multicultural and multiracial country with diverse ethnic groups from Arabia, Persia, Baluchistan, and Africa (Al-Gazali & Ali, 2010). The fast pace of economic development is making the UAE one of the most ethnically diverse countries in the world (Al-Gazali & Ali, 2010; Barakat-Haddad, 2013). Consanguineous marriages within most UAE subpopulations are still the norm, leading to a high frequency of recessive conditions and genetic disorders (Al-Gazali & Ali, 2010). The fields of genetics and genomics are key for detecting and preventing genetic disorders. Genomic medicine is defined as using an individual patient's genotypic information for their clinical care (Williams, 2019). Genetic testing is often crucial for accurate diagnosis and effective prevention and treatment of human genetic diseases (Zhang & Li, 2014). A few years back, genomic DNA sequencing in the UAE was restricted to

research settings, but is now integrated into clinical settings, making it possible to diagnose and treat diseases as well as to screen and prevent uncommon diseases (Zhang & Li, 2014). The advent of next-generation sequencing technologies has significantly reduced the cost and the time required for whole-human-genome sequencing (Lappalainen et al., 2019). Beyond the widespread use and technical requirements of genomic technology, there are real barriers that can impact the clinical implementation of genomics into healthcare systems. The level of readiness of healthcare systems to globally share clinical, epidemiological, and genomic data to optimize clinical benefits is important. Over the next 5 years, it is expected that genomic data from over 60 million patients will be generated within healthcare systems worldwide (Stark et al., 2019a). Although limited data is available on diagnostic yields, having population databases as a reference, and implementing, building, and sharing them will improve the interpretation of variants globally (Landry et al., 2018). The sharing of data on genomic variants and phenotypes globally will provide useful information necessary to improve clinical care and empower device and drug manufacturers who are promoting tests and treatments for patients (ACMG Board Of Directors, 2017). Despite the expansion in genomic testing worldwide, it still has major problems in many developing countries, where officials lack recognition of the importance of integrating medical genetics into clinical settings. In other cases, there is a shortage of trained personnel and laboratory infrastructure for genetic tests, although the management of patients with genetic disorders relies heavily on the laboratory infrastructure (Zhao et al., 2013). Despite the high frequency of genetic disorders in the UAE, only a few major centers are providing genetic testing and counseling. The Genetic and Thalassemia Center based in Dubai, the College of

Medicine and Health Sciences based in Al Ain, and the Mother and Child Health Department based in Abu Dhabi are among these centers. In addition, there is the United Arab Emirates Genetic Diseases Association and the Center for Arab Genomics Studies in Dubai (Al-Gazali & Ali, 2010). Within the UAE government, there is a strong focus on improving and developing fundamental data on the genetic basis of disease and diversity. Despite many genomic projects and other efforts made in the Arab countries focused on understanding the unique genetic makeup of this region's citizens, information on the genomes of populations from these nations remains limited. In addition, despite the progress made in recent years, many disorders in the UAE are still unstudied (Al-Gazali et al., 2005). Therefore, the establishment of a specific database would be valuable for planning and providing effective diagnosis and prevention systems for healthcare providers and researchers in the UAE and the region. In the literature, there is no precise information about the first genetic laboratory established in the UAE; however, a total of three genetic centers were established at an early stage in the country. A thalassemia and genetic center were established in Dubai back in 1989 (Al-Gazali & Ali, 2010). This center provided services for thalassemia patients from throughout the UAE and was equipped with cytogenetics, biochemical, and molecular laboratories (Al-Gazali & Ali, 2010). The second genetic center is at the College of Medicine & Health Sciences at United Arab Emirates University. It was established back in 1990 and has been providing services for patients from all over the country. The third one was under the remit of the maternity and child-care unit at the Ministry of Health in Abu Dhabi and was established in 1999. Genetic counseling was provided at the three centers by geneticists, who were not supported by genetic counselors, health visitors, or social workers (Al-Gazali et al., 2005). More

genetic centers are now being advertised across the UAE, but little is known about the general landscape in which genetic testing is operating in the country. Furthermore, there is no evidence of any assessment having been performed on the quality of genetic analysis services provided across the country. There is a need to map the genetic services in the UAE in order to establish a genomic infrastructure database that would provide an opportunity to resource and promote best practices and help in establishing a roadmap for implementing genomic medicine in the country.

1.3.5 Stakeholders' Interest and Attitudes

It has been 18 years since the first milestone of genomic medicine and pharmacogenomics occurred in 2004, when the FDA approved Gefitinib for the treatment of genetic mutation metastatic non-small cell lung cancer (Shendure et al., 2019). Cornucopia of studies had emphasized the evidence-based value of genomic medicine and pharmacogenomics in breadth of spheres like oncology, neurology, pediatric, nephrology (Evans et al., 2020; Geiersbach et al., 2020; Green et al., 2019; Lucas et al., 2020; Monaghan et al., 2020; Neill et al., 2020; Riggs et al., 2020; Uddin et al., 2020). For example, genomics took center stage in the COVID-19 pandemic and proved its value with sequencing the coronavirus genome (Murray et al., 2020; Randhawa et al., 2020; Uddin et al., 2020). Despite these leitmotif evidence, still there is a chasm between research and the full implementation of genomic medicine and pharmacogenomics in clinical practice (Brunette et al., 2020; Kochan et al., 2020; Lauschke & Ingelman-Sundberg, 2020; McClaren et al., 2020b). Extensive research efforts have investigated and diagnosed factors associated with the slow-uptake of the full implementation of genomic medicine and pharmacogenomics, and they concluded that knowledge gap of healthcare providers, current policy challenges, reimbursement

of the cost of genetic tests, stance of stakeholders are some of the attributes that hampered the full pragmatic implementation of genomic medicine and pharmacogenomics internationally (Best et al., 2020; Brunette et al., 2020; Klein, 2020; Kochan et al., 2020; McClaren et al., 2020a; McClaren et al., 2020b).

Directing the lens to the MENA region, additional and unique challenges are introduced. A perspective paper by Zgheib et al. (2020) mapped the landscape of precision medicine as well as the gap, challenges and needs in low- and middle-income countries. The researchers projected the model of "fast-second winner" that recommends pursuing country-specific genome wide association. This approach claims to create rapport with stakeholders and accelerates the implementation of genomic medicine in the region.

For effective introduction, set up and implementation of genomic medicine and pharmacogenomics, the pivotal role of stakeholders cannot be overlooked (Chenoweth et al., 2020; Mitropoulou et al., 2020; Mustapa et al., 2020; Rigter et al., 2020). Fourteen stakeholders were identified as key players in the micro, meso and macro levels of genomic medicine and pharmacogenomics (Mitropoulou et al., 2020). Mapping the power, interest and stance of aforementioned stakeholders is a mainstay in the endeavor of full genomic medicine and pharmacogenomics implementation (Chenoweth et al., 2020; Mitropoulou et al., 2020; Mustapa et al., 2020; Rigter et al., 2020).

Different tools, procedures, frameworks, and models are used to map the stakeholders' interest, power, and stance. Mendelow's matrix, PolicyMaker and PMP stakeholder management are examples of these tools (Altahtooh, 2020; Bernstein et al., 2020;

Mendelow, 1981; Mitropoulou et al., 2014; Potnis & Gala, 2020). Moreover, some of these tools had been previously employed and validated on the stakeholders of genomic medicine and pharmacogenomics to offer a vantage point for the systematic implementation of genomic medicine and pharmacogenomics (Chanfreau-Coffinier et al., 2019b; Esquivel-Sada et al., 2019; Faulkner et al., 2020; Mitropoulou et al., 2014).

There are several studies in UAE about genomic medicine (Al-Mahayri et al., 2019; Alblooshi et al., 2019; AlSafar et al., 2019; Jithesh & Scaria, 2017; Osman et al., 2019). Nevertheless, no studies about mapping the power, interest, and the attitude of the various stakeholders in the UAE pertaining to the implementation of genomic medicine and pharmacogenomics have been conducted. Therefore, mapping the power/interest of various stakeholders in UAE using the Mendelow's matrix is a pivotal step to facilitate constructing a roadmap for the full implementation of genomic medicine and pharmacogenomics in UAE.

1.4 Research Objectives

The overall aim of this research is to evaluate the current status of applying genomic medicine and pharmacogenomics in the UAE and assemble a roadmap for fully implementing these modern disciplines in the healthcare systems. The specific objectives of this research are to:

1. Assess the readiness and willingness of the higher education system in UAE to move forward with the implementation of genomic medicine and pharmacogenomics in the UAE.

2. Assess the level of knowledge and attitude of healthcare providers about genomic medicine and pharmacogenomics in addition to their perceived barriers toward full implementation of genomic medicine and pharmacogenomics in UAE.

3. Assess the level of knowledge and attitude of medical and health science students concerning genomic medicine and pharmacogenomics in supplement to their perceived barriers toward full implementation of genomic medicine and pharmacogenomics in UAE.

4. Map the current state of genetics and genomic testing services and regulatory aspects in the UAE.

5. Establish a stakeholders' matrix of power and interest toward genomic medicine and pharmacogenomics to facilitate the implementation of genomic medicine and pharmacogenomics in UAE.

1.5 Research Hypothesis

The research questions articulated as "Is the UAE ready to fully implement genomic medicine and PGx? "What is the level of readiness of the UAE to implement genomic medicine and PGx, and what would be of the most appropriate way to fully implement these in the country?"

The null hypothesis:

UAE is not ready to fully implement genomic medicine and PGx in terms of infrastructure, educational environment, stakeholder's stance, knowledge, and attitudes of health care providers.

Chapter 2: Methods

2.1 Research Design

To build the roadmap for the implementation of genomic medicine and pharmacogenomics in UAE, multi-objectives ought to be explored: starting with the current infrastructure of genetic services in UAE, the educational environment of genomic medicine and pharmacogenomics in the colleges and universities in UAE. Also, the knowledge and attitude of the medical and health sciences students, academia, and the healthcare providers should be looked at. Moreover, the views and vision of the stakeholders in UAE should also be taken into consideration.

To tackle these objectives, the researcher employed a mixed method approach of qualitative research designs (focus group discussions and semi-structured interviews) and quantitative research designs (cross-sectional survey) as well as mapping the current environment of education and genetic testing using website surfing augmented by site visit, questionnaires, and semi-structured interview. This is illustrated in Figure 1 in which the methods and stakeholders are represented by cars and buildings respectively.

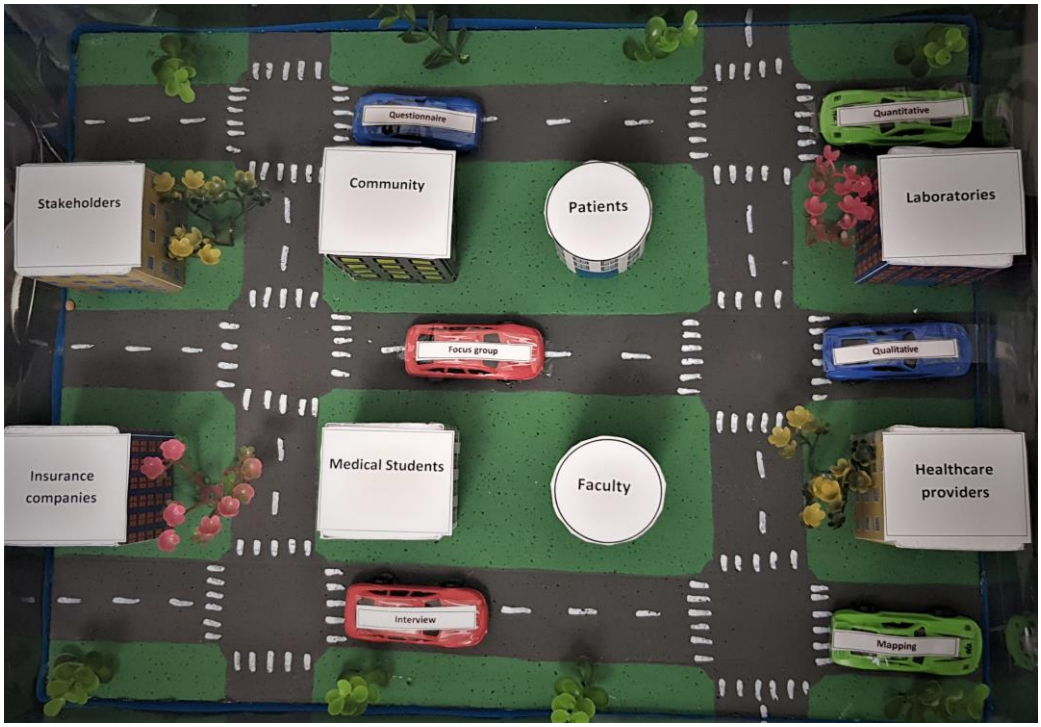


Figure 1: Prototype of the employed methods and stakeholders

Researcher employed mixed method methodology to assess the readiness and willingness of the higher education system in UAE to move forward with the implementation of genomic medicine and pharmacogenomics in the UAE. This was assessed by conducting semi-structured interviews with the academia and commissioners and mapping the medical and health sciences curricula of UAE universities. Moreover, to quantify the core of courses and assess the attitudes of academia, the researcher distributed a validated survey. Mixed methodology was adopted to assess the level of knowledge and attitude of healthcare providers about genomic medicine and pharmacogenomics in addition to their perceived barriers toward full implementation of genomic medicine and pharmacogenomics in UAE. Focus group discussions were employed as a qualitative tool to explore the attitudes and barriers of healthcare providers, namely pharmacists. Moreover, cross sectional

methodology was employed to quantify these objectives. A validated survey was distributed to assess the level of knowledge and attitude of medical and health science students concerning genomic medicine and pharmacogenomics and their perceived barriers toward full implementation of genomic medicine and pharmacogenomics in UAE. To map the current state of genetics and genomic testing services and regulatory aspects in the UAE, researcher exercised manual mapping of the websites of the laboratories in complement with quantitative questionnaires. Qualitative semi-structured interviews were conducted to establish a stakeholders' matrix of power and interest toward genomic medicine and pharmacogenomics. The compiled findings and results guided the construction of the roadmap to implementation.

2.2 Data Collection

2.2.1 Assessing the Educational Environment in UAE

The researcher employed a mixed method triangulated approach to map the genomics and PGx educational situation in the UAE. A qualitative approach was used, exploiting interviews and content analysis of the educational curricula of different UAE universities. This was coupled with interviews with teaching faculty members and higher education experts from the Commission for Academic Accreditation (CAA) at the Ministry of Educations in UAE, in addition to mapping the genomics and PGx curricula in medical and health sciences degrees in the accredited universities in UAE. Additionally, questionnaires had been distributed among the teaching faculty members in UAE accredited universities to get an in-depth understanding of their needs and vision of the future of genomics and PGx.

Qualitative approach:

Mapping the genomics and pharmacogenomics curricula in medical and health sciences degrees in the accredited universities in UAE:

The researcher identified all accredited universities, private and public, in the seven emirates of UAE utilizing the official website of the UAE ministry of education. Universities that do not offer health sciences, medical or dental programs were excluded. The university's latest syllabus and webpage were used to map the curricula in medical and health sciences degrees in identified universities. The keywords used were "genetics, genomics, molecular genetics, pharmacogenetics, pharmacogenomics, public health genomics, medical genomics, and molecular diagnostics". An excel sheet used to record and code the collected data. Course modules were grouped into 11 course categories: genetics, genomics, pharmacogenetics, pharmacogenomics, molecular diagnostics, molecular biology, molecular biology techniques, genetic engineering, gene therapy, clinical genetics, and biotechnology. Total course credits from all universities were summed up for each course category.

A total of four semi-structured interviews were conducted- two with teaching faculties and two with commissioners in UAE. The interview guide was constructed and then reviewed by experts in the field of genomic medicine, public health, qualitative study, and epidemiology. All interviews were audio recorded and field notes were logged during and after the interview. Each semi-structured interview took 40 to 60 minutes and was performed at participants' workplace. The interviews were transcribed in a verbatim manner. Grounded theory guided the independent extraction of the codes and themes by the two researchers. NVivo software version 12 was used for coding and themes extractions.

Quantitative Approach:

Assessing the current status of genomics and PGx teaching in medical and health sciences degrees in the accredited universities in UAE and the attitude of academia toward genomics implementation:

A validated and piloted questionnaire was used. The questionnaire was based on validated and published questionnaires that were used to assess PGx in the Curricula of Colleges and Schools of Pharmacy in the United States as well as other published work (Murphy et al., 2010; Pisanu et al., 2014). The questionnaire had been piloted among public health and pharmacy faculty members and amended accordingly. The questionnaire was randomly emailed by an identified focal person (dean, secretary identified from website of the colleges) to the academia teaching in the medical and health sciences degrees in the accredited universities in UAE. The Statistical Package for the Social Sciences (IBM SPSS) was used to perform descriptive statistics on the data such as frequencies and means.

This study had been approved by the social science research ethics committee of United Arab Emirates University (UAEU) ERS_2017_5671. Participants were asked to read the information sheet of the study and sign the consent form before participating in the study.

2.2.2 Assessing the Knowledge and Attitude of Healthcare Providers

A mixed method approach of both quantitative and qualitative methodology had been commissioned to ensure deep and comprehensive assessment. A cross-sectional study using a validated questionnaire was conducted (Albassam et al., 2018; Carver et al., 2017; Mai et al., 2014). Inclusion criteria embodied registered healthcare workers practicing in either public or private hospitals or clinics. Registered pharmacists,

nurses, physicians, managers, and allied health practitioners were invited as they were identified by literature as the stakeholders for the adoption of genetic testing and PGx. The online Shafafiya portal of the DOH that contains a population frame for all the healthcare providers working in the UAE had been accessed (data included: clinician license, clinician name, major, profession, category, gender, facility name, facility license, location, facility type, and the status). Facilities were stratified per location and then contacted by the researcher either by email or by site visit to grant approval and distribution of the questionnaire among the healthcare providers. Random selection sampling and chain sampling techniques had been employed. The survey was offered both in person and via the internet to accommodate the generally busy schedule of healthcare providers, as some preferred answering the questionnaire on the spot while others preferred filling it out online at a later time when they were less busy. Moreover, some hospitals and clinics asked for the online survey so that they could circulate it to their healthcare providers via email, while other clinics asked for printed versions to be distributed by their human resources staff. Furthermore, the internet-based medium was used for snowball sampling. The survey was administered between April and September 2019 in order to reach the calculated target sample size. The survey was also kept open longer to accommodate the summer break period. This study was approved by the Social Science Research Ethics Committee of United Arab Emirates University (UAEU) ERS_2017_5671. Participants were asked to read the study's information sheet and sign a consent form before answering the survey. The questionnaire was designed based on previously validated and used tools to explore and identify knowledge, awareness, attitude, behavior, and interest in genetic testing and PGx (Albassam et al., 2018; Carver et al., 2017; Mai et al., 2014). The

questionnaire had been piloted among 50 medical and health sciences professionals and amended accordingly. The questionnaire was administered in English and it was divided into 3 sections. Section 1: Demographic data, e.g., age, gender, occupation, years of experience, and nationality. Section 2: Knowledge; nine questions about specific facts about genomic and PGx. A knowledge score was calculated from nine true and false questions about genetics and PGx. Three knowledge levels were created based on the number of correct answers: good (7–9 correct answers), fair (4–6 correct answers) and poor (3 or less correct answers). Section 3: Attitudes of healthcare workers with regard to the ethical, social, and economic implications of genetic testing and PGx in addition to their perceived barriers for the full implementation of genetic testing and PGx in the UAE. For the attitudes, a 5-point Likert scale of strongly agree, agree, strongly disagree, disagree, and neutral was collapsed into agree, disagree, and neutral for ease of analysis and interpretation. For statistical analysis, the sample size had been estimated using the formula for cross-sectional studies; $(1.96^2 \times P\ (1 - P)/d^2)$, where P = 0.27 (27% is the prevalence reported in similar previous studies) and d = 0.05. Sample size = $3.84 \times 0.27\ (1 - 0.27)/0.0025$ = 303 healthcare workers. Accounting for an average response rate of 46% (reported in previous studies), the calculated sample size needed for this analysis was 444 healthcare workers. International Business Machines Corporation Statistical Package for the Social Sciences (IBM SPSS) Statistics 26 was used for data analysis. Descriptive statistics (means, standard deviation, SD) and frequencies (percentages) were used to represent the data. Chi-squared test and Monte Carlo exact test were used to determine any significant differences in the distribution of respondents' characteristics between the knowledge levels. Questions about genetics were selected from the literature with

validated questions which recommended that the cutoff for good knowledge is 75%, and we followed the analysis of the literature in giving all the questions of the knowledge the same weights.

A qualitative inductive grounded theory approach informed by the Corbin and Strauss (2008) methodological pathway was followed to develop a theory related to the field of pharmacogenomics in the UAE. Four focus group discussions were conducted to explore the knowledge, attitude and perception of registered pharmacists working in the UAE toward genomics and pharmacogenomics. Pharmacists were invited through hospitals, clinics and community pharmacies and using snowball techniques. Inclusion criteria included any registered pharmacists of any nationality working in either private or public settings and in any health care setting (tertiary hospitals, health clinics or community pharmacies) as either outpatient, inpatient or clinical pharmacists. Participants were invited in person, by telephone and via email. All who agreed to participate received an official invitation via email including details of the meetings as well as the information sheet of the study and time and location of the meeting. A reminder email and messages were sent one week before the session and repeated 24 hours and 2 hours before the session. The sessions were conducted over weekends at the College of Medicine and Health Sciences of the United Arab Emirates University to ensure that participants attend the meeting. Each session lasted 90 min. Saturation was reached after the fourth focus group discussion. Researchers followed an interview guide with questions and prompts that had been revised by experts in the field of qualitative studies, public health as well as genomic medicine. The Health Literacy Skills theoretical framework guided the elements of interview guide (Squiers et al., 2012). All four focus group sessions were audio taped during the sessions and field

notes were recorded during and after the focus group sessions. Participants were asked to read the information sheet of the study as well as to sign the consent form before starting the discussion. A verbatim transcription for all focus group sessions was reviewed by two researchers and then was returned for random participants for comments and/or corrections to ensure credibility and reflexivity. All four focus group sessions were coded, and themes were extracted. Inter-coder reliability was ensured. The transcription was uploaded on NVivo 12 (Windows version) for analysis to extract themes and visualize the findings.

2.2.3 Assessing the Knowledge and Attitude of Students in UAE

A cross-sectional study had been utilized. The targeted sample included undergraduate and postgraduate medical and health science students (medicine, pharmacy, laboratory, medical imaging, radiology, radiography, biochemistry, biomedical sciences, dentistry, pharmacology, physiology, psychology, public health, and occupational health) in the UAE, as they are the future adopters of genomic medicine and PGx. Random selection sampling techniques had been employed, in which all the universities and colleges in the UAE that offer degrees in medicine, pharmacy, laboratory, and nursing had been contacted and asked to distribute the questionnaire among their students. Furthermore, snowball sampling had been applied, where existing students recruit future subjects from among their acquaintances that meet our inclusion criteria. The survey was administered electronically between December 2018 and October 2019. The questionnaire was designed based on the literature to explore and identify knowledge, awareness, attitudes, behavior, and interest in genomic medicine and PGx among medical and health science students. It encompassed validated questions used in the Public Understanding and Attitudes

towards Genetics and Genomics (PUGGS) questionnaire (Carver et al., 2017), the United States (Murphy et al., 2010), and Southeast Europe (Pisanu et al., 2014). The questionnaire had been piloted among 50 medical and health science students and consequently modified it. The questionnaire was administered in English and it was divided into 3 sections: Section 1: Demographic data: age, gender, faculty, year of study, major, and type of university (government or private). Section 2: Knowledge: nine questions about basic genomic medicine and PGx facts. Section 3: Attitudes of the students toward ethical, social, and economic implications of genomics and PGx and their perceived barriers for the full implementation of genomic medicine and PGx in the UAE. Sample size had been calculated using the formula for cross-sectional study ($1.96^2 \times P\ (1-P) \div d^2$), where: P = 48 (48% is the prevalence of the knowledge of genomics among medical and health science students that was extracted from the literature of similar studies) and d = 0.05. The sample size (students) = $3.84 \times 0.48\ (1-0.48) \div 0.0025 = 383$ students. Similar regional studies showed an average response rate of 84%, therefore an additional 61 students were needed to reach a final sample size of 444 students. IBM SPSS Statistics version 26 had been applied to analyze the data. Descriptive statistics (means, standard deviation, and frequencies) was used to represent the data. The chi-squared test was used to determine any significant differences in the distribution of the students' characteristics between the knowledge levels. A knowledge score was calculated from nine true or false questions about genetics and PGx. Three knowledge levels were created based on the number of correct answers: good (7–9 correct answers), fair (4–6 correct answers) and poor (3 or less correct answers). For the attitudes, a 5-point Likert scale of strongly agree, agree, strongly disagree, disagree and neutral was collapsed into agree, disagree and neutral

for ease of analysis and interpretation. The frequency distribution of the Likert scale results was reported as percentages to recognize the challenging areas of genomic medicine and PGx that students identify with. This study had been approved by the Social Science Research Ethics Committee of United Arab Emirates University (UAEU) ERS_2017_5671. Participants were asked to read the information sheet of the study as well as to sign the consent form before starting the survey.

2.2.4 Mapping Genetics Testing Services in UAE

This study was conducted using two pronged and complementary approaches: (1) manual mapping of the laboratories in the UAE claiming to provide genetic and/or genomic testing, and (2) handing out questionnaires in person onsite at these laboratories in order to obtain information on the services that they provide and identify contrast between website and onsite. Researcher relied on the definition of genetic test of Holtzman (1999) as the analysis of human DNA, chromosomes, proteins, and metabolites to discover heritable disease-associated genotypes, mutations, phenotypes, or karyotypes for medical reasons. This study had been approved by the social science research ethics committee of United Arab Emirates University ERS_2017_5671. Participants were requested to read the information sheet of the study as well as to sign the consent form before contributing to the study.

2.2.4.1 Website mapping

In a Google search engine, the following search terms were entered: “Genetic/genomic testing, UAE; Genetic/genomic counseling, UAE; pharmacogenomic/pharmacogenetic, UAE; Genetic screening, UAE; Genetic service, UAE”. Such a wide range of search terms would allow capturing an accurate and

comprehensive picture of the laboratories in the UAE offering genetic tests; hence this is the first baseline in UAE. All websites were in English and/or Arabic. Using Microsoft Excel, the following data had been collected: name of the laboratory, location, contact number, type of services offered, availability of genomic biobank, availability of bioinformatics analysis, DNA source, availability and type of genetic counseling, accreditation, costs, insurance coverage, consent forms, and whether samples are processed locally or abroad.

2.2.4.2 Onsite mapping

A validated questionnaire by Balasopoulou et al. (2017) with 33 questions was handed onsite between June 2019 and the end of February 2020 to all the mapped laboratories claiming to provide genetic testing services. The questionnaire captured: the technical aspects of the provided services including availability of genomic biobank, availability of bioinformatics analysis, DNA source, availability and type of genetic counseling, accreditation, costs, insurance coverage, consent forms, and whether samples are processed locally or abroad, gene-panel selection, logistics, reporting of results, and cost / reimbursement. Responses were transcribed to Qualtrics survey software for standardized analysis and reporting of findings. The fact that several laboratories have more than two branches in more than two emirates was taken into consideration to avoid duplicate responses. Results were reported using frequencies and percentages. Percentages were calculated depending on the method of mapping: for the website-mapped laboratories the denominator was the total number of the mapped laboratories using web search while the denominator for onsite was the total number of laboratories that filled the survey. This distinction had been employed to avoid inflation and over

estimation or duplication and to identify contrast between website and onsite mapping. Qualtrics survey software was used to generate reports of onsite findings.

2.2.5 Establishing a Stakeholders' Matrix of Power and Interest

A qualitative approach using in-depth interview had been used to explore the power, interest, and the attitude of the stakeholders in the UAE toward pressing health genomics aspects. Various stakeholders were identified by experts in the field of epidemiology, genomic medicine and pharmacogenomics, and public health. The criteria of selecting the stakeholders are mainly involved in the micro, meso and macro pillars of the infrastructure of genomic implementation.

The interview guide had been constructed and then revised by experts in the field of genomic medicine, public health, qualitative study, and epidemiology. The inverted pyramid format had been selected for the interview guide and it composed blended of open ended and closed ended questions and prompts that gauge the attitude, commitment, power, and interest of the stakeholders toward genomic medicine and pharmacogenomics in UAE, as well as their legal and ethical concerns. The following are the focal points of the interview:

A- Clinical demand for genomic medicine and pharmacogenomics in UAE.

B- Infrastructure preference (in-house or outsource outside the country).

C- Opinion whether genomic medicine /pharmacogenomics is cost-effective.

D- Implementation approach: preemptive approach or gene-specific approach.

E- Attitude about their desire to undertake genetic test.

F- Attitude toward online direct to consumer kits.

G- Concerns about the ethical and legal aspects of genomic medicine in UAE.

H- Their perceived barriers and challenges for the full implementation of genomic medicine and pharmacogenomics in UAE.

The study sampling method was mainly purposive. Snowball technique was used to connect with some stakeholders. Thirteen in-depth semi-structured interviews were conducted with the identified stakeholders. All 13 interviews were audio recorded and field notes were logged during and after the interview. This study had been approved by social science research ethics committee of United Arab Emirates University (UAEU) ERS_2017_5671. Participants were asked to read the information sheet of the study as well as to sign the consent form before starting the interview. Each semi-structured interview lasted from 40 - 60 minutes and was conducted in a location convenient to the stakeholder.

A verbatim transcription for all interviews was reviewed by two researchers and then was returned for random participants for comments and or corrections to ensure credibility and reflexivity. The analysis of the qualitative research data was a hybrid of inductive grounded theory approach informed by the Corbin and Strauss (2008) to formulate the themes and concepts and deductive using the matrix framework of Mendelow for mapping the interest and power of stakeholders (Corbin & Strauss, 2008; Thornberg et al., 2014).

Inter-coder reliability was ensured and transcription was uploaded on NVivo 12 software for analysis to extract themes and visualize the findings. A tally matrix was created to signify the preponderance of categories and to isolate outliers and to provide

decisive confidence (Groenland, 2018). The standards for reporting qualitative research checklist by O'Brien et al. (2014) and COnsolidated criteria for REporting Qualitative research (COREQ) checklist guided the presentation of findings.

Chapter 3: Results

3.1 Assessing the Educational Environment in UAE

3.1.1 Mapping of Curricula for Genomics and PGx Courses

Out of the universities in all seven emirates, two universities were excluded as the degrees did not match criteria. The assessment of university curricula included a total of 21 universities: 7 in Abu Dhabi, 7 in Dubai, 3 in Ajman and 2 each in Ras Al Khaimah and Sharjah. All courses' credits in all universities were 368. Thorough searching of the curricula and websites resulted in "genetics" having a total of 140 credits out of the 368 (38%). Genetics credits all belonged to stand-alone courses with the exception being in medical and dental degrees, where only 8 out of 35 "genetics" credits belonged to stand-alone courses. PGx and genomics courses accounted for 15 and 9 credits respectively out of 368. Figure 2 displays the number of total credits per course category.

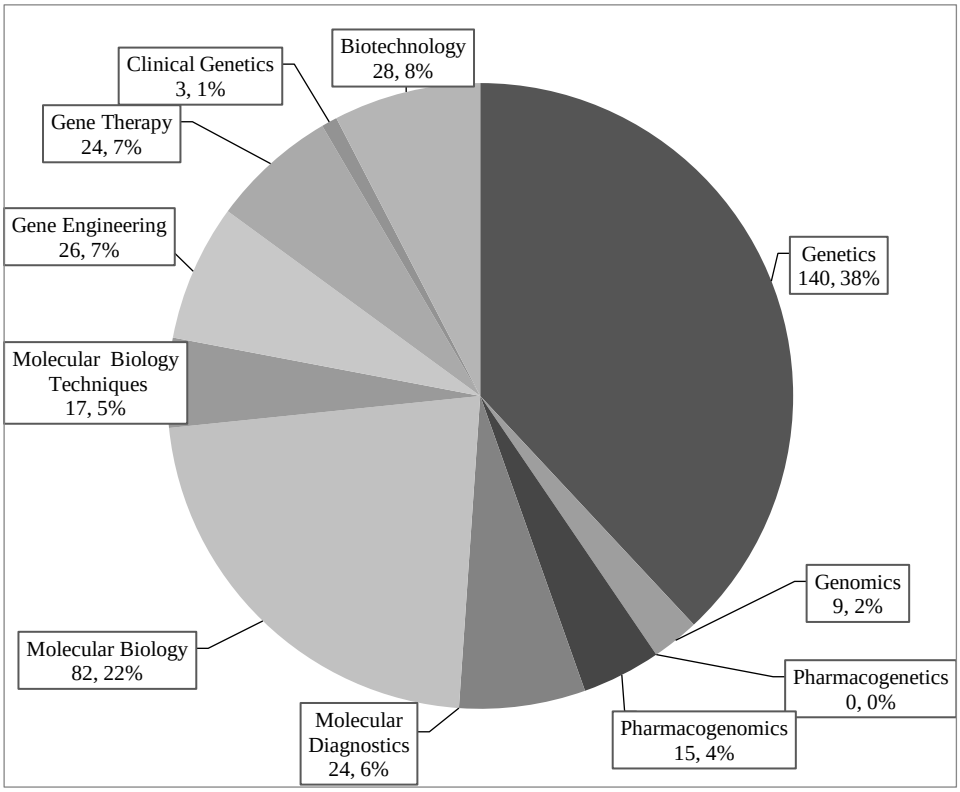


Figure 2: Total number of credits per course category (Total credits=368)

PGx was taught in the curriculum of 7 universities: United Arab Emirates University, Fatima College of Health Sciences, Al-Ain University, City University College of Ajman, Gulf Medical University, University of Sharjah, and Dubai Pharmacy College for Girls. However, it was mostly for Pharmacy majors. Only 3 out of the 7 PGx courses were stand-alone. When searching for "genomics", 5 universities yielded results. None of the genomics courses were stand-alone. When the keyword "pharmacogenetics" was searched in all universities' curricula, no results were found. Figure 3 displays the results per university, degree, and course level when "pharmacogenomics" and "genomics" was searched in the curricula.

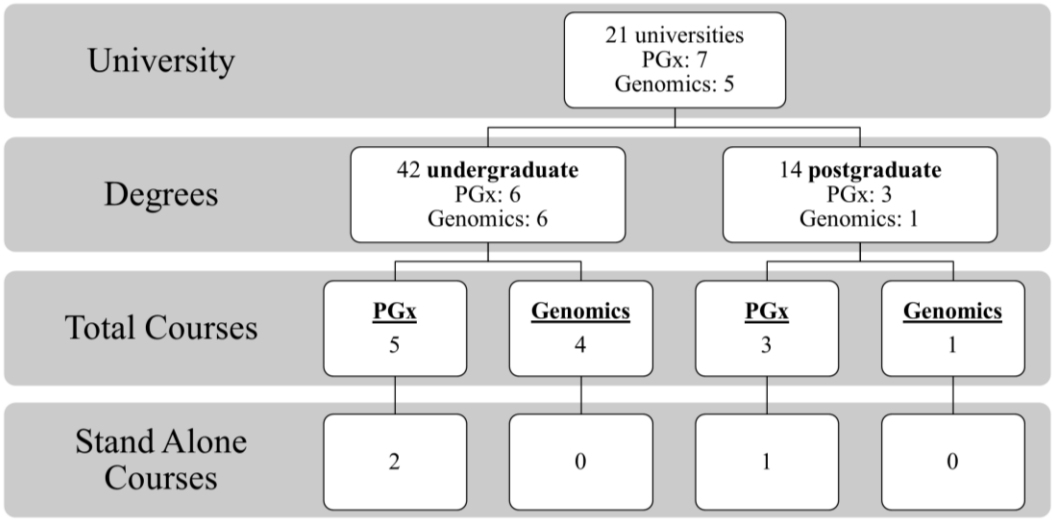


Figure 3: "PGx" and "genomics" search results

3.1.2 Findings of the Semi-Structured Interviews

The pinpointed main themes coded inductively from the iterative analysis of the semi-structured interviews with the teaching faculties in UAE, and the commissioners and higher education experts at the commission for academic accreditation at the Ministry of Education are:

- Recognizing the importance of genomic medicine and PGx to prepare the future healthcare providers to the personalized medicine era.

Interviewee 2: *"I graduated from the xxx medical school, so all what we had then was basic molecular biology, so I went abroad to study, but when I came back to teach here, I found there are courses about Genomic medicine and probably there is a lecture or two about pharmacogenomics."*

Interviewee 3: *"I've visited college of pharmacy just last week and they have a new curriculum, and, in the curriculum, there was a pharmacogenetics course and they*

told us that they added this based on international reviews, I think the international norms that there should be a pharmacogenetics course in pharmacy curriculum. "

Interviewee 4: *"My personal experience of accreditation of medicine and pharmacy programs is that if pharmacogenomics is insufficient in these programs, external review teams normally do require that curricular content be added. This can be either as separate courses but often better integrated into other courses."*

- Calling for translational and implementational research along with recruiting experts in the field.

Interviewee 1: *"I think the main barrier is ignorance, I would say ignorance on many levels, you know from healthcare workers who don't know much about genomic medicine, misconception in the community sometimes. Obviously, the decision makers again they don't have the full picture also studies or solid studies to implement genomic medicine into healthcare systems more effectively."*

Interviewee 4: *"I agree that many pharmacy colleges in the UAE do not have faculty with much expertise in pharmacogenomics. This can be addressed through faculty development and through use of visiting lecturers who do have the relevant expertise."*

3.1.3 Academia Survey Assessment

Respondents affiliated with the college of medicine constituted 70% of the sample, and 13.8% from pharmacy or pharmacology. Respondents were 51.2% male with all ages ranging between 28 and 70 with a mean age of 44. When asked on the current state of PGx teaching in most universities and schools in UAE, 36.2% of the sample considered it to be poor and 39.1% indicated that they do not know.

According to the survey, only 34.3% of participants indicated that PGx coursework was being taught within their curriculum. Respondents pointed out that 39.1% PGx coursework was taught at a master's level in their institution. Only 26.1% stated it was a stand-alone required didactic course. Majority of respondents (81%) estimated 1-2 credit hours are dedicated to PGx in their curriculum (Table 1).

Table 1: PGx/pharmacogenetics coursework information in universities

	Count (N)	**Percentage (%)**
Is PGx/ Pharmacogenetics coursework being taught within your curriculum? *(N=70)*		
Yes	24	34.3
No	26	37.1
I do not know	20	28.6
Where does the PGx/ pharmacogenetics coursework reside in the curriculum? *(N=23)*		
Stand-alone required didactic course in the area	6	26.1
Included as part of other required didactic course(s)	13	56.5
Elective didactic coursework (stand-alone or mixed)	3	13.0
Other	1	4.3
If you have a stand-alone PGx/ pharmacogenetics course, are there specific prerequisite courses that are required? *(N=21)*		
Yes	7	33.3
Maybe	9	42.9
No	5	23.8
I do not know	0	0.0
Please estimate the number of required credit hours dedicated to PGx/pharmacogenetics in the curriculum. *(N=21)*		
1-2 credit hours	17	81.0
3-4 credit hours	4	19.0
>5 credit hours	0	0.0
I do not know	0	0.0
At what academic level(s) is/are PGx/ pharmacogenetics coursework being taught? *(N=23)*		
PharmD	3	13.0
Master in Clinical Pharmacy	0	0.0
Master	9	39.1
Bachelor of Pharmacy	4	17.4
Other	7	30.4

The top 3 topic areas currently covered in respondents' PGx education is shown in Table 2.

Table 2: Topics covered in respondents' PGx curricula (N=23)

Topic areas currently covered as part of your PGX/Pharmacogenetics education	**Percent of Cases (%)**
The contribution of genetic variability to inter-individual variations in drug response	78.3
Basic genetic concepts and terminology	73.9
The drugs/drug classes/clinical situations where pharmacogenetic testing is likely to be most useful clinically	65.2
The influence (or lack thereof) of ethnicity in genetic polymorphisms and associations of polymorphisms with drug response	65.2
How identification of disease-associated genetic variations facilitates development of prevention, diagnosis, and treatment options	60.9
The ethical, legal and social issues related to pharmacogenetic/ genetic testing and recording of genetic information (e.g., privacy, the potential for genetic discrimination in health insurance and employment)	52.2
The importance of family history in assessing predisposition to disease	47.8
Specific methods of genotyping and phenotyping	39.1
Use of information technology to obtain credible, current information about pharmacogenetics	34.8
Important issues in pharmacogenetic study design, particularly those that differ from non-genetic clinical studies	30.4
The potential physical and/or psychosocial benefits, limitations, and risks of genetic information for individuals, family members, and communities	30.4
Pharmacogenetic testing is like all other clinical testing in that it will not have 100 percent reliability, but rather is used along with other clinical information	21.7
The resources available to assist clients seeking genetic information or services, including the types of genetics professionals available and their diverse responsibilities	17.4
Regulatory issues that may result from pharmacogenetics being incorporated into Phase II and III testing	8.7

Majority of respondents exhibited positive attitudes towards the availability and accessibility of genetic testing with 89% agreeing that the government should invest more money into its development. However, 74% agreed that the availability of genetic tests could be problematic for insurance companies and future employers. Figure 4 displays the results of the questions on genetic testing.

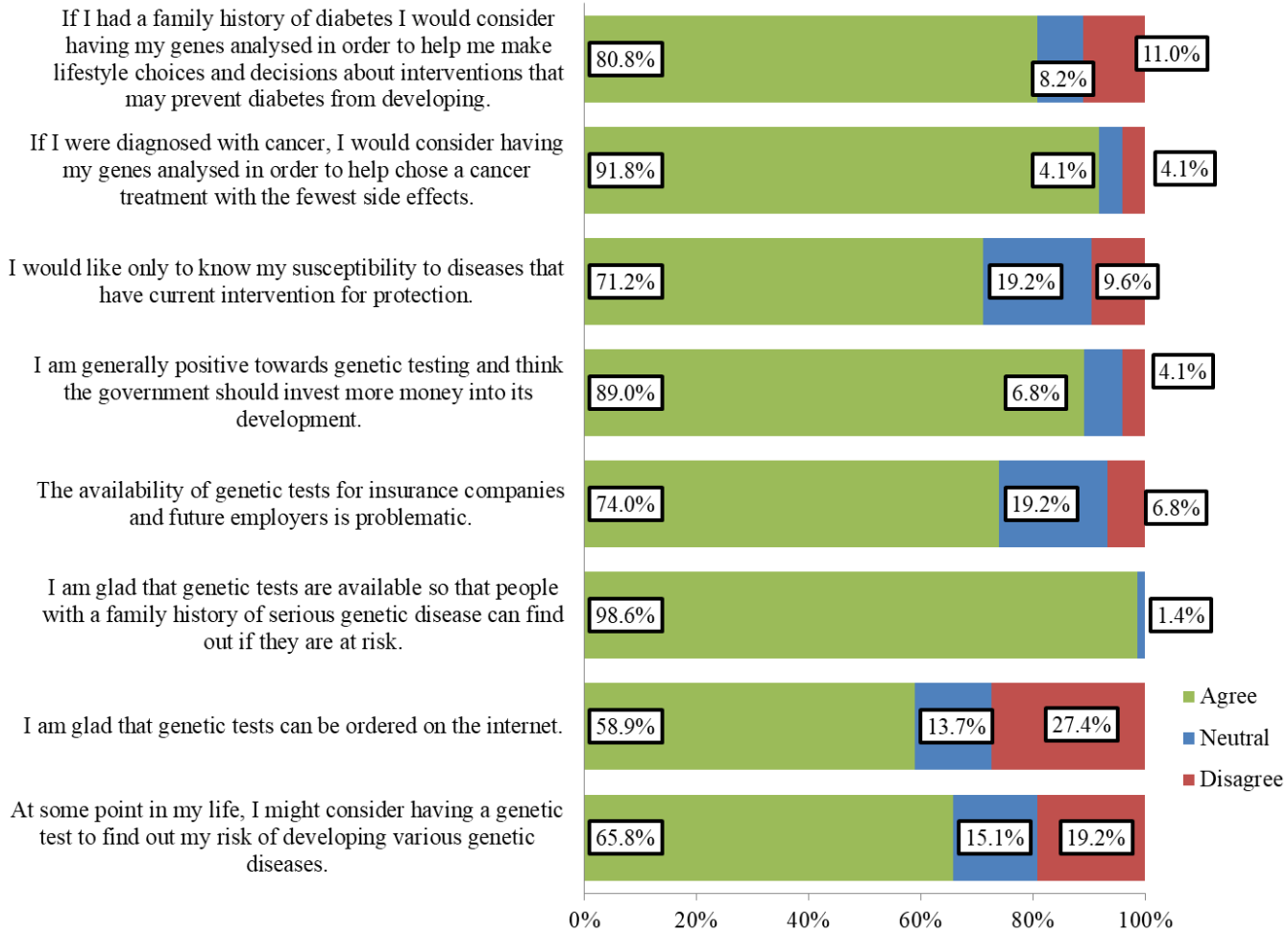


Figure 4: Views on genetic testing (N=73)

Respondents had a positive outlook on the future of personalized medicine and PGx (91.8%) with 82.2% agreeing that more study course time should be devoted to the teaching of PGx. However, 69.9% believed insurance companies and employers could exploit PGx. Confidentiality did not seem to be a top concern with only 35.6% not willing to get their genome analyzed due to confidentiality issues. When asked if they would prefer a physician or pharmacist to explain their genome report, 83.6% preferred a physician. Respondents' views on the concerns and outlook on the future is shown in Figure 5.

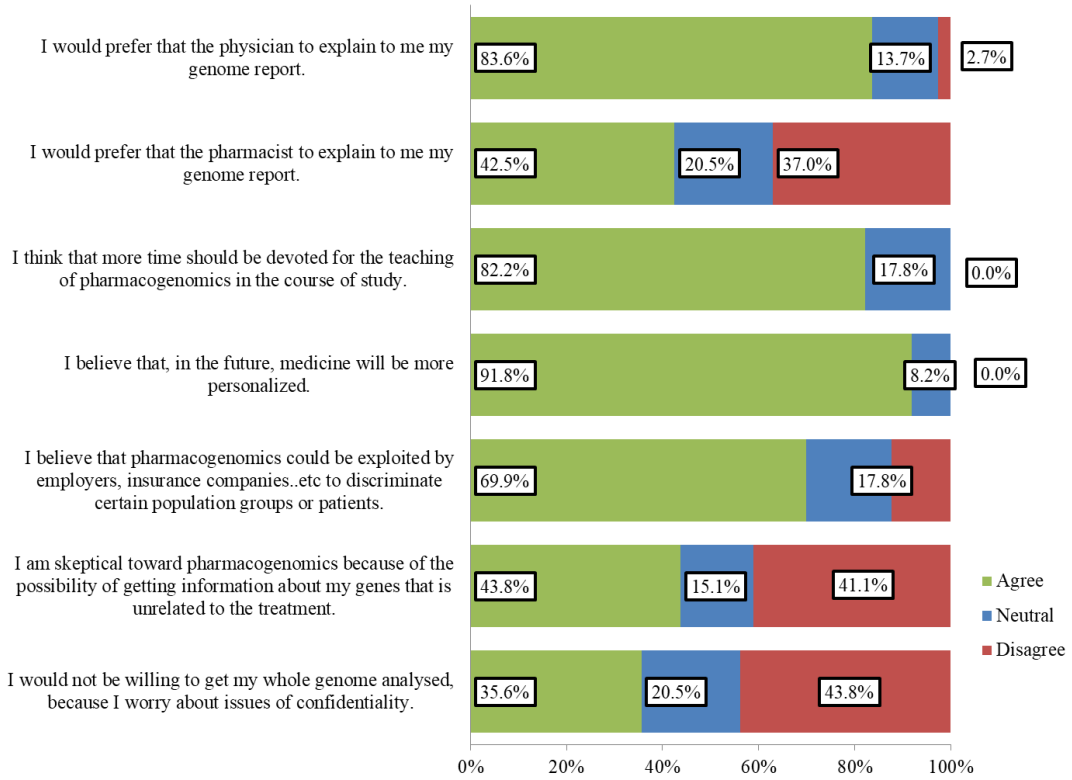


Figure 5: Outlook of academia on the future of PGx in UAE (N=73)

Respondents exhibited positive attitudes when questioned on their desire to participate in genetic research with 76.7% agreeing to participate and 74% interested in attending a PGx course and/or educational seminar. Moreover, 63% agreed to donate genetic materials for a bio-bank.

Respondents identified the top 3 barriers for PGx implementation to be lack of training or education (67.6%), lack of clinical guidelines on PGx/pharmacogenetics practice (64.8%), and lack of testing services and shortage of personnel (52.1% each). When asked on their preferred method to learning PGx, 56.3% chose workshops or seminars.

3.2 Assessing the Knowledge and Attitude of Healthcare Providers in UAE

Results presented here are for both quantitative and qualitative methods.

3.2.1 Quantitative

Table 3 presents the respondents' demographic characteristics. Out of 552 respondents, 63.4% were females. The mean age (± SD) was 38 (± 9.6) years old, and 67.7% of the respondents were aged between 20 to 41 years old, and 26.9% between 20 to 30 years old. Most respondents had a pharmacy related occupation (42%) followed by 52% belonging to either medicine or nursing occupations. More than half (52.2%) had over 10 years of experience.

Table 3: Demographic characteristics of healthcare providers in UAE (N=552)

Gender	**Count (Percentage %)**
Female	350 (63.4)
Male	202 (36.6)
Age Group	
20-30	148 (26.9)
31-41	225 (40.8)
42-52	124 (22.5)
53-63	53 (9.6)
64-74	1 (0.2)
Occupation	
Pharmacy Related	232 (42)
Nurse	153 (27.7)
Medicine	134 (24.3)
Business & Management	14 (2.5)
Administration	5 (0.9)
Allied Health	5 (0.9)
Governmental	5 (0.9)
Intern	2 (0.4)
Years of Experience	
>10 years	265 (52.2)
<10 years	149 (29.3)
Nationality	
Middle East	226 (40.9)
Asia	179 (32.4)
United Arab Emirates (UAE)	68 (12.3)
Africa	34 (6.2)
North America	14 (2.5)
UK	11 (2.0)
Gulf Cooperation Council (GCC) countries	8 (1.4)
Europe	4 (0.7)
Australia	1 (0.2)

3.2.1.1 Assessment of General Knowledge on Genetics and PGx

The mean knowledge score (SD) of the respondents was 5.2 (± 2.3) out of nine, which shows a fair level of knowledge according to the scale. The mean knowledge score for respondents of pharmacy related occupations was 5.1 (± 2.5), medicine 6.0 (± 2.0) and nursing 4.8 (± 2.1). Respondents working in business and/or management positions and allied health professionals both had scores of 5.6 (± 2.2 and ± 1.1, respectively). Only 2 respondents out of 552 (0.4%) scored nine out of nine.

For the second question, regarding nucleotide pairing, the percentage of respondents that answered correctly was only 1.7% higher than those who answered, “do not

know". A high percentage of 89.3% recognized correctly that genetic variances affect drug response. Table 4 summarizes the results of the general knowledge questions on genetics and PGx.

Table 4: Results of PGx knowledge questions of healthcare providers (N=552)

Choose the correct answer:	**Correct answer**	**True *n* (%)**	**False *n* (%)**	**Do not know *n* (%)**
1. Humans have 48 chromosomes.	False	196 (38.8)	281 (55.6)	28 (5.5)
2. Adenine (A) only pairs with cytosine (C) and Thymine (T) only pairs with Guanine (G).	False	148 (29.3)	183 (36.2)	174 (34.5)
3. Pharmacogenomics seeks to individualize therapy based on patient's genetic profile.	True	407 (80.6)	32 (6.3)	66 (13.1)
4. Genetic changes can cause adverse reactions.	True	395 (78.2)	45 (8.9)	65 (12.9)
5. Pharmacogenomics testing is recommended by FDA for certain drugs.	True	335 (66.3)	16 (3.2)	154 (30.5)
6. Genetic changes can affect the patient's response to certain drug.	True	451 (89.3)	16 (3.2)	38 (7.5)
7. Genes can be activated or deactivated by other genes.	True	379 (75.0)	38 (7.5)	88 (17.4)
8. Every cell of the body contains the whole genome.	False	338 (66.9)	67 (13.3)	100 (19.8)
9. Environmental factors, such as cigarette smoke, can affect gene activity.	True	379 (75.0)	52 (10.3)	74 (14.7)

Table 5 summarizes the distribution of the levels of knowledge between different characteristics of the healthcare workers. The knowledge levels were significantly different between men and women (p=0.01). Moreover, significant differences in knowledge levels were found between occupation groups (p=0.00), completion status of a PGx training or education (p=0.01) and having a patient who asked about taking a genetic test in the last two years (p=0.02).

Table 5: Comparison of the level of knowledge between different groups

	Level of Knowledge			
	Good n (%)	**Fair n (%)**	**Poor n (%)**	***p*-value**
Gender				0.01*
Female	95 (27.1)	196 (56.0)	59 (16.9)	
Male	74 (36.6)	87 (43.1)	41 (20.3)	
Age Group				0.12**
20–30	46 (31.1)	73 (49.3)	29 (19.6)	
31–41	63 (28.0)	119 (52.9)	43 (19.1)	
42–52	34 (27.4)	71 (57.3)	19 (15.3)	
53–63	25 (47.2)	19 (35.8)	9 (17.0)	
64–74	1 (100)	0 (0.0)	0 (0.0)	
Years of Experience				0.88
<10	72 (30.0)	126 (52.5)	42 (17.5)	
>10	97 (31.1)	157 (50.3)	58 (18.6)	
Occupation Category				0.00 **
Administration	0 (0.0)	3 (60.0)	2 (40.0)	
Pharmacy Related	69 (29.7)	117 (50.4)	46 (19.8)	
Allied Health	1 (20.0)	4 (80.0)	0 (0.0)	
Nurse	31 (20.3)	88 (57.5)	34 (22.2)	
Governmental	0 (0.0)	3 (60.0)	2 (40.0)	
Business & Management	5 (35.7)	7 (50.0)	2 (14.3)	
Medicine	61 (45.5)	59 (44.0)	14 (10.4)	
Intern	1 (50.0)	1 (50.0)	0 (0.0)	
Previous Exposure to Genetic Issues				0.30
Yes	54 (35.3)	75 (49.0)	24 (15.7)	
No	115 (28.8)	208 (52.1)	76 (19.0)	
Completed PGx/ Pharmacogenetics Training or Education				0.01 *
Yes	51 (41.5)	55 (44.7)	17 (13.8)	
No	118 (27.5)	228 (53.1)	83 (19.3)	
Have you ever advised any of your patients to undertake a genetic test?				0.31
Yes	57 (38.0)	83 (55.3)	10 (6.7)	
No	71 (34.6)	112 (54.6)	22 (10.7)	
Have you had any patients who asked about undertaking a genetic test in the last two years?				0.02 *
Yes	59 (45.7)	62 (48.1)	8 (6.2)	
No	74 (31.6)	132 (56.4)	28 (12.0)	
Have you had any patients who asked your advice about the results of a genetic test in the last two years?				0.28
Yes	50 (41.7)	57 (47.5)	13 (10.8)	
No	85 (34.1)	140 (56.2)	24 (9.6)	

*significant value from Chi-square test ** significant value from Monte Carlo exact test

3.2.1.2 Attitudes towards the genetic testing and the applications of PGx

Researcher found that 74% of respondents would consider having a genetic test themselves performed at some point in their lives (Figure 6). The vast majority of respondents (91.9%) exhibited a positive attitude regarding availability of genetic testing. More than half (57.6%) reflected a positive response towards the accessibility of genetic tests.

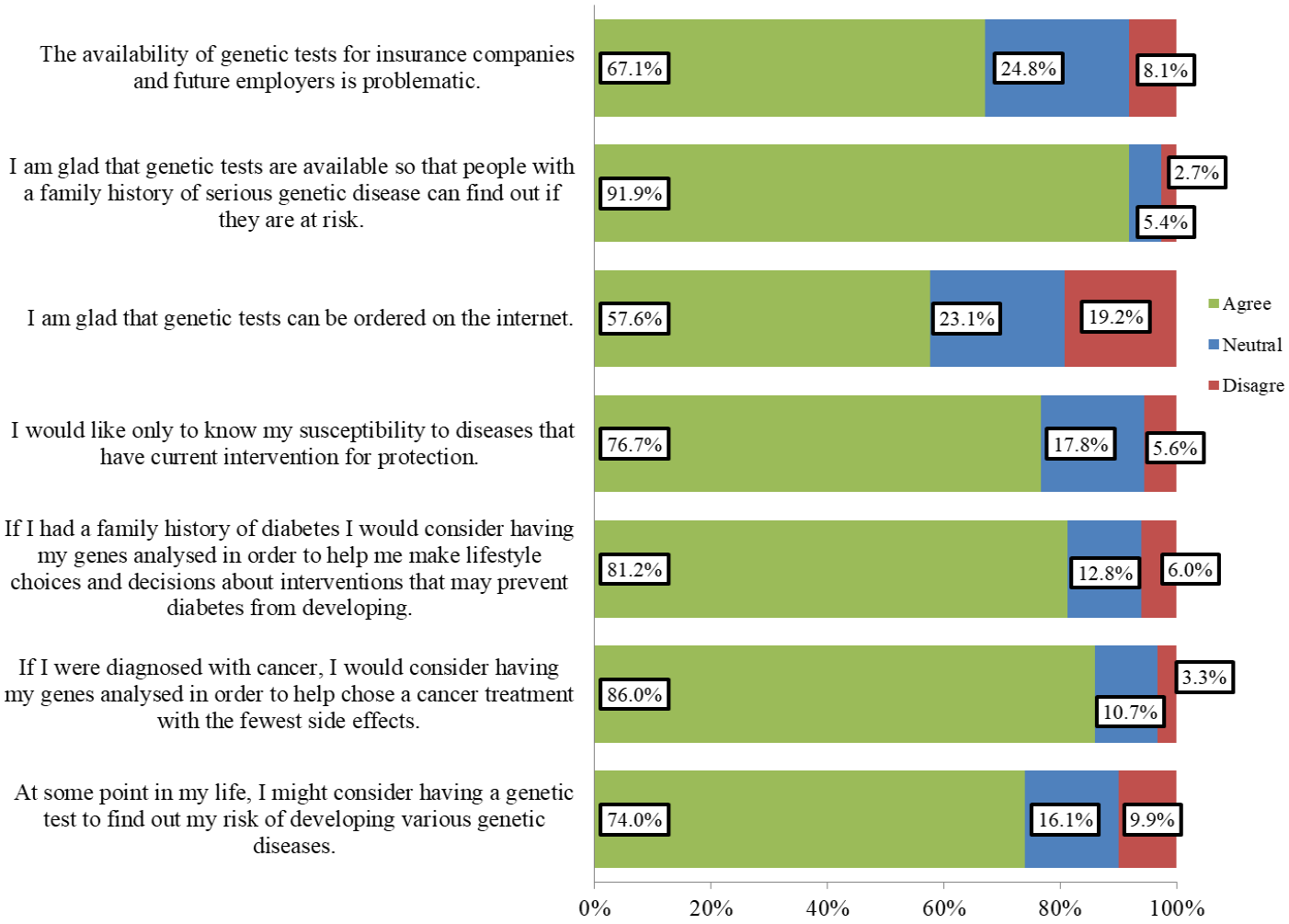


Figure 6: Attitudes of healthcare providers on genetic testing (N=388)

3.2.1.3 Concerns and Ethics

A common concern expressed by 74.4% of the recruited healthcare workers was that genetic test results would affect the quality of the patient's medical care. Among the sample, 71.5% believed that PGx could be exploited and used as means of discrimination (Figure 7).

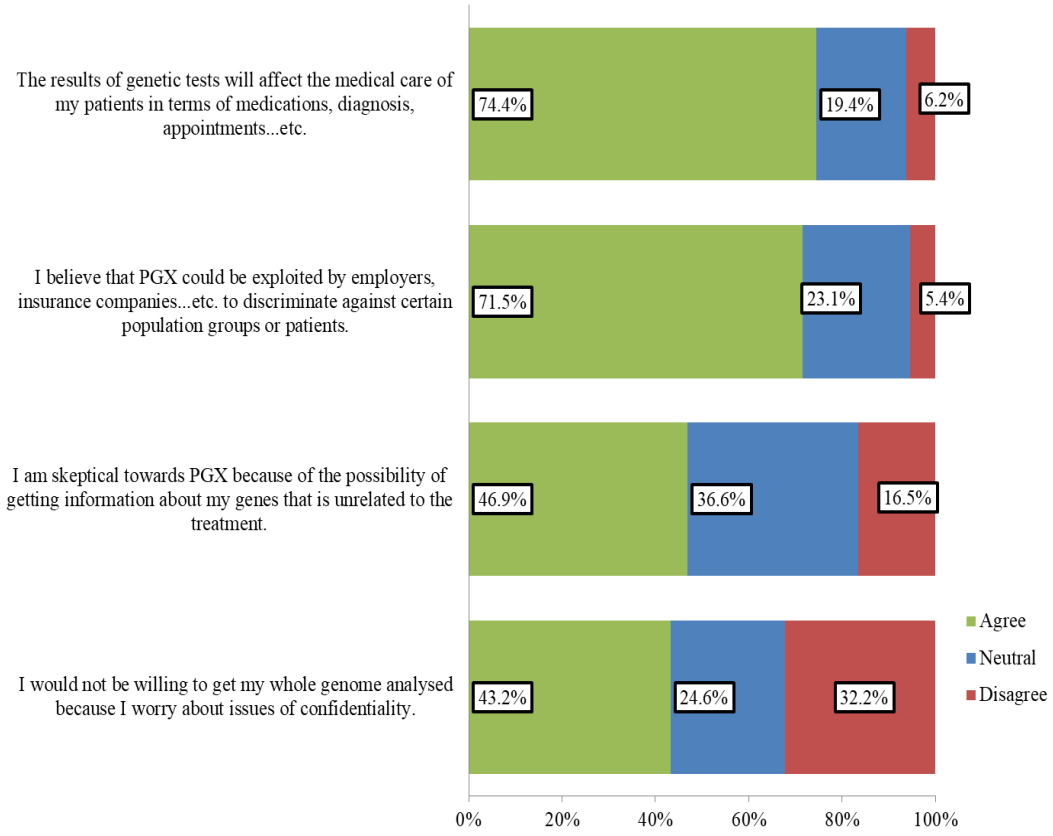


Figure 7: Concerns of healthcare providers on genetic testing (N=388)

3.2.1.4 Desire to Participate in Genetic Research

Statements questioning interest in genetic testing and PGx research was met with more overall positive responses, where 68.2% of respondents expressed a desire to participate in genetic research. Of the respondents, 83.7% indicated they would be

interested in attending a course or educational seminar on PGx, and 43.4% would like to donate genetic material to a biobank.

3.2.1.5 Current and Future Outlook on Genomics and PGx

On the subject of legal frameworks, only 47.7% agreed that policies and procedures exist in the field of genetic tests in the UAE, with 44% taking a neutral stance. When questioned on the future of medicine, 87.4% of respondents believed medicine will become more personalized, and 85.3% agreed in thinking the government should invest more money in genetic testing development. Moreover, 87.2% think more time should be allocated to teaching PGx during studies. The majority of respondents (83.9%) agreed that the expenses of genetic tests should be covered by insurance companies.

3.2.1.6 Barriers to Implementation

Out of 474 respondents who answered the question on barriers to implementation, of PGx testing in the UAE, 62% identified the cost of testing being a major barrier. Lack of training or education and insurance coverage followed as the second and third largest barriers (57.8% and 57.2% respectively). Only 6.3% thought there was no clinical need for PGx testing.

3.2.1.7 Type of Preferred Education

Out of 472 respondents, a majority (73.9%) chose workshops or seminars as their preferred learning method on PGx. Blended and internet-based learning received a similar reception to each other (30.9% and 27.3% respectively).

3.2.1.8 Assessment of Personal Knowledge and Attitudes

When questioned on their own personal experience with genetic testing and PGx, 39.9% stated that PGx was involved in their current work and 33.5% stating it was not. Less than half (41.7%), agreed when asked on whether they would be able to explain without external elaboration, the results of genetic tests to their patients. Only 38.4% believed their undergraduate studies provided them with sufficient knowledge on genetics and PGx. Only 31% of respondents reported advising at least one of their patients to undertake a genetic test, as opposed to 43.2% of respondents reporting they have not previously advised it. The majority (64.5%) reported that patients have not asked about taking a genetic test in the last two years. Only 32.5% stated that patients asked for their advice on genetic test results in the last two years. When asked on whom they thought should provide counseling on genetic and pharmacogenetics testing and results, 51.5% selected genetic counselor and 35.9% selected physician. Only 9.3% believed a pharmacist should assume this role.

3.2.2 Qualitative

Participants' demographics are presented in Table 6. More than half of the participants were expatriates, females and above 30 years old. The sample included pharmacists working in the inpatient setting and the outpatient setting as well as clinical pharmacists and pharmacy residents. Some participants have postgraduate qualifications, and some have experience working outside the UAE, with most of them having more than 11 years of experience. The vast majority of the participants stated that they did not receive formal education about genomics and pharmacogenomics at a higher education level.

Table 6: Demographics of pharmacists participated in FGD (N=38)

	No. of pharmacists participated = 38
Age :	
<30 years old	10
>31 years	28
Gender:	
Male	14
Female	24
Total years of experiences:	
<4 years	6
5- 10 years	4
> 11years	28
Studied Pharmacogenomics in college:	
Yes	9
No	29
Current position:	
Pharmacist (outpatient)	7
Pharmacist (inpatient)	15
Clinical Pharmacist	6
Pharmacy supervisor	5
Resident	4
Community pharmacist	1
Type of facility:	
Tertiary care Hospital	34
Secondary care Hospital	0
Health clinic	3
Other	1
Facility operated by:	
Government.	35
Non-Government	3
Nationality:	
Locals (UAE citizen)	7
Non-locals	31

Table 6: Demographics of pharmacists participated in FGD (N=38) (continued)

	No. of pharmacists participated = 38
Qualification:*	
BSc	18
Master	9
Pharm.D	8
Board Certified	12
Practiced outside UAE:	
Yes	23
No	15
Number of declined participation	43

*Sum exceeds 100% as participants can pick more than one choice.

Themes extracted were based on the interview guide, which explored knowledge, attitude and current practice, future direction and needs in the area of genomics and pharmacogenomics. However, many themes have emerged from the focus group sessions that have been classified as emerging themes. Below is the presentation of the main themes in different sections (knowledge, attitude, practice, and future directions). Followed by a presentation of the emerging themes: pharmacists' role and power, skills, trust and blame as well as cultural and religious beliefs.

3.2.2.1 Main Themes

Knowledge:

The knowledge of pharmacists about genomic medicine and pharmacogenomics in particular had been identified as a main theme. Moreover, sub-themes extracted included knowledge about the practice and services of genomics and pharmacogenomics, as well as sources of information and coverage of the costs of testing as seen in Figure 8.

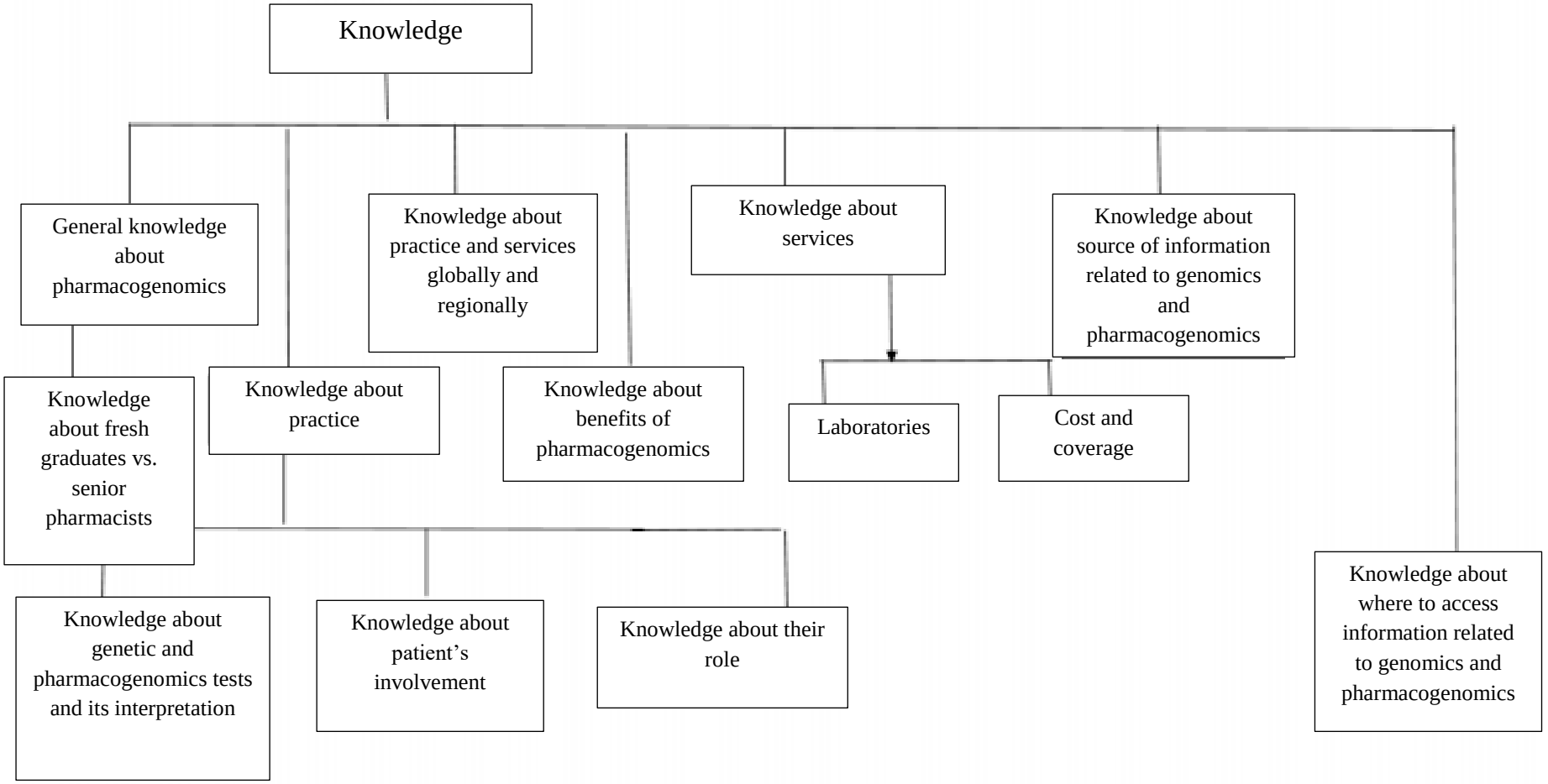


Figure 8: Main themes of the PGx knowledge of pharmacists in FGD

Knowledge about the Science of Genomics and Pharmacogenomics, Practice, and Services:

During the focus group discussion, participants were asked to rank their knowledge about pharmacogenomics on a scale from 0 to 5 (0 is poor knowledge and 5 is excellent knowledge) (Figure 9). More than third of the pharmacists rated their knowledge of genomics and pharmacogenomics as poor; one pharmacist said: "*Actually, we didn't hear about genomics and pharmacogenomics before this invitation*" FG2M9.

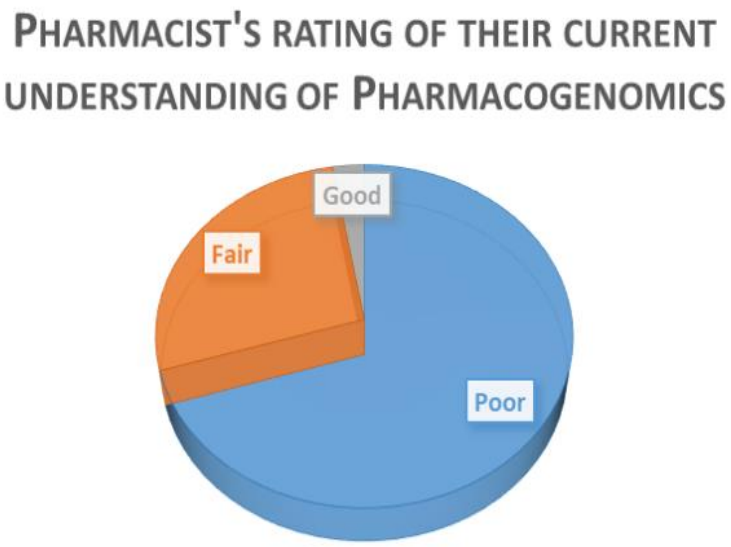


Figure 9: The rating of the perceived pharmacists' PGx knowledge

Most of the participants indicated that they are not sure where genetic testing is conducted in the UAE. Moreover, most of them had no knowledge about where to locate tests results in patients' electronic records. In addition, they felt there is poor dissemination of information from stakeholders to consumers and healthcare providers. "*They [stakeholders] are not sharing it with staff so we do not know*" FG4M12.

When asked if they are aware of the application of genomic medicine or pharmacogenomics in their hospitals, they were unsure; one pharmacist pointed out

that his hospital is conducting a test for Glucose-6-Phosphate Dehydrogenase (G6PD) deficiency but was not sure if this is a pharmacogenetic test.

Knowledge about Sources of Information Related to Genomics and Pharmacogenomics:

Most of the senior pharmacists in the sample did not receive formal education related to genomics and pharmacogenomics at universities and the few (nine pharmacists) who studied pharmacogenomics before classified their knowledge as being poor.

"we took a course on pharmacogenomics but did not benefit even professor was lost" FG1F4.

Even some fresh graduates from a semi-governmental university in the UAE stated that they did not receive formal education about genomics or pharmacogenomics at all during their pharmacy bachelors' years. As for the most frequently utilized sources of information regarding genomics and pharmacogenomics among the participants, Google search and YouTube videos were the most utilized sources. However, it was noted that all clinical pharmacists in the focus group discussion indicated that databases and trusted organizations (outside the UAE) are their sources of information, believing that there is a gap in the available resources by the UAE health authorities. A couple of participants indicated that the sources of their information are enough to give them the needed knowledge.

"I watched a video on YouTube last night about pharmacogenomics, so I know what I am talking about . . ." FG2M9.

Pharmacists agreed that they lack competency in interpreting genomics and pharmacogenomics test reports, and they were not aware that the drug leaflets contain sections related to pharmacogenomics.

"if you did not invite me to this focus group, I wouldn't know this piece of information or any other knowledge discussed. So, I think there is no awareness" FG1M4.

Knowledge about Cost and Coverage of Genetic Tests:

Outpatient pharmacists in the focus group discussion were more aware about the cost and coverage of genetic testing. An example used by participants is the case of patients with cystic fibrosis and how the insurance companies are mandating and covering the genetic tests before the initiation of the therapy. Another example is anticoagulant coverage by health insurance.

"We know many cases where patient get stents and the inpatient cost is covered by insurance, but when discharged and they have to pay they refuse to take their anticoagulant medications (Plavix) and they are readmitted again with thrombosis" FG4M13.

Attitudes:

The second major theme underscored is the attitude of pharmacists toward genomics and pharmacogenomics. Researcher identified the following sub-themes: benefits of pharmacogenomics, disclosure of genetic testing and biobanking, and the implementation of pharmacogenomics within services (Figure 10).

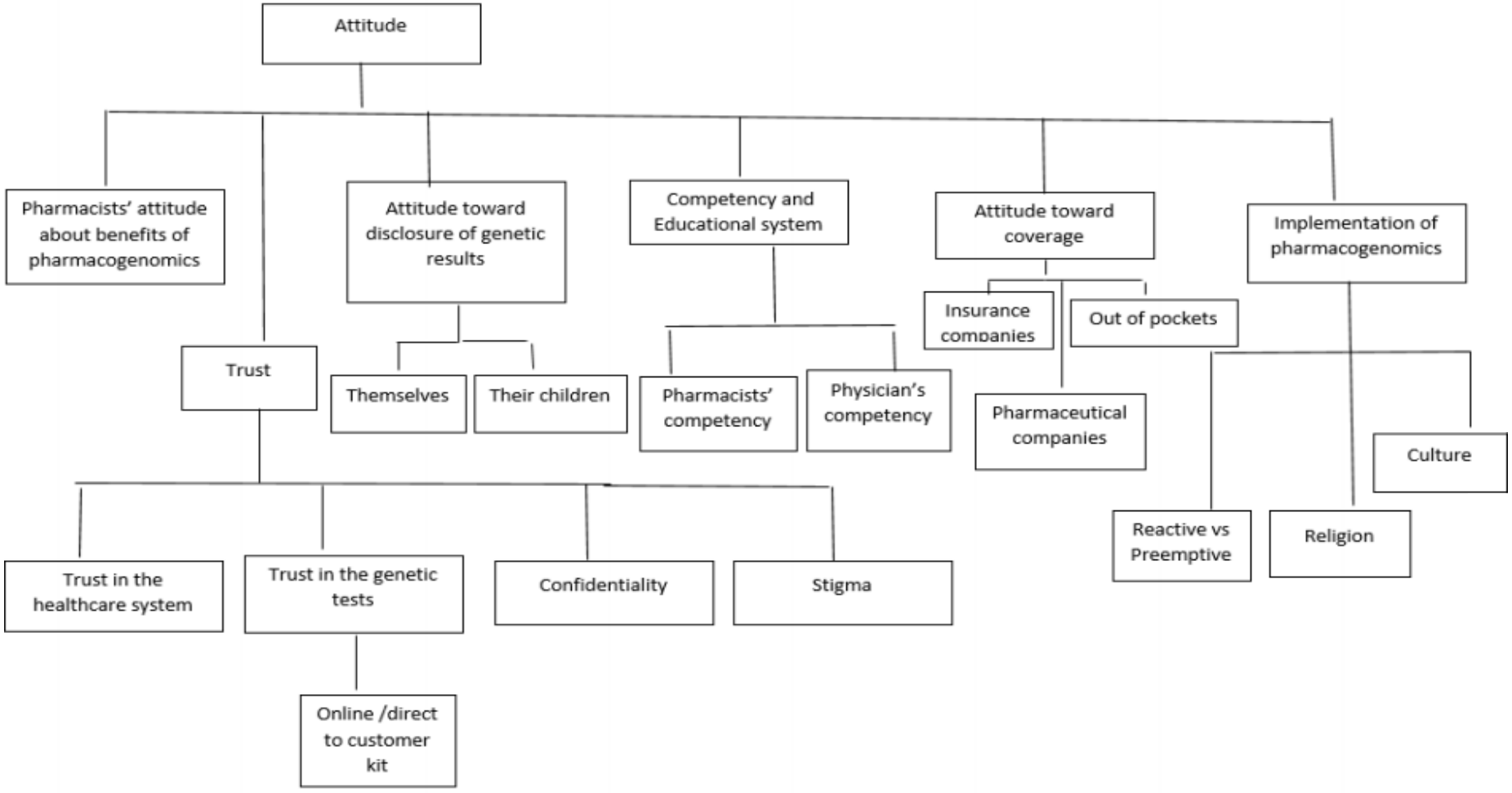


Figure 10: Themes and subthemes on the attitudes of pharmacists in FGD

Pharmacists' attitude about benefits of genomics and PGx:

Most participants showed an overall positive attitude toward PGx, despite their lack of knowledge in the sciences of PGx and genomics. Nevertheless, some of them consider pharmacogenomics as a science fiction and an area that lacks solid evidence.

"A lot of things was pending investigations, everything was not clear, as I just said earlier it is uncharted territory, so a lot of new thing was introduced and nothing basic, so I think it is a good branch and I am enthusiastic about it but still it is a new branch, so no one had

solid things to give it to you, it was like watching something that will happen in the future" FG2F8.

However, some had negative attitude toward the importance of learning and the use of pharmacogenomics:

"What is the point of learning something that will be implemented 20 years later" FG1M5.

"Why to waste money in something that will not benefit me" FG4M14.

"*What is the point of knowing about it if we are not going to practice it. In UAE, there is no market for genetics"* FG1M2.

Pharmacists' attitude toward disclosure of genetic test results and biobank:

Pharmacists had a mixed attitude toward knowing the results of their whole genome sequencing; some wanted to know so they can lead a healthy lifestyle and keep an eye on research, looking for interventions. The others did not want to know out of fear and religious belief as well as its impact on their social and family life "*Leave it to God"* FG2M9.

"take the example of Angelina Jolie she was doing so fine before the test then after that she lost weight and get divorced, so doing the test was bad for her!" FG3F13.

However, when it was related to their children, there was a consensus on the desire to know how to protect their children.

"From my personal experience with vision problem and my mother have cancer disease I want to protect my children from the disease I have, or my mother have it. I see how my mother suffer with cancer and whatever it takes not to go through that suffering will drive you to protect yourself or your children." FG1M2.

When their attitude toward participating in biobanking had been explored, there were mixed attitudes, with some being supportive of the idea as they believed it is vital to research and consolidate community health, while others did not show any support for it. For example, one expatriate pointed out that biobank should be directed only toward UAE nationals, rather than expatriates since the expatriates may leave at any time, affecting the follow up and research logistics.

Pharmacists' attitude toward the implementation mechanism of genomic medicine and PGx:

Pharmacists did not agree on the proper and ideal mechanism of implementing genomic medicine and pharmacogenomics in the UAE. Some pharmacists advocated a preemptive pharmacogenetic testing approach, which seeks proactive testing and obtaining the results of the genetic test at the time of prescribing, and their arguments were: *"Test will be cost effective, because you will do it once, for example most of the drugs are metabolized by the Cytochrome P450 (CYP450) enzyme. So, by doing this test alone we will be able to identify poor or rapid metabolizers which will protect them from the harm of certain medications. Let us say the test will cost 200 $ once per*

life and it will stay in the chart of the patients for long time, and this is for value for expensive medications." FG4M13.

On the other hand, other participants were advocates of the reactive pharmacogenetic testing approach, in which specific drug–gene tests will be requested at the time of dispensing:

"when the guidelines for hypertension was to use diuretics first, beta blockers second etc the old guidelines, they said for Africans you should go for calcium channel blockers. That was good, but do I need to do genome test that will cost me thousand dollars to know? I do not think so. simply you can use the diuretics for couple of days if it is not working then I will put beta blocker, if I have enough numbers of patient that will prove the theory that this medication is not effective in this ethnicity at that point I will go for genetic test, but I will not go before that." FG4M12.

3.2.2.2 Emerging Themes

Power:

One emerging theme identified by this study was the lack of power and feeling of powerlessness of pharmacists in making decisions related to pharmacogenomics.

"Even the stakeholders will not focus on pharmacists, their main focus is physicians. Pharmacists are always out of the picture in any decision" FG1M2.

Moreover, they linked that attitude to stakeholders' influence, no clear guidelines about genomics and pharmacogenetics and their roles in the implementation.

"we can't do it on our own, we cannot make decisions" FG3F14. Only clinical pharmacists working in oncology services could envision their role, but they disclosed that the knowledge gap hinders this role and that they do not have the power.

Trust and responsibility:

Another emerging theme is the fear of losing their patients' trust. Participants stated that since they do not have the knowledge of genomics and pharmacogenomics, they worry that they may lose the trust and rapport that they have with their patients.

"To be honest for us currently as a healthcare provider who don't know much about genomics and pharmacogenomics, so how we will initiate the talk with the patient" FG3M11.

They also exhibited concerns about trusting the system in terms of confidentiality and they worried that they may lose their jobs based on their genetic test results.

"I will never do the genetic test, if they find out that I have certain disease they may fire me from my job, I will never do it even if they said there is confidentiality, there is no law, and I will not take the risk" FG4M12.

Pharmacists declared that they do own patient counselling because they have the skills, as well as being trained in their workplace about how to conduct counselling. Nevertheless, they questioned their competency to do counselling about pharmacogenomics to the patients when they do not have the knowledge of pharmacogenomics. They worried that they may lose the trust and rapport that they have with their patients.

Fatalism and stigma:

Pharmacists believed that it is all in God's hand and nothing they can do will change destiny. Some have revealed doubts that religion might constitute a barrier for the implementation of genomic medicine in the UAE.

"who are we to interfere in destiny" FG2F8.

Pharmacists assumed that culture had a powerful impact on the adoption of genomic medicine more than religion.

"culture is one of the biggest challenges and barriers and should be factored in while drafting laws and policies" FG2M6.

Nevertheless, they perceived culture as dynamic and they supported that by comparing the era of genomic medicine to the era of organ transplant and in vitro fertilization and how the community were opposers and now they are adopters. The fear of stigma was not exclusive to the UAE; even pharmacists from other nationalities fear the labeling and stigmatizing of their families with certain genetic diseases. One pharmacist stated: *"… …they change the law in Palestine, so the couples will not do the premarital test at the same time, we will start with the man and based on the results of his test they will decide if to do the test for the lady . . . . . see they change the law for the effect of the culture and the fear of stigma"* FG3F22.

The findings of the FGD lead to the conceptualizing of a personalized literacy framework for the adoption of pharmacogenomics by pharmacists in UAE with possible regional and global relevance. The researcher named the framework as Pharmacogenomics Genomics Literacy for Pharmacists (PGLP). Figure 11 introduces it.

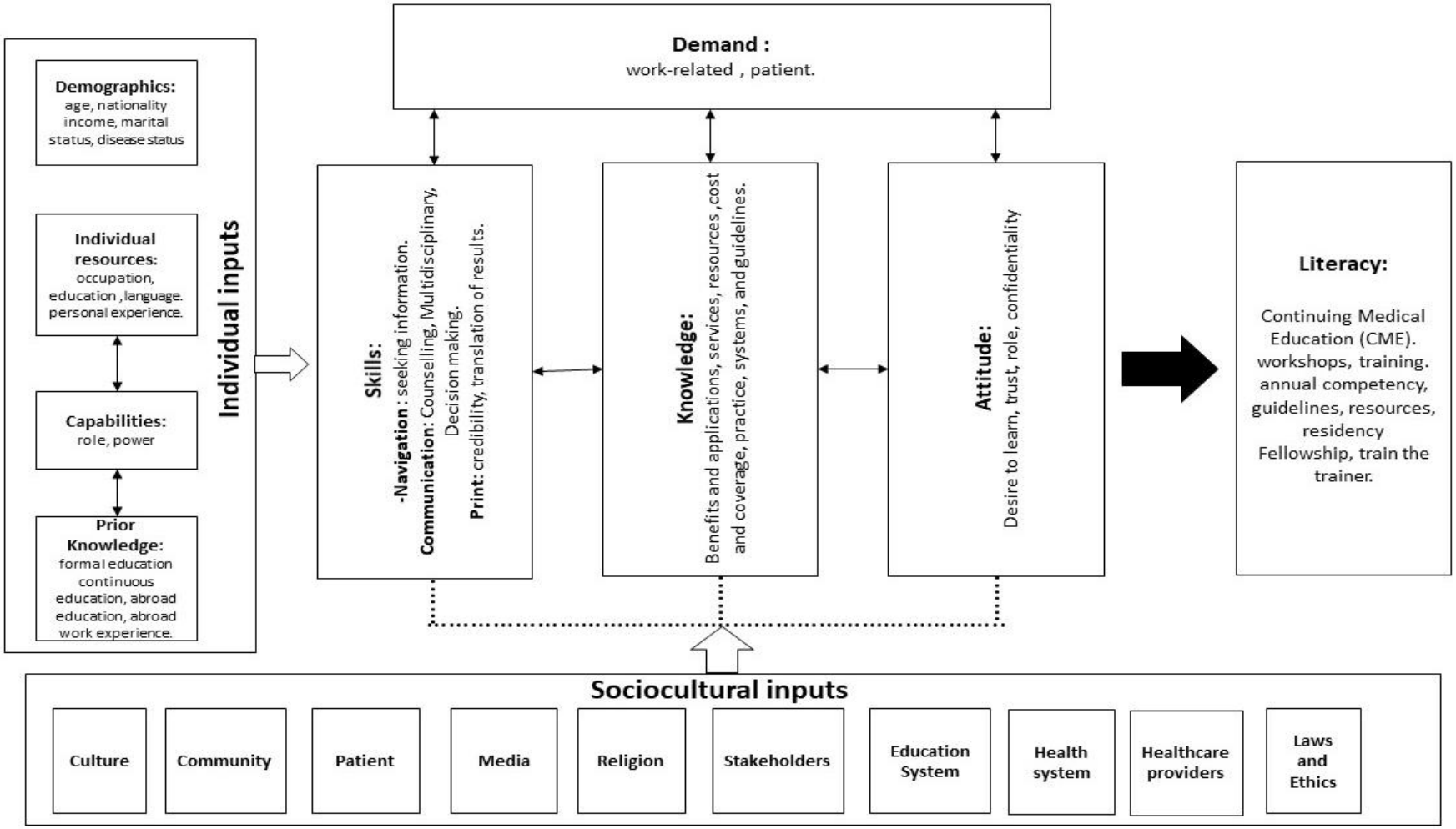


Figure 11: PGx Genomics Literacy Framework for Pharmacists (PGLP)

3.3 Assessing the Knowledge and Attitude of Students in UAE

3.3.1 Students' Demographic and Academic Characteristics

A total of 510 students consented and completed the questionnaire between December 2018 and October 2019. Of the participating students, 82.7% were female. The mean (SD) age was 22 (± 4.7) years old and 76.1% were between the ages of 18 and 28. Most responses (68.6%) came from students who were studying in universities located in Al Ain city. Of the students, 52.2% were studying Medicine and 29.3% were studying Pharmacy. Most of the students (73.9%) were in pursuit of a bachelor's degree and were in third and fourth year (22.2 and 23.4%, respectively). Table 7 summarizes the students' demographic and academic characteristics.

Table 7: Medical and health sciences students' demographics (N=510)

	Count (%)
Gender	
Female	421 (82.7)
Male	88 (17.3)
Age Group	
<18	69 (13.5)
18-28	388 (76.1)
29-39	38 (7.5)
40-50	6 (1.2)
University Location	
Al Ain	245 (68.6)
Dubai	83 (16.5)
Sharjah	55 (10.9)
Abu Dhabi	17 (3.4)
Ajman	1 (0.2)
Fujairah	1 (0.2)
Ras Al Khaimah	1 (0.2)
Program	
Medicine	265 (52.2)
Pharmacy	149 (29.3)
Laboratory	35 (6.9)
Other[a]	59 (11.6)

[a] medical imaging, radiology, radiography, biochemistry, biomedical sciences, dentistry, pharmacology, physiology, psychology, public health, occupational health

3.3.2 Assessment of Students' Knowledge on PGx

Only 4.2% responded correctly to all the knowledge questions. The highest proportion of correct answers was for question 6 about the impact of genetics on drug response and the lowest proportion of correct answers was for question 8 regarding cell composition. Table 8 summarizes the results of the knowledge questions.

Table 8: Results of PGx knowledge questions among students (N=506)

Knowledge questions	**Correct answer**	**Answered "True" n (%)**	**Answered "False" n (%)**	**Answered "Do not know" n (%)**
1. Humans have 48 chromosomes.	False	149 (29.4)	350 (69.2)	7 (1.4)
2. Adenine (A) only pairs with cytosine (C) and Thymine (T) only pairs with Guanine (G).	False	79 (15.6)	385 (76.1)	42 (8.3)
3. Pharmacogenomics seeks to individualize therapy based on patient's genetic profile.	True	418 (82.6)	12 (2.4)	76 (15)
4. Genetic changes can cause adverse reactions.	True	426 (84.2)	20 (4.0)	60 (11.9)
5. Pharmacogenomics testing is recommended by FDA for certain drugs.	True	261 (51.6)	25 (4.9)	220 (43.5)
6. Genetic changes can affect the patient's response to certain drug.	True	455 (89.9)	11 (2.2)	40 (7.9)
7. Genes can be activated or deactivated by other genes.	True	412 (81.4)	16 (3.2)	78 (15.4)
8. Every cell of the body contains the whole genome.	False	314 (62.1)	112 (22.1)	80 (15.8)
9. Environmental factors, such as cigarette smoke, can affect gene activity.	True	423 (83.6)	43 (8.5)	40 (7.9)

Table 9 summarizes the distribution of the knowledge score and levels by the demographic and academic characteristics of the students. The mean knowledge score (SD) for all students was 5.4 (± 2.7). The mean knowledge scores for students studying medicine and pharmacy were 5.5 (± 2.7) and 5.6 (± 2.7), respectively. The mean score of students in pursuit of a bachelor's was 6.4 (± 1.7), master's 5.9 (± 1.5) and PhD 6.6 (± 1.2). A higher mean knowledge score was found in students who completed a PGx or pharmacogenetics related training or education (6.5; ± 2.2) than those who did not (5.6; ± 2.1).

Table 9: Comparison of students' knowledge with different groups (N=510)

	Level of Knowledge				
	Mean score (± SD)	**Good n (%)**	**Fair n (%)**	**Poor n (%)**	**p-value**
Overall	5.4 (± 2.7)	219 (42.9)	191 (37.5)	100 (19.6)	
Gender					0.47
Female	5.3 (± 2.7)	176 (41.8)	161 (38.2)	84 (20.0)	
Male	5.6 (± 2.6)	43 (48.9)	30 (34.1)	15 (17.0)	
Age group					0.56
<18	5.0 (± 2.5)	23 (33.3)	31 (44.9)	15 (21.7)	
18-28	5.5 (± 2.8)	177 (45.6)	137 (35.3)	74 (19.1)	
29-39	5.3 (± 2.8)	14 (36.8)	16 (42.1)	8 (21.1)	
40-50	5.0 (± 2.6)	2 (33.3)	3 (50.0)	1 (16.7)	
Program					0.12
Medicine	5.5 (± 2.7)	123 (46.4)	95 (35.8)	47 (17.7)	
Pharmacy	5.6 (± 2.7)	69 (46.3)	52 (34.9)	28 (18.8)	
Laboratory	4.7 (± 2.9)	11 (31.4)	15 (42.9)	9 (25.7)	
Other	4.8 (± 2.4)	16 (27.1)	29 (49.2)	14 (23.7)	
Degree					0.44
Bachelor	6.4 (± 1.7)	185 (44.5)	148 (35.6)	83 (20.0)	
Master	5.9 (± 1.5)	14 (33.3)	20 (47.6)	8 (19.0)	
PhD	6.6 (± 1.2)	19 (40.4)	20 (42.6)	8 (17.0)	
Other	5.8 (± 1.0)	1 (25.0)	3 (75.0)	0 (0.0)	
Year of study (Bachelor)					0.00*
First	5.1 (± 2.0)	11 (5.9)	29 (19.6)	13 (15.7)	
Second	6.4 (± 1.7)	37 (20.0)	22 (14.9)	15 (18.1)	
Third	7.0 (± 1.4)	52 (28.1)	26 (17.6)	22 (26.5)	
Fourth	6.6 (± 1.6)	55 (29.7)	35 (26.3)	20 (24.1)	
Fifth	6.5 (± 1.5)	23 (12.4)	12 (8.1)	7 (8.4)	
Sixth	6.1 (± 1.3)	5 (2.7)	12 (8.1)	3 (3.6)	
Other	5.8 (± 1.2)	2 (1.1)	12 (8.1)	3 (3.6)	
Year of study (Master)					0.35
First	5.8 (± 1.4)	5 (35.7)	9 (45.0)	3 (37.5)	
Second	5.8 (± 1.6)	5 (35.7)	10 (50.0)	3 (37.5)	
Third	6.3 (± 1.2)	2 (14.3)	1 (5.0)	2 (25.0)	
Other	7.5 (± 0.7)	2 (14.3)	0 (0.0)	0 (0.0)	
Year of study (PhD)					0.08
First	6.2 (± 1.1)	7 (36.8)	12 (60.0)	1 (12.5)	
Second	6.9 (± 1.2)	5 (26.3)	4 (20.0)	1 (12.5)	
Third	7.0 (± 1.3)	3 (15.8)	3 (15.0)	2 (25.0)	
Fourth	7.5 (± 0.6)	4 (21.1)	0 (0.0)	4 (50.0)	
Fifth	5.0 (± 0.0)	0 (0.0)	1 (5.0)	0 (0.0)	

Table 9: Comparison of students' knowledge levels with different groups (N=510) (continued)

	Level of Knowledge				
	Mean score (± SD)	**Good n (%)**	**Fair n (%)**	**Poor n (%)**	**p-value**
Previous exposure to genetic issues					0.56
Yes	5.9 (± 2.1)	94 (45.2)	92 (44.2)	22 (10.6)	
No	6.0 (± 2.2)	125 (49.6)	99 (39.3)	28 (11.1)	
Completed PGX/pharmacogenetics training or education					0.00*
Yes	6.5 (± 2.2)	110 (62.5)	51 (29.0)	15 (8.5)	
No	5.6 (± 2.1)	109 (38.4)	140 (49.3)	35 (12.3)	
Completed internship or study abroad program					0.00*
Yes	5.9 (± 2.2)	191 (47.0)	169 (41.6)	46 (11.3)	
No	3.2 (± 3.4)	29 (27.4)	22 (20.8)	55 (51.9)	

**significant p-value <0.05*

There were significant differences in the levels of knowledge by the year of study of bachelor's degree students, the completion status of training or education in PGx or pharmacogenetics and the completion of an internship or study abroad program (p-values <0.05). Higher proportions of bachelor's students in years 2-6 reported good to fair levels of knowledge. Higher proportions of master's students in years 1 and 2 reported fair levels of knowledge. Of the students who completed PGx/pharmacogenetics training or education, 62.5% reported a good level of knowledge. Out of the 510 students, 406 (79.6%) reported to have completed an internship or study abroad program; 47% and 41.6% of these students reported good and fair levels of knowledge, respectively.

3.3.3 Attitudes towards Genomic Medicine and PGx

Results on the attitudes towards genomic medicine and PGx were categorized into five categories; views and considerations, desire to participate, accessibility and availability of genetic tests, concerns, and ethics and, lastly, outlooks on the future.

3.3.4 Views and Considerations on Genomic Medicine and PGx

Majority of students (82.7%) would consider having genetic testing done at some point in their life to find out their future risk of developing genetic diseases, whereas 74.7% would only like to know their susceptibility to diseases that have current interventions for protection (Figure 12).

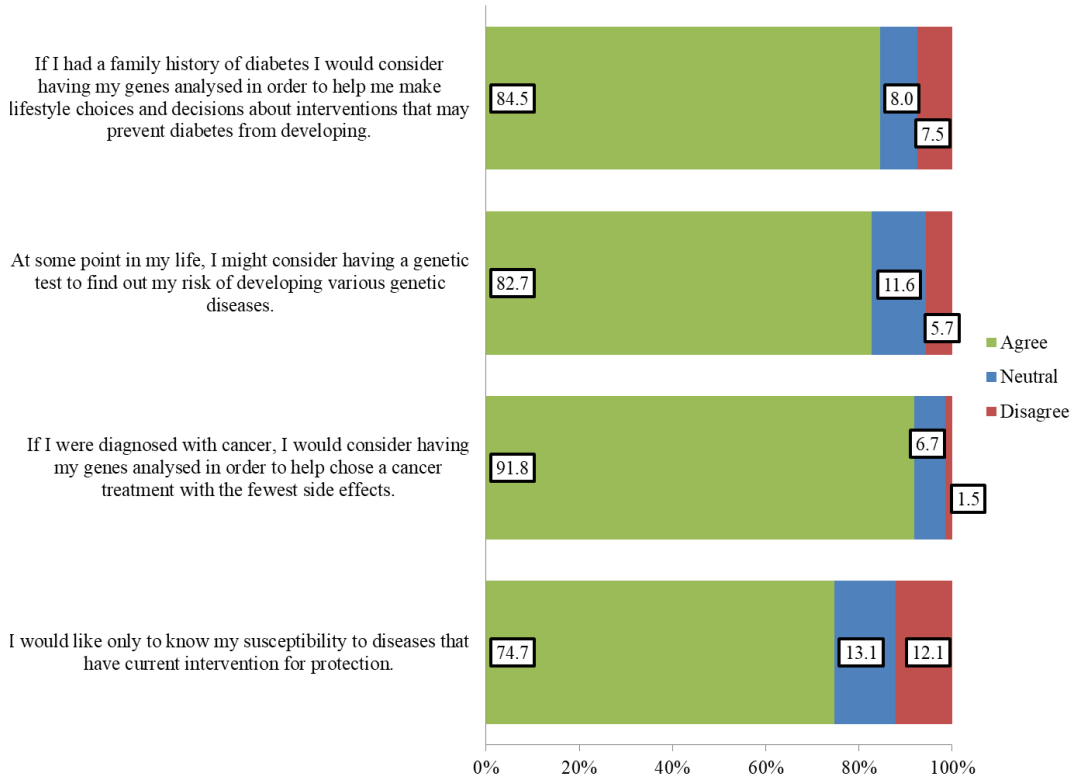


Figure 12: Views and considerations of students on PGx (N=388)

When asked if they prefer a pharmacist or physician to explain their genome report, 79.4% preferred a physician while 44.8% preferred a pharmacist (Figure 13).

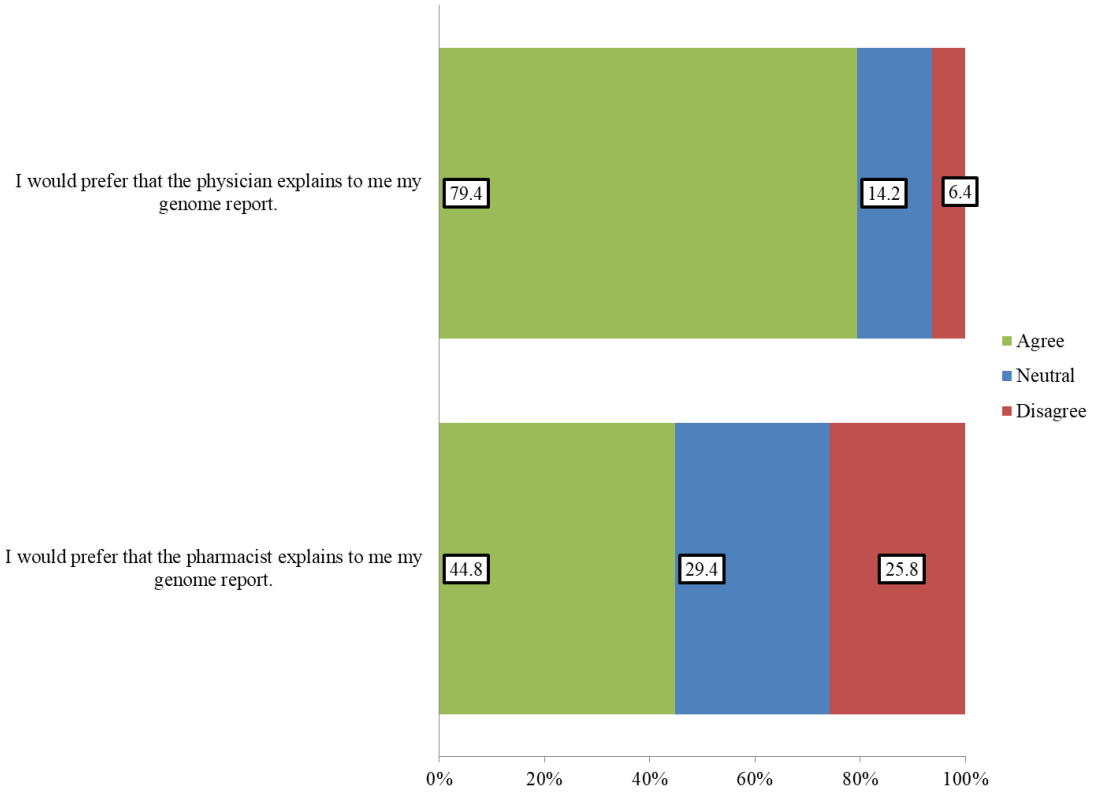


Figure 13: Pharmacist vs. physician in genome report explaining (N=388)

3.3.5 Desire to Participate in Genetic Research

A high percentage of students (78.1%) stated to be interested in participating in genetic research. The majority (79.4%) indicated that they would be interested in attending a course or seminar for PGx education (Figure 14).

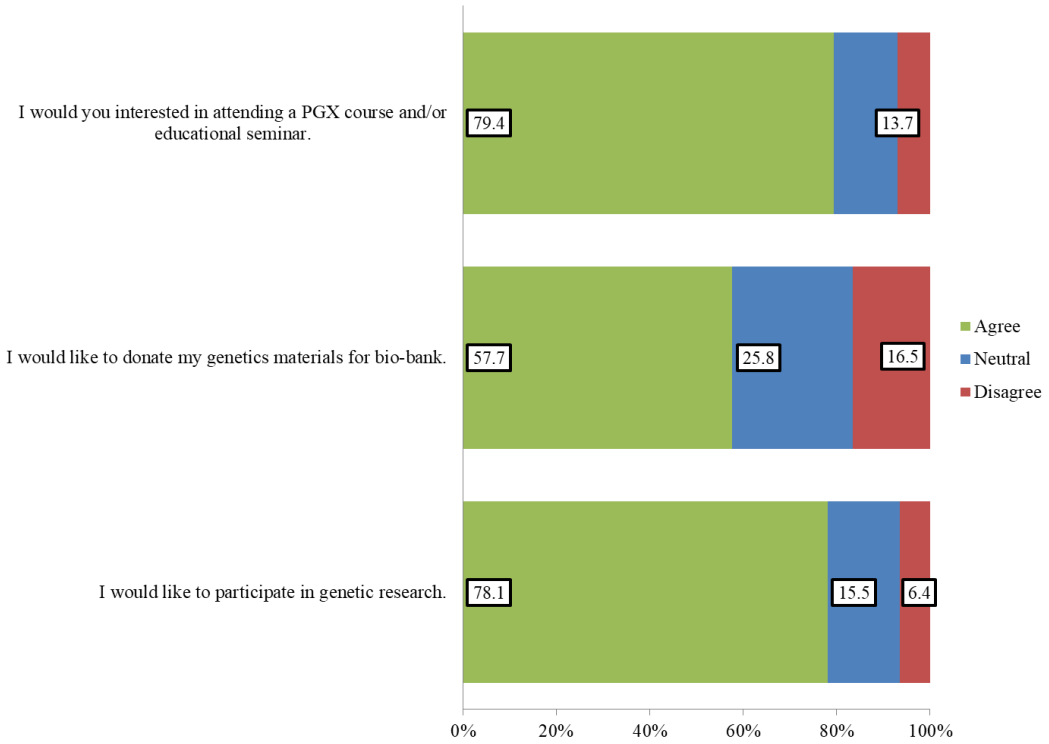


Figure 14: Desire of students to participate in genetic activities (N=388)

3.3.6 Accessibility and Availability of Genetic Testing

The vast majority of students, respectively, 96.4% and 66.8%, reflected positive attitudes towards the availability and accessibility of genetic tests. However, 57.5% did agree that the availability of genetic tests could be problematic for insurance companies and future employers (Figure 15).

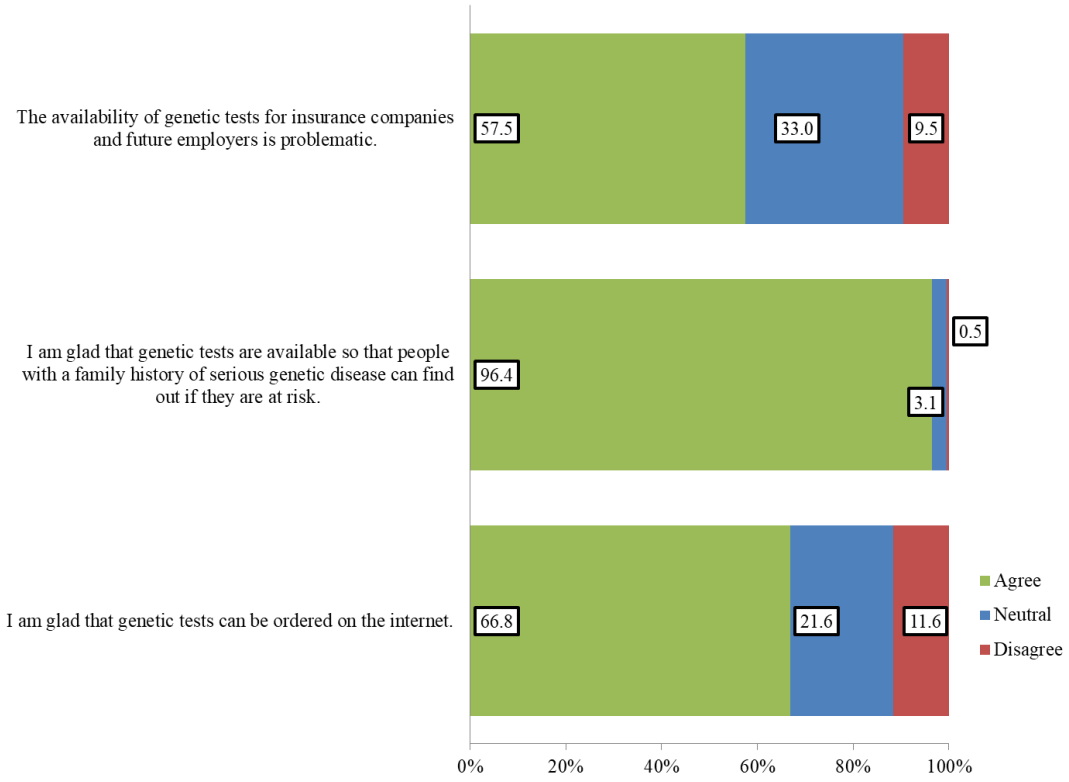


Figure 15: Students' attitude on genetic testing (N=388)

3.3.7 Concerns and Ethics Regarding Genomic Medicine and PGx

The highest concern (66.8%) was that genomics could be exploited and used as means of discrimination (Figure 16). The next concern by percentage (40.2%) was due to issues of confidentiality and a similar percentage of 38.1% were skeptical toward PGx testing due to a possibility of getting gene information unrelated to the treatment.

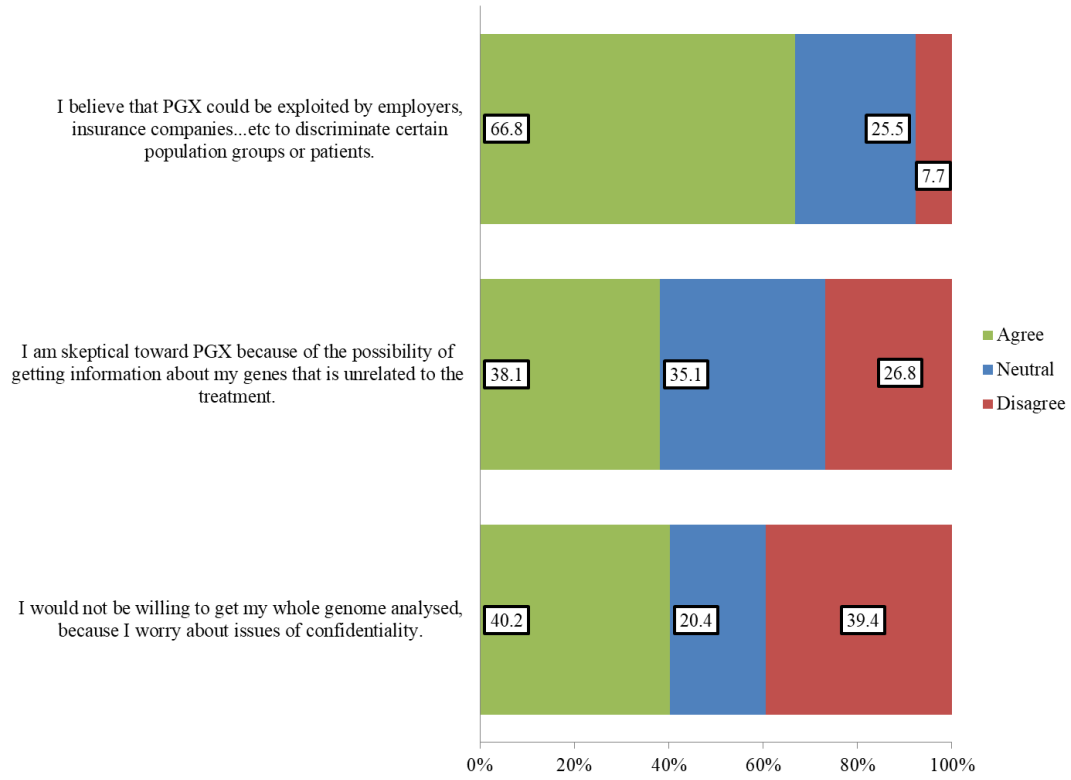


Figure 16: Concerns and ethics of students regarding genomics (N=388)

3.3.8 Outlooks on the Future of Genomic Medicine and PGx

The majority of students were optimistic about the future; 87.1% believing medicine will be more personalized. Most of them (89.9%) had a positive view on genetic testing and agreed that the government should invest more money into its development. Moreover, 73.2% thought more time should be dedicated towards studying PGx.

The top two barriers students identified to the implementation of genomic medicine and PGx were lack of training or education (59.7%) and lack of clinical guidelines (58.7%). The next two highly perceived barriers were cost of testing and lack of testing services (46.3% and 44.7% respectively). Other answers included lack of awareness and cultural/religious inhibitions. In order to improve future education on genomic

medicine and PGx, students were asked for their preferred method of learning. The majority (70.8%) preferred workshops or seminars while 34.2% and 30% preferred internet-based learning and self-directed learning, respectively. Others preferred learning during their internship year (37.6%).

3.4 Mapping the Current State of Genetics Testing Services in UAE

3.4.1 General Mapping of Private Genetic Services in the UAE

Twenty-seven laboratories were mapped through website search while 23 laboratories responded to the onsite questionnaire. Their characteristics are presented in Table 10. Most of the mapped laboratories that provide genetic services in UAE are located in Dubai followed by Abu Dhabi, the capital of UAE. Only three laboratories claimed that they have a genomic bank and stated that their consent form is tailored to such a service.

Table 10: Characteristics of the mapped laboratories in the UAE

Demographics	Survey (N = 23)	Website (N = 27)
Location of the laboratory in the UAE by emirate: *		
Abu Dhabi	4	7
Dubai	15	21
Sharjah	3	3
Ras Al-Khaimah	1	2
Ajman	0	1
Umm Al Quwain	0	1
Fujairah	0	1
Laboratories that have a genomic bank	3	3
Laboratories that offer bioinformatics analysis	6	2
Type of stakeholders:		
Directly to clients	3	1
Medical referrals (hospitals/clinics/doctors)	4	0
Both	11	5
Not mentioned/missing	5	21
Completeness or knowledge of completeness of the information on the website:		
Yes	9	2
No	3	23
I do not know/not mentioned/missing	11	2
Availability or knowledge of availability of the costs on the website:		
Yes	3	4
No	13	21
I do not know/not mentioned/missing	7	2
Accreditation by national or international bodies:		
Yes	15	12
No	3	1
I do not know/not mentioned/missing	5	14
Location of the processing of the samples:		
In-house within UAE	15	4
Sent out of the country	7	2
Both	0	3
I do not know/not mentioned/missing	1	18

* Some laboratories had multiple branches in different emirates.

With regard to the type of clients, 11 of the surveyed laboratories indicated that they serve medical referrals from hospitals and clinics as well as directly providing services to clients. However, such information was not disclosed on the websites of the 21

mapped laboratories. Prenatal testing was the genetic service most commonly offered among the laboratories included in the study, whereas onsite data revealed that blood samples was the main sample type for genetic testing followed by saliva (Figure 17)**.**

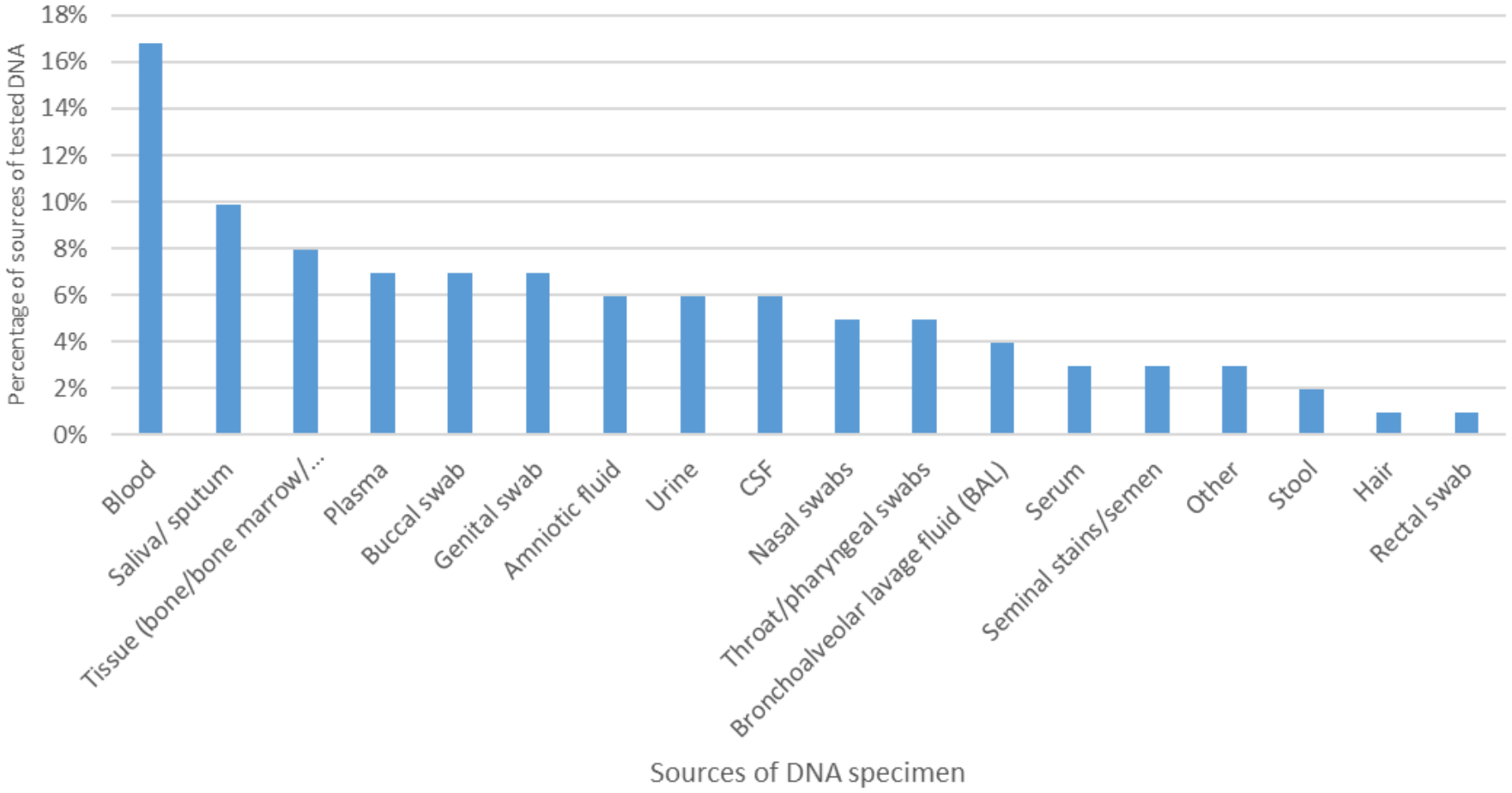


Figure 17: Sources of the tested DNA at the mapped laboratories in UAE

3.4.2 Inconsistency between Onsite and Website Mapping

There were inconsistencies between onsite-questionnaire responses and the findings of the website search. For example, six laboratories claimed to provide bioinformatics analysis, but analysis of their websites showed that only two of them stated that they provide this service.

Another example of such discrepancy was detected upon assessing the sufficiency of information provided on the laboratories' websites. Interestingly, nine laboratories claimed that their websites were accurate and comprehensive with regard to their services**;** however, through website mapping, only two can be considered thorough and comprehensive. Three of the surveyed laboratories considered the information posted on their website to be incomplete and not representative of the services they provide, while 11 of the surveyed laboratories did not annotate on the question.

The study identified a contrast with regard to the location of processing of samples, as 15 laboratories claimed to have an in-house facility for sample processing, but a website search confirmed that only four of them do (Table 10).

3.4.3 Accreditation

One of the surprising findings in the mapping was that staff of three of the surveyed laboratories stated that they did not seek any accreditation because they consider themselves as window-laboratories (only a reception for a lab located abroad), where the actual testing services are done abroad (Table 10). There was no standardization of the accreditation bodies as different laboratories have different accreditations, including, but not restricted to: ISO 15189, Joint Commission International, the College of American Pathologists, and Health Authority of UAE.

3.4.4 Genetic Counseling

Twelve laboratories coupled their genetic service with in-house genetic counseling, while three laboratories refer their clients to an external counselor (Figure 18). Unfortunately, half of the counseling provided by the facilities is limited. Few laboratories provide in-house counseling services and the rest refer patients to external counseling services.

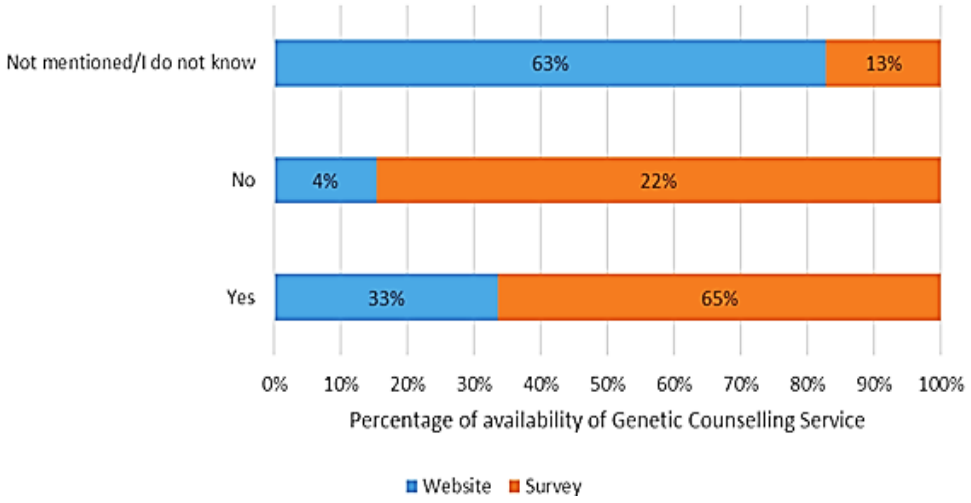


Figure 18: Availability of genetic counseling services at the mapped laboratories

3.4.5 Coverage of the Cost

In the UAE, insurance companies are somewhat lagging in terms of covering genetic tests, so only six laboratories claimed full coverage of the cost of genetic testing through health insurance, mainly for UAE nationals. It was observed that websites did not detail the cost of tests, and when asked about it on the onsite visit the personnel responded that concealing such information would create market competition.

3.4.6 Gene-panel Selection

Twelve laboratories stated that disease-specific panel is the most selected panel by stakeholders, and nine of them stated that their laboratory can provide customized panel of genes. Six of the mapped laboratories claimed providing pharmacogenomics sequencing or genotyping tests.

3.4.7 Turnaround and Reporting of the Results

Turnaround of results ranged from 2 days to 8 weeks depending on the type of the genetic tests and the destination of the shipping and processing of the samples (abroad vs. in-house). The most common method of reporting results was through in-house system followed by website and written reports. Additionally, 94% of the surveyed personnel stated that their reports are easy to interpret by stakeholders (physicians and patients). The majority of the laboratories (42%) follow the American guidelines and database.

3.5 Establishing a Stakeholders' Matrix of Power and Interest

Thirteen in-depth semi-structured interviews were conducted. The stakeholders interviewed are presented in Figure 19.

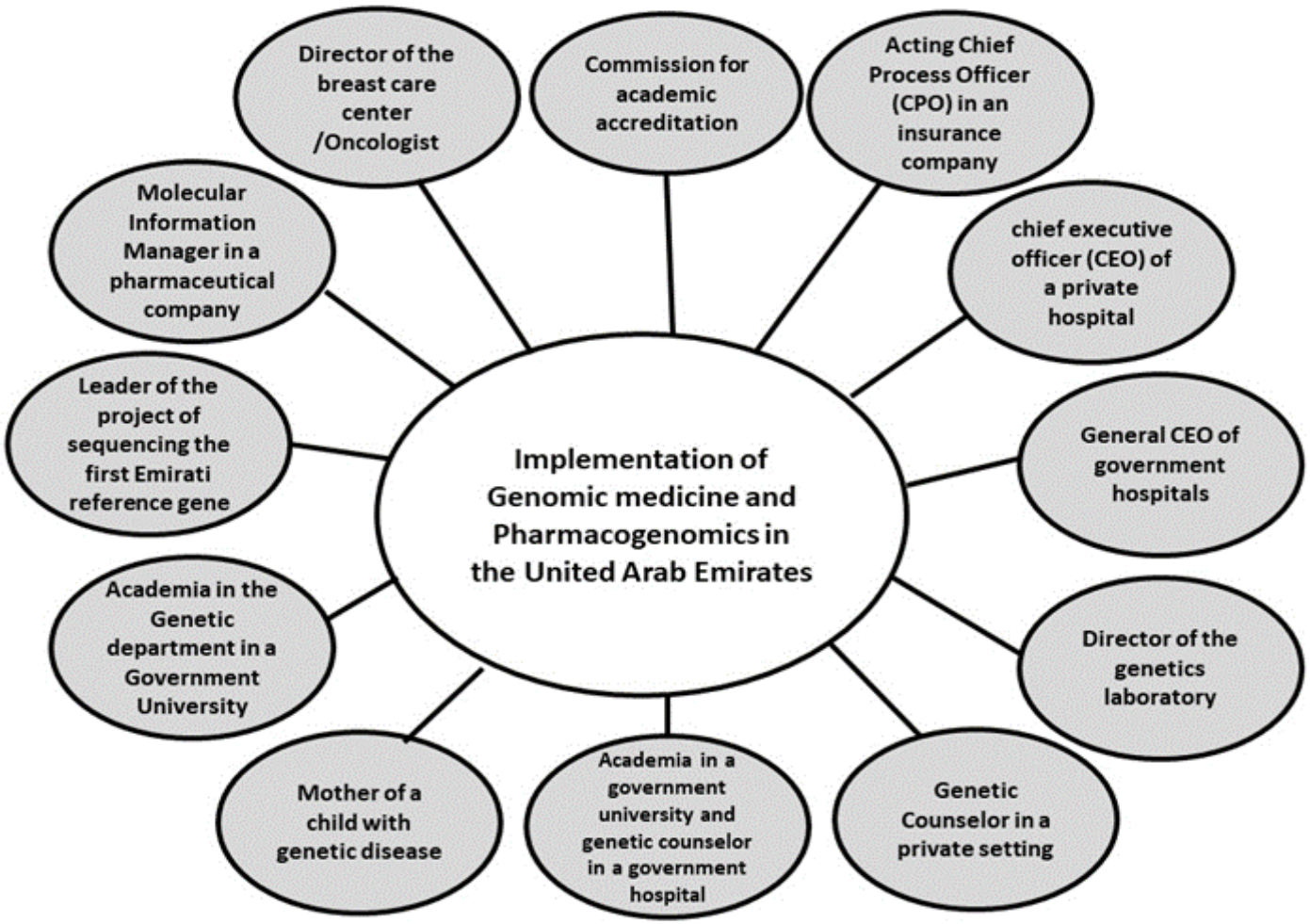


Figure 19: Bubble representation of the interviewed stakeholders

The identified main themes extracted inductively from the iterative analysis of the aforementioned stakeholder's interviews are the attitude of the stakeholders toward a variety of facets of genomic medicine and pharmacogenomics. Besides the second main theme which is their perceived barriers and challenges for the full implementation of genomic medicine and pharmacogenomics in UAE. In addition, the researcher underscored an emerging theme of the role of both genetic counselors and the media in the implementation of genomic medicine and pharmacogenomics in UAE which will be annotated under the emerging themes.

3.5.1 Main themes

3.5.1.1 Attitude of the stakeholders toward a Variety of Facets of Genomic Medicine and Pharmacogenomics

Subthemes:

Attitude of stakeholders about the clinical demand for genomic medicine and pharmacogenomics in UAE:

Most of the interviewed stakeholders emphasized the clinical demand for genomic medicine in UAE due to arrays of justifications like the prevalence of consanguinity in UAE, the high burden of genetic diseases, the urge to utilize the genomic technology to personalized medications, and the raise in awareness among physicians about the power of genetic services that motivated them to demand genomic medicine.

"Yes,, we need genomic medicine in the UAE because we have very young patients with cancer, like from my own practice, the prevalence of breast cancer in very young patients is higher in UAE than western world, I am trained in Germany and I didn't see this much." Stakeholder #1

"The opportunity here is unique, because once you identify one patient you are actually serving a big family as they all share the DNA and that open the door for prevention of the genetic disease." Stakeholder #5

In terms of the demand to pharmacogenomics, many of the stakeholders were less inclined to articulate the need for pharmacogenomics at the moment, however, they believe that a shift in the demand may occur in the future.

"*Pharmacogenomics currently is very limited, you know there are various factors to that, you know it is not widely used but again there will be more demand in the future."* Stakeholder #2

Inclination about the infrastructure to implement genomic medicine and pharmacogenomics in UAE:

The majority of stakeholders in UAE favored building the genetic testing infrastructure in UAE rather than sending the samples for testing abroad. They vindicated this stance to variable factors of cost, confidentiality, building database and logistics. However, few stakeholders opt to postpone building infrastructure in UAE until the demand increases in order to have return on investment.

"It should be local. I think because one panel at a time will cost. because when you send them outside you usually send them one at a time, so that will cost more and you add more cost to the hospital and the patient, and those people are not geneticist they do not speak the language, so you can't talk directly to the lab, so that result in communication gap and delay communication and hence diagnosis, that in the logistic side.

Another side, is when you have a lab in house you build your own database, currently all testing is done in Portugal, in Germany, so no one knows what the most common mutation in UAE is, having this database will help you plan where to put your resources, treatment" Stakeholder #5

"I am here to build internal capacity in UAE, internal capacity means people, infrastructure, science, international recognition and these elements are very important. So whether we are going to have another genome sequencing center? probably not, but those will have small scale, for example Al-Ain has the ability to have breast cancer diagnostic center, so it would be more like diagnostic of focus areas, but the diagnostic lab that we are building will have broader scale of tests and will cover the population need, so I see it as constant collaboration between all of us, we will not stand alone on high tower, we need to connect to meet the locals need." Stakeholder #9

"so, at the moment as you know, samples are sent-out, when you are doing enough volume it is cheaper to do it in-house, doing few it is easier and cheaper to send it out." Stakeholder #8

Demeanor of stakeholders about the cost-effectiveness of genomic medicine and pharmacogenomics:

Most of the stakeholders in UAE agreed that genomic medicine and pharmacogenomics is cost-effective, and some were able to bring evidence from their current practice or cited published papers that support that. One of the stakeholders is in the process of studying this in UAE and has received approval from the institutional

review board to do so. A stakeholder working in an insurance company had an opposite stance about the cost-effectiveness of genomic medicine and pharmacogenomics.

Stance of the stakeholders' strategy of the implementation of genomic medicine and pharmacogenomics:

Albeit Preemptive approach or gene-specific approach:

The majority of the stakeholders favored preemptive approach, which seeks testing proactively once in a lifetime and having the results of the genetic test ready at the time of prescription.

"If you have proper equipment and proper screening then preemptive absolutely, as you do more help there, right? you don't wait for the patient to become patient to react." Stakeholder #5

However, they had two approaches; some supported newborn screening preemptive approach while others preferred pre-marital screening preemptive approach. Genetic counselors' attitude was skewed toward gene-specific approach because they anticipated the dilemma of incidental findings.

Attitude about their desire to undertake genetic test:

Mixed results were identified. Many agreed to undertake the genetic test to gain better control of their life and to have a motive to lead a healthy lifestyle. On the other hand, many disclosed that they will not take the test as they are scared of the consequences.

"I would not do it for myself, it will open a door I will not be able to close." Stakeholder #1

Those who have children were more inclined to conduct the tests on their children but not themselves.

Attitude toward online direct-to-consumer kit:

Most of the stakeholder's attitude about online direct-to-consumer kit was skewed toward rejecting it. Their justification is represented in the words of one of the genetic counselors:

"I think it is misleading the consumer, it is not giving them correct and clear information, and the client walking away thinking that he had been tested for everything under the sun and he is immune now and that is not true. I really believe that counseling should support the testing everywhere and every time." Stakeholder #4.

3.5.1.2 Stakeholders Perceived Concerns for the Full Implementation of Genomic Medicine and Pharmacogenomics in UAE

Concerns about the ethical and legal aspects of genomic medicine:

Stakeholders exhibited blended views in regard to the ethical and legal aspects of genomic medicine. Some of them did not voice any concern while others had concerns related to confidentiality of the genetic tests results especially with the use of cloud for bioinformatics. Many were worried about the ramifications of disclosing genetic tests results to insurance companies. They are anxious that insurance companies may increase the insurance price (this concern was confirmed by stakeholder from insurance company) or cause discrimination by employer by denying jobs to those with high probability of having a disease. Few of the stakeholders had not thought about it nor consider it in their planning agenda.

3.5.1.3 Stakeholders Perceived Barriers and Challenges for the Full Implementation of Genomic Medicine and Pharmacogenomics in UAE

The barriers and challenges perceived by the stakeholders in UAE can be categorized using the PESTLE tool borrowed from the business model of risk management (Rastogi & Trivedi, 2016) as follows:

P= Political: The slow pace of implementation, fragmented system and lack of unity, and ineffective regulation of curriculum by professional bodies and health regulators.

E= Economic: Cost of bioinformatics support, coverage of the genetic tests to all citizens.

S= Social: confidentiality, apathetic and latent stakeholders, ignorance, lack of awareness about genomic medicine in the UAE community, role of media.

T=Technological: Bioinformatics.

L= Legal: Ineffective regulation of curriculum by professional bodies and health regulators and lack of laws to protect confidentiality of genetic tests.

E=Environmental: Lack or the gap in education about genomic medicine and pharmacogenomics, lack of evidence pertaining to the UAE population, ineffective regulation of curriculum by professional bodies and health regulators, ineffective curriculum, lack of experts in the field whether in the academic field or the health setting, and limited numbers of well-trained genetic counselors.

3.5.2 Emerging Themes

The inductive methodology allowed researcher to code emerging themes. The emerging themes are the added value of genetic counselor and the role of media as a

stakeholder in the awareness of genetic diseases. Below is an elaboration on these themes.

3.5.2.1 Stance of the stakeholders of the added value of genetic counselors

The added value of genetic counselors emerged when talking to stakeholders in the health setting as well as academic fields. They pointed out that the genetic counselor is the proposed model that will address the knowledge gap of genomics among healthcare providers. Thus, their role is crucial for guiding physicians, saving cost and timely intervention as well as their traditional role of counseling the index case and their pedigree.

"*Those physicians who are not competent in genomics, the genetic counselor will actually go to the round with them, so she recommends microarrays or gene panel for epilepsy for example or if it is a more complex case, she guides and navigates the doctors to find the cost-effective route and test. When the results are back, all of them need help with what does the result mean? so our genetic counselor will do both, she will talk to the family and explain the result and its consequences, also the genetic counselor will talk to the doctors to explain what these results mean in term of management of the disease. For example, is the results diagnostic findings or not, maybe they need axiom sequence instead of microarray. She will explain the etiology as well. Some doctors can do that, but the current model even in the State they have genetic counselor in every specialty to do that, and in UAE with the burden of disease and lack of healthcare providers you need to depend on genetic counselor"* Stakeholder #5

3.5.2.2 Role of media in the awareness about genomic medicine and genetic diseases

The mother of the child with a genetic disease voiced that media is lagging behind in spreading the awareness about genetic diseases and the value of genomic medicine.

"My daughter is a teenager now, and her peers are giving her a hard time at school, most of the time she comes home crying and there is nothing I can do, I cannot educate them or ask their families to do so. Unfortunately, the media did not bring justice to children with genetic diseases, as they are always viewed as retarded. My daughter is not retarded, and she should not go through all this pain and sadness. That added extra weight on my shoulders" Stakeholder #13

3.5.3 Mendelow's matrix

The interest and power (Mendelow's matrix) of the stakeholders in UAE had been mapped based on the preponderance of the emanated themes using a deductive methodological approach. Figure 20 visualizes this mapping.

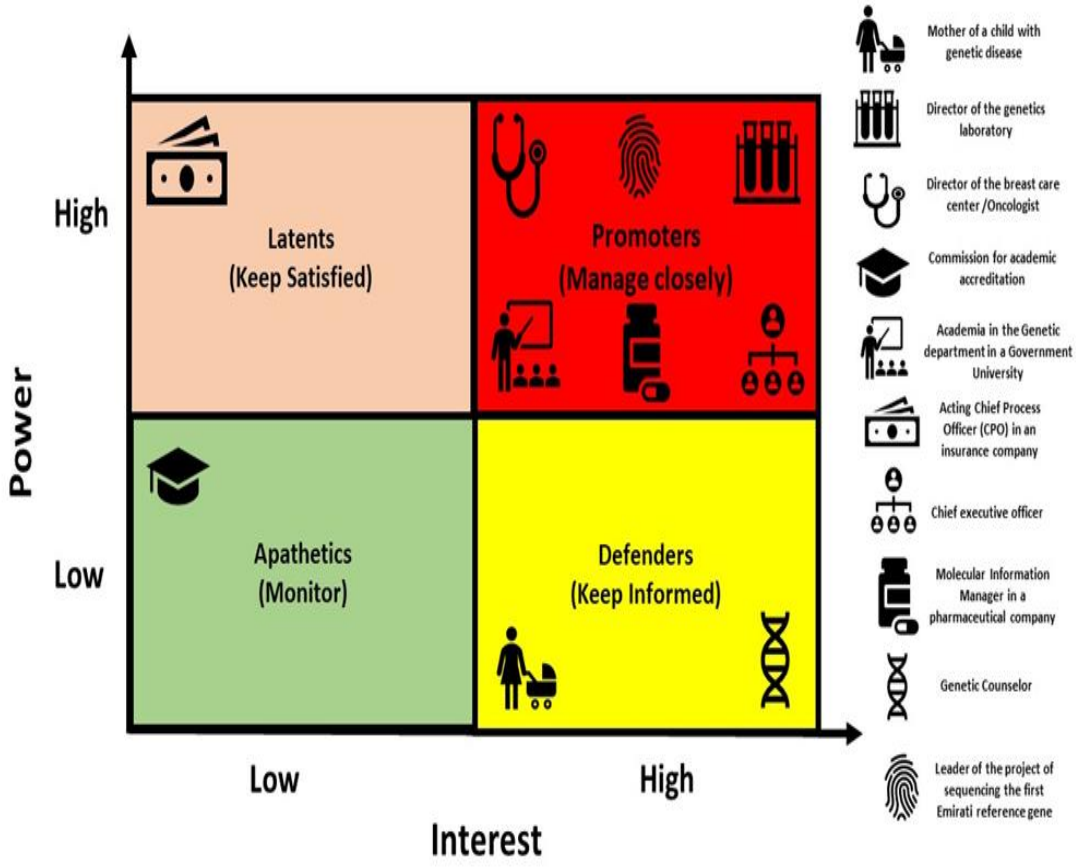


Figure 20: Mendelow's matrix of the interviewed stakeholders

The Mendelow's model of the stakeholders in UAE (Figure 20) is an essential and validated strategic step in the business management that will empower policy makers and interested parties to a full implementation of genomic medicine and pharmacogenomics. The following categorization of the types of stakeholders identified using Mendelow's model will provide a systematic communication and action plan strategy for future genomic medicine and pharmacogenomics implementation (Mendelow, 1981). The first category identified is the promoters for full implementation of genomic medicine and pharmacogenomics in UAE, which in this study are the researchers, academics, and health-care administrative and pharmaceutical companies. As per the stakeholders' model, the strategy to deal with

important and interested stakeholders is to manage closely as they are the key players. The second category, on the contrary, is stakeholders with low interest and low power (the apathetic); in this study, they are the commissions for academic accreditation. According to Mendelow's model, the recommended strategy is to keep them under monitoring without engaging them in the plan of the implementation. The third category is the stakeholders with high power but low interest; these are the real challenge (the latent). In this study, they are the insurance company, so the solution is to keep them satisfied and engaged. Finally, the last category is stakeholders with high interest but low power (the defenders). In this study, they are the genetic counselors and parents of the child with genetic disease; they ought to be informed and engaged.

Chapter 4: Discussion

The reiteration of discussion will be categorized according to the main objectives of the study and follow the same pattern of the results.

4.1 Assessing the Genomics Educational Environment in UAE

In this part, the researcher attempted to navigate through the educational environment of genomic medicine and PGx in UAE. The researcher did not limit the research to specific field of genomics to allow broader mapping of the current educational environment. This will act as a baseline for other researchers as well as a point of comparison for the stakeholders.

Breadth of studies attributed the poor knowledge of healthcare providers toward genomics and PGx to the dearth of official tutoring in the universities and recommended incorporating genomics and PGx in the curriculum (Chair et al., 2019; Rahma et al., 2020a; Rahma et al., 2020b; Sharoff, 2020; Stark et al., 2019a; Whitley et al., 2020). The mapping of the medical and health sciences curriculum of the accredited universities in UAE, pointed out that basic genetics is included in the majority of universities' syllabi both undergraduate and postgraduate, however PGx and human genetics deviated from this inclusion. Even the curriculum was not standardized among universities nor covering topics in the same significance. The survey and the interviews of the academia disclosed that regulatory aspects and clinical resources had less weight in the curriculum of PGx.

In the assessment of the knowledge of medical and health science students in the UAE toward genomic medicine and PGx, only 4.2% responded correctly to all the

knowledge questions which can be attributed to the scarce coverage of genomics in the curriculum of the accredited universities in UAE.

The commissioners and higher education experts at the commission for academic accreditation at the Ministry of Education in UAE ascribed this gap to the shortage of the experts in the field of genomics and PGx in UAE as well as the paucity of partnership with the specialists. A study by Shaffer et al. (2010) advocated the genomics education partnership and concluded that it was fulfilling for both students and faculty. This was also highlighted by Perkmann and Schildt (2015) in their review of the structural Genomics Consortium case study, as well as in three-year case study in genomics by LeBlanc and Dyer (2003).

A positive attitude was detected among academia and commissioners toward harnessing genomics and PGx to prepare the future healthcare providers to the personalized medicine era. The majority (82.2%) agreed that more room should be allocated in the curriculum for genomics and PGx and 74% were interested in attending PGx courses or seminars. These results are in consonance with the international educational strategies (Adams et al., 2016; Frick et al., 2018; Gálvez-Peralta et al., 2018; Guy et al., 2020; Karas Kuželički et al., 2019; Perry et al., 2016; Weitzel et al., 2016). Furthermore, the researcher contextualized the personal attitude of the academia and commissioners toward conducting genetic tests and participating in genetic research and biobanks, as researcher hypothesized that such positive attitude would influence the pace of adoption of genomics in the curriculum. This area has not been examined in the literature and warrants further research.

Academia and education commissioners shared an optimistic view of the future. They captured the strides that map the implementation of genomic medicine and PGx in the UAE. The profound strategy is education. This finding is in line with literatures and recommendations of international societies like the ISP and The International Society of Nurses in Genetics (ISONG) (Beamer & Rosinski, 2019; Gurwitz et al., 2005; Gurwitz et al., 2003; Hickey et al., 2018; Karas Kuželički et al., 2019; Lesko & Johnson, 2012; Ziegelstein, 2015).

In the systematic review by Talwar et al. (2019), they analyzed the current genomics courses offered to health professional students and concluded that the field of genomic education incubates evolving pedagogical methods like self-genotyping, which can be adopted by the academia in UAE.

The strength of this research is the overlapping mixed method approach that countenances a comprehensive assessment and mapping of the educational environment of genomics in UAE. Additionally, the triangulation with other results about the assessment of knowledge of medical and health sciences students allows attribution and postulation. Furthermore, assessing the attitude of the academia is a novelty that fosters the implementation strategies. Including the commissioners and higher education experts at the commission for academic accreditation at the Ministry of Education delineated the stakeholders stand and fostered a top up viewpoint.

The limitations include the inherited bias of both quantitative and qualitative methods involving lack of generalization, selection and information bias. To mitigate these biases, the researcher employed random sampling and disseminated the questionnaires to all the accredited health sciences universities in UAE. The snapshot feature of the

research is another limitation that can be considered as a baseline for further research comparison and analysis.

4.2 Assessing the Knowledge and Attitude of Healthcare Providers in UAE

4.2.1 Quantitative

Evaluating the knowledge and attitudes of the frontline workers of the health system is imperative for the seamless implementation of genetic testing and PGx. In the UAE, there are strides to implement genetic testing and pharmacogenomics; therefore, these findings will delineate the stringent approach of implementation. The researcher assessed the knowledge and attitudes of the entire cluster of the cohort healthcare workers including physicians, pharmacists, nurses, allied health and administrative as the stakeholders in UAE foresee a multidisciplinary approach for the implementation of genetic testing and PGx. All participants in the cohort exhibited a fair knowledge level about genetic testing and PGx. Most of the respondents showed a positive attitude regarding availability of genetic testing. The top identified barrier to implementation was the cost of testing followed by lack of training or education and insurance coverage.

Advances in genetic testing facilitated discovering genetic variants, which guided the drug prescription and tailored dose selection and replaced the trial-and-error approach. In fact, several guidelines and algorithms are incorporating and adopting PGx in their clinical pathways, which in turn paved the road to personalized medicine (Cavallari et al., 2017b; Crews et al., 2012; Morash et al., 2018; Morganti et al., 2019; Relling et al., 2010; Relling et al., 2011; Singh, 2020). Studies signify that physicians immersed in PGx modules were more auspicious towards genetic testing as they sought it

clinically beneficial. Furthermore, their awareness fueled their confidence in their skills to implement personalized medicine into their patient-centered care (Owusu Obeng et al., 2018). In her paper, Swan (2012) highlighted personalized medicine as one of the plans and routes for the Health Vision of 2050 (Swan, 2012). Additionally, Mason-Suares et al. (2016) highlighted the new spectrum of skills required from healthcare providers in order to implement personalized medicine; some of these skills include managing diagnostics facilities, gauging the relevance of tests and implementing cost-effective procedures (Mason-Suares et al., 2016). In this research, the investigator assessed the knowledge and attitude of healthcare workers in the UAE to gauge their position within the personalized medicine spectrum. This aimed to provide the stakeholders in UAE with the information needed to strategize their implantation approaches. From these findings, stakeholders should prioritize educating healthcare providers about basics of genetics and translational aspects.

Studies have consistently demonstrated a gap in the knowledge of healthcare workers about genetic testing and PGx in almost all countries: United Kingdom, Greece, Canada, USA, Japan, Germany, Netherlands, Egypt, Africa, Brazil, Qatar, Kuwait and KSA (Algahtani, 2020; Alharbi et al., 2019; Bernhardt et al., 2012; De Denus et al., 2013; Elewa et al., 2015; Feero & Green, 2011; Lopes-Júnior et al., 2017; Mai et al., 2014; Nagy et al., 2020; Owusu Obeng et al., 2018; Rahawi et al., 2020; Yau et al., 2015). Similarly, these findings fall along the same line.

Interestingly, this research shows significant differences in the levels of theoretical knowledge of genomics and PGx by gender. The proportion of healthcare workers with good knowledge levels was higher in male than female workers, while more females scored moderate or fair knowledge levels than male healthcare workers. One study by

Powell et al. (2012) reported that the inconsistent levels of knowledge and understanding is significantly associated with gender. Consequently, in their study, male workers were two times more likely to feel prepared to answer questions related to direct-to-consumer genetic tests than female workers (Powell et al., 2012). Gender gap of knowledge had been addressed in other scientific domains, but not in genetic testing and PGx. Many studies highlighted the reversed gender gap in education. This disparity warrants in-depth investigation and further research; as such, it requires a pivotal strategy (Quenzel & Hurrelmann, 2013; Van Bavel et al., 2018).

This research revealed significant statistical differences in the levels of genomics knowledge between different occupations. Respondents working in the field of medicine scored higher than those working in the field of pharmacy or nursing. However, all exhibited a fair knowledge level. In part, this can be attributed to the narrow application of genomics in the field of medicine in UAE (Abou Tayoun et al., 2020; Akawi et al., 2012; Al-Ali et al., 2018; Al-Mahayri et al., 2019; Al-Mahayri et al., 2020; AlSafar et al., 2019; Osman et al., 2018).

Remarkably, in the research sample, knowledge scores for genomic basics were significantly associated with healthcare workers having patients asking them about undertaking a genetic test in the last two years. Notably, this was not the case if the patients asked them for advice about the results of a genetic test. This can potentially be explained by the fact that healthcare workers felt responsible and duty-bound to learn more about genomics and genetic tests to maintain the physician-patient rapport (Gupta et al., 2020; Shaya et al., 2019). Another significant attribute to the knowledge of the healthcare workers is completing a training or education in genetic testing or PGx. A survey on Canadian physicians working in oncology, cardiology and family

medicine concluded that physicians with prior training on genomics medicine had a significantly higher mean knowledge score (Bonter et al., 2011). In fact, education and training is the foundation of most of the platforms, frameworks and consortia that coined the implementation of genetic testing and personalized medicine (Abu-Elmagd et al., 2015; Korf et al., 2014; McClaren et al., 2020a; Nembaware et al., 2019).

Studies have repeatedly reported the positive attitude towards genetic testing and PGx that resides among healthcare workers. This research is in line with this finding. The vast majority of respondents in this cohort exhibited a positive attitude regarding availability of genetic tests, biobank, and application of genetic testing and PGx. A review by Yau et al. (2015) concluded that doctors working in USA, Canada, Japan, Germany, and Netherlands had positive attitude toward pharmacogenetics despite the poor knowledge. Another systematic literature review disclosed that healthcare specialists saw merit in PGx (Dodson, 2011). Moreover, a study on pharmacists working in Québec (Canada) voiced that pharmacists were very optimistic about the prospective role of PGx (De Denus et al., 2013). In this cohort of healthcare workers in the UAE, a genetic counselor was voted higher for assuming the role and responsibilities of counseling on PGx and genomic test and results, followed by physicians. Only 9.3% believed a pharmacist should assume this role, thereby conflicting with the previous findings of pharmacists having significantly more positive attitude than doctors toward assuming the roles and responsibilities of PGx application and counseling (Elewa et al., 2015). This research's findings fall along the same line as the findings of pharmacists and physicians in Greece, wherein they reported feeling incapable of clarifying the results of PGx tests to their customers or

patients, and the authors tied that to the low level of undergraduate education in genetics and PGx (Mai et al., 2014).

Most healthcare workers in UAE have considered having a genetic test performed at some point in their career in order to make better informed decisions about their respective interventions and treatments. Therefore, a positive attitude toward perceived clinical utility of genomic results can be extrapolated. A mixed method approach conducted by Stark et al. (2019b) on Australian health professionals echoed that genetics professionals perceived higher clinical utility towards rapid genomic testing in neonatal and pediatric intensive care than the intensivists themselves. More than half of the healthcare workers in UAE reflected a positive attitude towards the accessibility of online direct-to-consumer genetic tests. However, primary care workers in Italy deemed the direct to customer genetic tests for chronic complex diseases to not be clinically useful (Baroncini et al., 2015). A systematic review of the literature regarding the standpoint of health professionals concluded that health professionals specializing in genetics were most likely to express concerns toward direct-to-consumer tests due to their deep knowledge in comparison with other healthcare workers (Goldsmith et al., 2013). Another study by Patrinos et al. (2013) exploring the good, bad, and ugly manifestation of direct-to-consumer genetic tests concluded that pharmacists need to be presented with tutoring in genetic testing and counseling (Patrinos et al., 2013).

The top barrier for the implementation of genetic testing and PGx in UAE identified by the respondents was the cost of testing, followed by lack of training or education and insurance coverage, lack of clinical guidelines, insufficient infrastructure, and lack of laws governing privacy and confidentiality. Implementing genetic testing and PGx

in UAE will first require addressing the aforementioned barriers on both individual and systematic levels. Physicians in the USA echo similar opinions as those of healthcare workers in this sample, whereby they rated costs of gene-based therapies and genetic testing as the most significant barrier (Haga et al., 2011; Petersen et al., 2014). A study by Najafzadeh et al. (2012) investigated the barriers to integrating personalized medicine into clinical practice using a best–worst scaling choice experiment and labeled both education and guidelines as barriers to the implementation of genetic testing.

A variety of studies echoed the role of pharmacists in leading the implementation of pharmacogenomics within their work settings (Bain et al., 2018; Bank et al., 2019; Brown et al., 2018; Knapp & Ignoffo, 2020; Schuh & Crosby, 2019a; van der Wouden et al., 2019). Given the UAE's endeavors to follow a multidisciplinary approach for project implementation, ensuring harmony, commitment and unity, including a large variety of healthcare worker specialties in this cohort was very important (Alsaadi et al., 2019; Antoniak, 2004; Haleeqa et al., 2020; Hawamdeh et al., 2013; Manda et al., 2012; Rahmani & Afandi, 2015; Rowland-Jones, 2012). In the focus group discussion conducted among pharmacists working in UAE, they voiced their preference to have a multidisciplinary approach to implement pharmacogenomics (Rahma et al., 2020a).

Aggregating all healthcare workers in one pool is a limitation in this research; therefore, researchers recommend conducting studies focusing on each specialty to insure in-depth and tailored assessments of the gaps in knowledge, attitudes, and existing challenges. Moreover, researchers recommend conducting qualitative studies to physicians, nurses, and genetic counselors as that will lead to opening the door to a more comprehensive understanding of the attitudes of healthcare workers in the UAE.

4.2.2 Qualitative

Lessons from the implementation of genomic medicine and pharmacogenomics worldwide suggest that gauging the knowledge and attitude of healthcare providers is a prerequisite to exploring the road map for the implementation of pharmacogenomics and possibly genomic medicine within the routine healthcare systems. Nevertheless, it is not clear if this is happening now in the UAE. The novelty of these findings is that it is the first qualitative research in the UAE that will allow stakeholders to follow a clear pathway/framework for the adoption of genomics and pharmacogenomics in clinical practice. The findings provide multilayers of factors and inputs like knowledge, attitude, perception, sociocultural factors, and power that will be useful in implementing pharmacogenomics in the UAE.

Several studies evaluated the knowledge and attitude of pharmacists toward genomics and pharmacogenomics world-wide and this research is the first to do so in the UAE. Despite the geographical spaces, pharmacists shared similar attitudes and concerns toward pharmacogenomics (Abdela et al., 2017; Albassam et al., 2018; AlEjielat et al., 2016; American Society of Health-System, 2015; Bush et al., 2019; Muzoriana et al., 2017; Romagnoli et al., 2016; Snyder et al., 2014; Squiers et al., 2012; Tai et al., 2018; Tuteja et al., 2013; Yau et al., 2015). In this sample, the perceived knowledge of pharmacists who worked or studied outside the UAE did not differ from those who worked or studied in the UAE. In addition, being a fresh graduate did not influence the level of the perceived knowledge of pharmacists about genomics and pharmacogenomics and that is in contrast with what Snyder et al. (2014) reported; that new graduates had better knowledge in pharmacogenomics in comparison to senior graduates. Pseudo-knowledge was observed as pharmacists in this sample were mixing

between genomic medicine and genetic engineering or screening and that can be attributed to the poor knowledge and the gap in the curriculum. This calls for incorporating genomics and pharmacogenomics education more effectively in the current training programs. Yau et al. (2015) assessed the practice of genomic medicine and pharmacogenomics by pharmacists as well as their knowledge and attitude in a systematic review and they concluded that pharmacists ought to be taught how to read genetic test reports and act upon them. The research's findings are in accordance with that conclusion, as despite the positive attitude that pharmacists in this sample had toward genomic medicine and pharmacogenomics, they ranked their knowledge level as poor or fair.

The American Society of Health-System Pharmacists (ASHP) highlighted the responsibilities, roles and functions of the pharmacist in the pharmacogenomics era (American Society of Health-System, 2015). However, limited studies assessed pharmacists' health literacy skills and factors prominent to the adoption of pharmacogenomics. A study by Romangnoli et al. (2016) used a qualitative method to assess the resource requisite of the pharmacists in Pittsburgh, United States, and they concluded that whenever a pharmacogenomics tool will be designed, pharmacist's requirements is an essential step to be factored in, particularly in terms of translation of the genetic test. A gap was identified in the tools that pharmacists use to seek information. Most pharmacists in this research identified internet surfing, Google and YouTube as their main source of information, except for a few clinical pharmacists who navigate databases and scientific journals and stated that the internet may have unscientific information. It is worth mentioning that these skills are dynamic in nature and are an integral component of the framework of the pharmacogenomics literacy of

pharmacists. To bridge this gap, authorities and policy makers may provide official clinical practice pathways and references for healthcare providers in the UAE. Pharmacists in this research have agreed that the decision to implement genomics and pharmacogenomics in the UAE is in the hands of stakeholders. A wide range of papers discussed the role of stakeholders and the gaps that hinder the adoption of genomic medicines (Bush et al., 2019; Snyder et al., 2014; Tai et al., 2018).

Fatalism is one of the emergent themes in this study; Elbarazi et al. (2017) had investigated the influence of religion on opinions related to health in the UAE and they highlighted the necessity of having a personalized set of religious values in decision making (Elbarazi et al., 2017). Nevertheless, this research is the first to shed light on the implication of religion on the adoption of genomic medicine among healthcare providers. Pharmacists in this sample were advocates of genetic testing to their offspring and they attributed that to their maternal and paternal instincts of protecting their children; these findings are parallel to the findings of Hallowell et al. (2013) in which participants value the genetic tests in promoting the health of their relatives, particularly their children.

Pharmacists did not agree on the proper and ideal mechanism of implementing genomic medicine and pharmacogenomics in the UAE. Some pharmacists advocated a preemptive pharmacogenetic testing approach, which seeks proactive testing and obtaining the results of the genetic test at the time of prescribing (Keeling et al., 2019). On the other hand, other participants were advocates of the reactive pharmacogenetic testing approach, in which specific drug–gene tests will be requested at time of dispensing (Arwood et al., 2016). Pharmacists perceived that a multidisciplinary team of a physician, pharmacist and genetic counselor may be the best approach to tackle

pharmacogenomic communication in the light of the current scene of the lack of knowledge, workload and shortage of personal (Wurcel et al., 2019).

Myriad studies postulated the feasibility of pharmacists' role in implementing pharmacogenomics at bed side and health settings. A pilot study by Bank et al. (2019) in the Netherlands underscored the efficient role of community pharmacists in recommending intervention based on the drug–gene of the patients, and these recommendations were acknowledged by the clinicians in 88.7% of the patients (Bank et al., 2019).

Stark et al. (2019a) advocated the global liability of transforming genomics into healthcare. In their paper, they delineated the different implementation strategies taken by 15 countries, namely: the UK, France, Australia, Saudi Arabia, Turkey, the US, Estonia, Denmark, Japan, Qatar, Switzerland, the Netherlands, Brazil, Finland and China. These strategies and initiatives can be tools for the adoption of genomic medicine and pharmacogenomics in the UAE to avoid reinventing the wheel and squandering resources.

Pharmacists in the UAE are thirsty for resources and tools to foster their competency in genomics and pharmacogenomics. The Implementing GeNomics In PraTticE (IGNITE Toolbox) is one of many open peer reviewed resources that consolidate the knowledge and implantation efforts of pharmacists and other healthcare providers. The Clinical Pharmacogenetics Implementation Consortium (CPIC) provides guidelines on converting genetics results to actionable interventions (Cavallari et al., 2017a). This is accompanied by the PharmGKB, which grants knowledge incorporated in pathways (Thorn et al., 2013).

Scholars are equipping healthcare providers with tools to overcome the gap in their knowledge. Zarei et al. (2020) coined a web-based pharmacogenomics search instrument for the pharmacogenomics of drugs used in anesthesia. The Genotype-Tissue Expression (GTEx) Consortium is another resource (Keen & Moore, 2015). Ziegelstein (2017), in his commentary, diagnosed personomics as the gap of the adoption and evolution of personalized medicine. In consonance with this punch line, it was hypothesized that the healthcare providers and, more specifically, pharmacists are rooted in the personomics concept. Moreover, addressing their knowledge, attitude and perception will reshape the face of medicine in the country (Ziegelstein, 2017).

As recommended by the 9th Santorini Conference conducted in Greece, establishing a research link between academics and businesses will bridge the gaps and chasm in the roadmap for full implementation of genomic medicine and pharmacogenomics (Visvikis-Siest et al., 2018). These recommendations can guide the UAE in its strategy for implementing genomic medicine and pharmacogenomics.

The strength of this research is that it is the first qualitative research to be conducted among pharmacists in the UAE that discusses the adoption of genomics and pharmacogenomics in the UAE. The qualitative nature of the research allows researcher to dig deeper and enables a comprehensive picture. A limitation of this research was lower representation of the community pharmacists; they declined the participation in the focus group due to workload shifts and their difficulties in obtaining manager approval. Another limitation is the lack of representation of all the seven emirates of the UAE; despite the snowballing sampling technique, researcher could not have enough representation from cities other than Abu-Dhabi city. Researcher found difficulty in recruiting pharmacists to participate in the focus group

discussions; 43 invitations were rejected, mainly due to lack of knowledge about the topic.

4.2.3 PGLP Framework

In the era of personalized medicine, it is plausible to have a personalized framework for genomics and pharmacogenomics literacy which is a tool for the adoption of pharmacogenomics among pharmacists. The researcher factored the individual's factor of the pharmacists and their skills, knowledge, and attitude as well as the sociocultural factors and demands as the input dependent. This PGLP framework can guide the stakeholders in any country as it is comprehensive and systematic.

There is conflict among researchers about the definition of health literacy. For the pharmacogenomics literacy, this research advocates the definition of Baker (2006) as "the dynamic skills to work in the health care setting. These skills vary according to the traits and key features of both individual and the health care system." Baker (2006) stated that health literacy is context specific and fluctuates depending on the type of health problem, the provider and the setting (Baker, 2006). On the other hand, genetic literacy has been defined as "adequate understanding and awareness of genomics foundation to permit knowledgeable outcome" (Syurina et al., 2011).

In the literature, there is an aggregating evidence of the gap in knowledge of pharmacogenomics among healthcare providers (Abdela et al., 2017; Dodson, 2011; Giri et al., 2018; Kim et al., 2020; Rahma et al., 2020b; Stanek et al., 2012; Tsermpini et al., 2019) specifically pharmacists (AlEjielat et al., 2016; Elewa et al., 2015; Karuna et al., 2020; Muzoriana et al., 2017; Rahma et al., 2020a; Tuteja et al., 2013; Adamu Yau et al., 2015). Preponderance of literacy frameworks are dedicated to patients

(Syurina et al., 2011). However, having a literacy framework for pharmacogenomics dedicated for healthcare providers will systematically pave the knowledge gap. The complexity and the multifactorial challenges of the health system coupled with the multidimensional aspects of health literacy necessitate a comprehensive framework to address literacy in pharmacogenomics (Qiang, 2003; Syurina et al., 2011).

Assuring a competent healthcare provider is one of the 10 essential public health wheel of tasks deciphered by Institute of Medicine (Curry, 2005). It spurs empowering all healthcare providers from all levels with ongoing knowledge. Literacy in pharmacogenomics is challenged by the unprecedented advances in technology and research in the field coupled by the need of lifelong learning (Owen, 2011; Romagnoli et al., 2016; Syurina et al., 2011).

Researcher devoted the framework to pharmacists hence they are the hardcore of pharmacogenomics, as articulated in the statement of The ASHP (American Society of Health-System, 2015).

The health literacy skills framework captures a holistic approach toward literacy and it takes into account individual and sociocultural influences; therefore, researcher exploited it to conceptualize the Pharmacogenomics Genomics' Literacy Framework for Pharmacists (PGLP) (Squiers et al., 2012). Researcher tailored it and personalized it to pharmacists in the light of the wealth of codes and data obtained from pharmacists from focus group discussions (Rahma et al., 2020a). The PGLP framework tackled pharmacogenomics' genomics literacy through variety of lenses.

4.2.3.1 How to use PGLP framework?

This framework will guide stakeholders in their mission of equipping pharmacists and potentially genetic counselors, doctors and nurses with skills required for the adoption and implementation of pharmacogenomics. It is consolidated based on a validated theoretical framework for health literacy, which gives PGLP credibility.

PGLP is a personalized literacy framework for the adoption of pharmacogenomics in the era of personalized medicine. It encompasses bundle inputs namely individual and sociocultural factors and highlights the role of demand, skills, knowledge and attitude of pharmacists and potentially other healthcare providers to learn and implement genomics and pharmacogenomics and appeals to their beliefs and instincts.

PGLP strategizes the attempts of stakeholders to educate pharmacists about pharmacogenomics taking in account their individual factors and tailoring modules to meet their role, occupation, and capabilities, whether they are clinical pharmacists or inpatient or outpatient or community pharmacists or a pharmacist setting in a Pharmacy Therapeutic Committee (PTC) or Institutional Review Board (IRB). Personalizing tuition to the type of patients they are serving whether oncology patients, psychiatric, transplant, cardiology, metabolic or geriatric.

Stakeholders occupied by implementing pharmacogenomics in their countries should not isolate their approach from the sociocultural factors incubating and nourishing their infrastructure and resources. They have to tailor their map to their current educational system, health system and cultures. They have to utilize media and call for laws and policy. Moreover, they need to factor religion and literacy of the community.

The demand will set the pace for the pharmacogenomics implantation and hence educational efforts and utilization of PGLP framework.

Catalyzing the three dynamic pillars of skills, knowledge and attitude of pharmacists and healthcare providers will be compelling formula for developing a cost-effective personalized and profound modules and approaches. Knowing the pharmacists' skills will guide the stakeholders in purchasing platforms and databases and other resources and will tailor orientation. Mapping the knowledge and attitude of the pharmacists will help shaping the resources, workshops, seminars, and competencies. This PGLP framework is comprehensive, and researcher theorizes that it will tailor the implementation strategies in a standardized and systematic manner.

Individual inputs to literacy:

Both health literacy skills and PGLP framework embraced the individual traits as input into literacy. Individuals' inputs like age, education, power, roles, and capabilities are traits that need to be acknowledged and factored in while designing any training in any field and pharmacogenomics is not an exception. One uniform approach had been abandoned and replaced by a more tailored and personalized approach that put learner as the center and consider individuals' inherited factors and capabilities to empower them (Crown et al., 2020; Martins et al., 2020; McClaren et al., 2020a; Shuster et al., 2020; Tsai et al., 2020). Many medical and health sciences colleges are embracing this evidence-based shift in paradigm and putting learner in the center stage and tailor the pedagogy according to their individual traits (Berlin et al., 2010; Gálvez-Peralta et al., 2018; Garten & Altman, 2010; Lee et al., 2012; Patrinos & Katsila, 2016). In the pharmacists' cohort, researcher deciphered how diverse the pharmacists' role, power,

and capabilities. Pharmacists working as clinical pharmacists were more familiar with pharmacogenomics than those in community settings. Pharmacists with children were keener to learn about pharmacogenomics as they appreciate and foresee its value. Stakeholders planning a workshop about pharmacogenomics to pharmacists, need to know their audience regarding their demographic, role, occupation, prior knowledge, and experiences. Researcher hypothesizes that this will be a cost-effective approach (Assem et al., 2021; Nicholson et al., 2021; Ward et al., 2020). A study by Owusu-Obeng et al. (2014) scrutinized the role of pharmacists in the pharmacogenomics' era and aligned with this research's findings. In their model, some of the individual's input required from pharmacists are skills in informatics, background in medication safety, insight in medication-use policies and procedures, education, and conquest of literature assessment.

In the published implementation models of pharmacogenomics and in accordance with research's findings, clinical pharmacists were appropriately situated to implement and lead clinical pharmacogenomics programs, as they own individual's input that are plausible such as expertise in pharmacodynamics, kinetics, genomics, informatics, and patient care (Bain et al., 2018; Hicks et al., 2016; Owen, 2011; Owusu-Obeng et al., 2014; Schuh & Crosby, 2019b; Schwartz & Issa, 2017).

Demand or Stimuli:

Researcher adopted demand in the PGLP framework from the HLS framework as it is the switch on button. The demand can originate from the patient and or the clinical setting in a micro, meso and macro-levels (Schuh & Crosby, 2019a).

The American Society of Health-System Pharmacists (ASHP) statements highlighted the pharmacist's patient-care loop. In their statement, patients were at the center-stage for the demand for pharmacogenomics implementation (American Society of Health-System, 2015).

Skills:

Critical skills of accessing, understanding, appraising, and applying knowledge and information are an essential dimension of health literacy and health literacy skills (Freedman et al., 2009; Squiers et al., 2012; Syurina et al., 2011). A study by Peterson-Clark et al. (2010) pointed out that pharmacists scored a shallow general skills in surfing online information and e-health. A randomized clinical trial by Basheti et al. (2009) reported that the retention of the pharmacists' skills was significantly improved after training them on the proper technique of using inhalers and providing them with printed materials and tools. These findings are in congruence with research's findings (Rahma et al., 2020a). It is pivotal to add skills to the PGLP framework; electronic resources and databases are the mainstay of pharmacogenomics like Clinical Pharmacogenetics Implementation Consortium (CIPC) (Caudle et al., 2014) and PharmGKB (Thorn et al., 2005).

Knowledge:

Knowledge of pharmacists is a profound repertoire of literacy. It eluded the health literacy skills framework; however, we advocate and anchor its impact on health literacy in general and pharmacogenomics in particular. Breadth of studies highlighted the gap in knowledge of genomics and pharmacogenomics among pharmacists and other healthcare providers as well as the impact of this gap on implementation (Abdela

et al., 2017; Albassam et al., 2018; AlEjielat et al., 2016; Berenbrok et al., 2019; Karuna et al., 2020; Muzoriana et al., 2017; Nagy et al., 2020; Rahma et al., 2020a; Rahma et al., 2020b; Tuteja et al., 2013; Yau et al., 2015). Knowledge is beyond prior knowledge of basics of pharmacogenomics, it is a bundle of information concerning benefit and applications, knowledge of the available resources, services and practices, knowledge of the cost and insurance coverage, knowledge of the local, national, and international guidelines. Researcher foresees it as a dynamic pillar that needs to be addressed regularly by stakeholders planning literacy in pharmacogenomics and genomics. Knowledge will speed the implementation and adoption of pharmacogenomics in the practice setting of pharmacists. Pharmacists' literacy and competency in pharmacogenomics ought to be assessed and updated regularly (American Society of Health-System, 2015; Benzeroual et al., 2012; Berenbrok et al., 2019; Formea et al., 2013; Papastergiou et al., 2017). Therefore, this pillar and component of the PGLP framework is vital. Credibility of the pharmacists has been pointed out as being essential to the community 'trust or patients 'trust of any health information (Nelson et al., 2009; Hesse et al., 2005; Squiers et al., 2012). Therefore, pharmacists' knowledge of pharmacogenomics will assert such trust from patients and community (Rahma et al., 2020a).

Attitude:

Health skills literacy framework posed attitudes, feelings, incentive, and self-worth, as mediators between health literacy and outcome (Squiers et al., 2012). In the PGLP framework, researcher stressed attitude as an imperative cornerstone toward literacy in pharmacogenomics. Studies have shown that attitude of pharmacists or other healthcare providers or students is a leverage on implementing pharmacogenomics and

genetic testing (AlEjielat et al., 2016; Assem et al., 2021; Dodson, 2011; Elewa et al., 2015; Laskey et al., 2003; Martins et al., 2020; Olwi et al., 2016; Rahma et al., 2020c; Roederer et al., 2012; Stanek et al., 2012; Tuteja et al., 2013; Weir et al., 2010; Yau et al., 2015).

In line with the health literacy skills framework, researcher labeled a dynamic nature to skills as well as the knowledge and attitude. Hence, these elements are interconnected and influence each other and are influenced by the sociocultural inputs as well.

Sociocultural influencers of literacy:

The sociocultural determinants of PGLP framework are more ample than the health literacy skills framework as it incorporated 10 inputs tackling culture, community, patient, media, religion, stakeholders, educational system, laws and ethics, health systems and healthcare providers. Researchers conceptualize that these elements are cross-roads for genomics and pharmacogenomics literacy. The World Health Organization (WHO) apprehended the same sociocultural factors that were appointed in this PGLP framework; Pang (2009) named the fragile health care delivery systems as an obstacle to be addressed. Furthermore, WHO advises stakeholders to implement the following strategy to pursue pharmacogenomics: efficient networks , society confidence, embracing a multidisciplinary tactic to research, intensifying ethical and regulatory contexts, and engaging all relevant stakeholders (Pang, 2009).

Pharmacists are not isolated from the community, health system or other healthcare providers. Pharmacists in the cohort advocate a multidisciplinary approach to implement pharmacogenomics. Studies favored this methodology. A study by

Caraballo et al. (2017) employed a multidisciplinary task force of professionals to strike a balance in the implementation of pharmacogenomics at the point of care. Another study by Dunnenberger et al. (2016) concluded that a multidisciplinary pharmacogenomics clinic can expedite the incorporation of pharmacogenomics into clinical care.

The strength of this work is conceptualizing a novel, comprehensive and personalized pharmacogenomics and genomics literacy theoretical framework tailored for pharmacists. Moreover, PGLP framework is based on published health literacy skills framework that was synthesized upon a number of literacy frameworks (Squiers et al., 2012). Additionally, PGLP framework has been tailored to meet specific individual and sociocultural factors pertaining to pharmacists and pharmacogenomics. Furthermore, researcher added knowledge, attitude as new pillars inherited with pharmacogenomics literacy. Another strength is building the PGLP framework using mixed methods which added thoroughness and depth. Additionally, this framework can be a platform to pharmacogenomics and genomics literacy to other healthcare providers or even other health related literacy.

The PGLP framework is a theoretical framework that needs to be validated. Future implementation research can validate this framework and extrapolate it to other healthcare providers.

4.3 Assessing the Knowledge and Attitude of Students in UAE

The majority of medical and health science students in the UAE had a positive attitude toward genomic medicine and PGx; they would consider having genetic testing done

at some point in their life to find out their future risk of developing genetic diseases. Nevertheless, they had a fair level of knowledge about genomic medicine and PGx.

Dearth of knowledge on genomic medicine and PGx is one of the identified barriers and challenges for the full implementation of genomic medicine and PGx. Studies denoted that healthcare providers had a gap in their knowledge about genomic medicine and PGx (Kim et al., 2020; McCullough et al., 2011; Taber & Dickinson, 2014). Medical and health science students are the future adopters of genomic medicine and pharmacogenomics. Therefore, it is crucial to identify the students' knowledge and attitudes toward genomic medicine and PGx in an early stage so policy makers can intervene and strategize the roadmap for the full implementation of genomic medicine and PGx in the UAE.

Most of the students in the sample did not demonstrate a good level of knowledge in the area of genomic medicine and pharmacogenomics, which could reflect the gap in the educational landscape of genomic medicine and pharmacogenomics in the UAE. This identified gap is aligned with what other investigators had identified in undergraduate medical students in southeast Europe and the United Kingdom (Higgs et al., 2008; Pisanu et al., 2014).

Researcher found significant statistical differences between the level of knowledge of the undergraduates and the year of study. This can partly be attributed to the fact that, based on the mapping of UAE universities' curricula, genetic and PGx courses available to the medical and health science students are incorporated starting from second year. This mimics the trend of genetics and PGx education in the United States and Canadian medical schools (Plunkett-Rondeau et al., 2015). Additional significant

differences were found between the level of knowledge and engagement in a training or educational activity pertaining to genomic medicine or PGx and with the completion of an internship or study program abroad. This finding underpins the infancy of the universities' omics programs in the UAE and articulates the urgency in revisiting these programs to avoid the bottleneck situation warned against by the International Society of Pharmacogenomics in their recommendations to the deans of medical and health sciences schools (Gurwitz et al., 2005).

Researcher anchored a positive prospect in terms of the principles of PGx in the cohort; around 90% of the students articulated that genetic changes affect responses to drugs. This aligns with the positive outcome reported by Talwar et al. (2019) in their systematic literature review. By the same token, students in this sample and pharmacy students in Jordan and West Bank of Palestine lagged behind in denoting the pharmacogenomics' recommendation of the FDA (Jarrar et al., 2019).

Medical and health science students in the UAE are united in terms of their attitudes toward genetic tests under the same banner with medical and health science students worldwide. In this sample, the majority of the students (82.7%) would consider having genetic testing done at some point in their life to find out their future risk of developing genetic diseases. In a study conducted by Laskey et al., (2003) among African American and other marginal students, 95% of them endorsed genetic testing for preventive care. Interrelating attitudes were found among college students in the Kingdom of Saudi Arabia and Greece (Mavroidopoulou et al., 2015; Olwi et al., 2016). Nevertheless, 74.7% of the students in this sample would only like to know their susceptibility to diseases that have current interventions for protection and that synchronized with the Common-Sense Model of Self-Regulation (CSM) framework

for understanding illness self-management, in which students can formulate action plans in response to the threat of genetic tests' results (Cameron & Reeve, 2006; Leventhal et al., 2016).

The overwhelming majority of the students in this sample (around 80%) selected the physician to fill the role of explaining the report of the genetic tests to them, while around 45% of them voted for the pharmacist. This can be a stereotype of the current health system that the students had trained in as well as a reflection of their limited knowledge. Research proposed a partnership between pharmacists, physicians, and genetic counselors as a model to adjust for the gap in knowledge (Kennedy, 2018; Mills & Haga, 2013). Students in the sample stated a myriad of legal and ethical concerns and liabilities. They voiced concerns that the availability of genetic tests could be problematic for insurance companies and future employers. These concerns match those of students in the USA, KSA, Qatar and Greece (El Shanti et al., 2015; Laskey et al., 2003; Mavroidopoulou et al., 2015; Olwi et al., 2016). A heuristic qualitative study conducted in Belgium, explored the direct and indirect worries of genetic tests, and concluded that legislative powers need to be clear and subtle to relieve these concerns about genetic discrimination (Wauters & Van Hoyweghen, 2018).

The majority of students in this sample was optimistic about the future and believed that medicine in the UAE will be more personalized. Most of them agreed that the government should invest more money into its implementation and more time should be dedicated towards tutoring PGx. These stands boost the sporadic effort to implement personalized medicine in the UAE in particular and the GCC, Middle East and North Africa (MENA) region in a wider spectrum. A study by Shah and Shaheen

(2016) foresees the UAE as a fruitful landscape in the genomic era as the UAE is a host to a substantial expat population which translates to versatility in phenotypes in addition to the UAE locals and their unique signature genetic traits. Another study by Mitropoulos et al. (2015) shed light on success stories on the implementation of genomic medicine, and, in their article, they recounted PGx research that launched in 1996 in the UAE and led to the discovery of many novel variants.

Students in the UAE are eager for literacy in genomic medicine and PGx and they highlighted workshops, seminars, and internship to be their preferred pedagogy. The students ranked internet-based courses as their third preference in educational approach, which can craft the strategy to remedy the current gap in knowledge. Existing resources on the Internet consolidate this reciprocity of knowledge (Barh et al., 2013; Berlin et al., 2010; Duong et al., 2020; Gálvez-Peralta et al., 2018; Gurwitz et al., 2003; Hoehndorf et al., 2012; van den Boom et al., 2013). Moreover, researcher explored the students' perceived barriers to the full implementation of genomic medicine and PGx in the UAE. Students in this sample ranked lack of training and education as the first barrier. The breadth of research tackled this barrier. Ta et al., (2019) highlighted in their paper the robust role of PGx education as a panacea toward generating well-informed clinicians who will champion personalized medicine. The students also foresee lack of clinical guidelines, cost of testing, lack of infrastructure as well as lack of community awareness as a bundle of barriers deterring the full implementation of genomic medicine and PGx in the UAE. Corresponding research studies tackled the same barriers and investigated strategies towards overcoming these barriers (Knowles et al., 2017; Mitropoulou et al., 2020).

Assessing the attitudes and knowledge of medical and health science students in the UAE about genomic medicine and PGx is an added tool to the implementation kit needed to construct a roadmap for the full implementation of genomic medicine and pharmacogenomics in the UAE. It empowers stakeholders to tackle the gaps in knowledge and conquer the barriers and challenges.

The inherited bias of information bias and selection bias will be a limitation that had been accepted by previous studies. Snowball sampling is prone to selection bias or community bias, unknown sampling population size, and hence difficulty in calculating an accurate response rate. To address these limitations, researcher scanned all the medical and health science universities in the UAE and employed random selection sampling techniques. However, scarce representation of the Northern Emirates had been detected and this might impact the generalizability of the findings.

4.4 Mapping the Current State of Genetics Testing Services in UAE

The knowledge of the genetics of diseases has been growing exponentially, creating new opportunities for genetic testing, and incorporating such testing into clinical practice (Burke et al., 2001). This has impacted the advancement of diagnostic tools for genetic diseases, which has proven to be very useful for preventing, managing, or treating these diseases. Also, it has proven useful for the timely management of certain diseases, in which screening and early intervention have been effective for controlling the symptoms and complications and improving the prognosis of some genetic diseases (Burke et al., 2001). In the mapping, researcher sought to create a baseline of the genetic testing landscape in UAE. Moreover, researcher attempted to examine the

information provided on the website of the laboratories in UAE and compare it to the onsite information provided by laboratory's personnel.

Genomic medicine is defined as using an individual patient's own genotypic information for their clinical care (Manolio et al., 2013). Despite its great potential to contribute to the advancement of clinical care, genomic medicine was restricted to research purposes until 5 years ago. It has taken a long time for this knowledge to be applied in clinical practice (Landry et al., 2018; Manolio et al., 2013). Globally, a range of academic medical centers and integrated health systems have already initiated programs to implement genomic medicine (Manolio et al., 2013).

Rapid progress has been made in identifying the molecular basis of human inherited disorders. This has been driven by new technological developments that have dramatically reduced the cost of genetic analysis. This has resulted in increased numbers of genetic testing centers emerging in many parts of the world (Sagia et al., 2011). The current population of the UAE is estimated to be 9,960,509. Nearly 75% of the population of UAE is clustered on the northeast. The two main cities Dubai and Abu Dhabi have more than 3 million residents each. All UAE citizens can access private sectors but not vice versa. However, insurance companies do not fully cover costs of genetic tests which is a concern with regard to accessibility and acceptability (World Population Review, 2021; Nyika, 2009).

In the Gulf countries, including the UAE, there is a high frequency of consanguineous marriage (estimated to be 12% – 70%), which is responsible for the high frequency of genetic diseases. This includes, but is not limited to, hemoglobinopathies and inborn errors of metabolism. Previously, in certain Gulf countries, molecular diagnostic

samples were sent abroad for testing and analysis, but the results of significant numbers of samples came back negative or inconclusive. This can be attributed to the established differences in genetic profiles between the Gulf region and the West as supported by a number of studies where novel and distinctive hotspots for disease-causing mutations that are unique to the Gulf Arabian patients were identified. Therefore, Gulf countries have adopted local strategies to develop and establish their own accredited molecular diagnostic laboratories through research and development (Zayed & Ouhtit, 2016).

In general, the findings indicate rapid growth in the field of genetic services provided in the UAE, reflected by the rapid increase in the number of laboratories and the variety of tests provided. The increased number of laboratories in Abu Dhabi and Dubai clearly reflects the need for a broader range of health services due to the larger population and greater cultural diversity in these two emirates in particular. There was a general reluctance among the private laboratories to participate in the survey. The same hesitance was also reported in a similar study from Greece (Sagia et al., 2011) .

This research indicated that prenatal testing appears to be the most required test across the centers. This is expected given the high number of birth defects reported in the UAE compared to the levels in other countries with similar rapidly developing health services such as Malaysia, where clinical tests are in higher demand (Balasopoulou et al., 2017).

Only six of the surveyed laboratories claimed to provide pharmacogenomic testing among their services. This is a low level compared with that reported in similar studies performed in Greece (61.5%) and Malaysia (15%) (Balasopoulou et al., 2017; Sagia

et al., 2011). This is possibly due to a lack of awareness of the role of pharmacogenomics in personalized medicine, resulting in its limited implementation in patients' management. In Greece, the relatively limited implementation was attributed to discouragement from pharmaceutical companies as implementation of the results can affect their profit margins (Sagia et al., 2011). The genetic tests and tools offered in UAE are not comprehensive and may hinder genomics implementation in UAE. According to Monte et al. (2012) myriads of omics screening and tools are vital for the therapeutic safety and efficiency in pragmatic setting including genomics, epigenomics, transcriptomic, proteomic and metabolic polymorphisms.

As genetic technology advances, the practices of genetic testing have become more heterogeneous, with many different types of tests being added to the list of tests provided to the public in different settings and for a variety of purposes (Balasopoulou et al., 2017). A good example of this is increased demand for wellness and fitness tests, which were advertised through the websites of 33% of laboratories in this research. Researcher thinks that this is one of the repercussions of a growing focus on health awareness issues and wellness in the media. This rise has occurred despite the fact that such tests lack a robust evidence-base (Balasopoulou et al., 2017).

The results showed that among all DNA sources for genetic testing listed by the different laboratories, blood samples were the most common, followed by saliva and sputum, in agreement with studies performed elsewhere (Balasopoulou et al., 2017; Sagia et al., 2011). Despite the debate in literature, it seems that physicians and the general public still tend to believe that peripheral blood provides a more solid scientific basis as a DNA source for genetic testing than other sources (Sagia et al., 2011).

The genetic services provided by the genomic centers are mainly directed to clinical services through hospital referrals. Complete genetic counseling services are available in 8 of the 15 laboratories providing counseling. Complete genetic counseling is defined here as the presence of a certified genetic counselor/clinical geneticist that waives the need for referring stakeholders to another place to interpret the reports and act on the consequences of the results. As most of the surveyed laboratories deal directly with hospital referrals, this can explain the absence of complete counseling services, which was also reported by Sagia et al. (2011) in Greece. The fact that only 1 of 27 laboratories provides information about consent forms raises serious ethical concerns about privacy, confidentiality, anonymity of individual tests, and the fate of the genetic material. Similar concerns have been raised about genetic testing practices in Greece and Malaysia (Balasopoulou et al., 2017; Kechagia et al., 2014; Sagia et al., 2011).

Most of the laboratories, as per the questionnaire survey, stated that they maintain high standards and keep a positive reputation among the public by maintaining accreditation, giving a sense of reliability and accuracy of their test results. However, this did not match our findings from examining the websites of these laboratories. Only 40% clearly stated the type of accreditation and the accredited body on their websites. In addition, only 4 of 27 laboratories have been certified for the provision of genetic testing services, specifically ISO-15189 and/or ISO-17025. The rest of the laboratories were accredited by different accreditation bodies, including Royal College of Pathologists of Australia/National Association of Testing Authorities, College of Canadian and American Pathologists (4 laboratories) and Joint commission international (2 laboratories). Other labs stated they are accredited with ISO with no

other specifications. The status of accreditation renewal on the companies' webpages could not be tracked.

The findings highlighted a discrepancy between the data collected by the two adopted methods and that raised a red flag. The discrepancy was noticed in types of services provided, DNA sources, type of genetic counseling provided and the updated status of the relevant websites. Genomic medicine is a new field to the community of the UAE, and no studies have evaluated the genomic literacy of the population of the UAE. Thus, the community and health professionals may be misled by the information advertised in the websites of those laboratories, especially since some of the laboratories are not accredited by accreditation bodies which is another red flag. A study by Sabatello et al. (2019) concluded that society has some understanding of genetic vocabulary but has gaps in the interpretation of its constructs. A recent study by Bukini et al. (2020) highlighted the correlation of low genomic literacy with consenting to genomic tests and the need to execute more techniques to enhance the public's understanding of genetic tests and preserve their safety and privacy. Another recent study by Comess et al. (2020) voiced the need for empowering investigators and public health society with artificial intelligence methodologies to bridge gap and translate data from in silico to bedside. Stakeholders in UAE must tackle this challenge to fully implement genomics in the country.

The results showed that different types of health insurance are accepted by most of the laboratories covered in the survey. Most of these centers provide services for which the cost is partly covered by health insurance, while very few have services fully covered by health insurance.

By mapping the data using an internet search, it was clear that most laboratory websites lack critical information, which might be a concern for patients and clinicians. This includes information about legal issues, sample storage, consent forms, standardization of tests, and costs. Researcher believes that written consent and ensuring ethical and legal principles including autonomy, confidentiality, privacy, and equity should be mandatory for all laboratories to protect both parties. Public debates about the ethics of developments in human genetics research has a complex history. In an attempt to distance present practice from past abuses, debate in Europe and USA has been focused on the implications of developments in genetics for individuals rather than populations and societies. The debate has led to the emergence of three principles: consent, privacy, and confidentiality. The genetics ethics state that genetic information should be only obtained from people who have given genuine consent—meaning information has been communicated appropriately and consent has been given freely. Confidentiality in genetic testing means that genetic information should not be communicated to others or used for new purposes without the person's consent. Privacy in the context of genetic testing is understood as a person's right to not be obliged to disclose information about his or her genetics characteristics (Thomas, 2004).

The strength of the research is being the first attempt of mapping the genetic services in the UAE and having a baseline of the genetic services landscape in UAE. To ensure accuracy of the data gathered from the laboratories on their services, researcher adopted two methods for collecting data: a web survey and an onsite survey.

It is difficult to draw a definitive conclusion based on the information gathered from the survey, since some laboratory managers were either selective in which questions

in the survey they responded to or did not know the definitive answers to some questions. There was a general reluctance among the laboratories to participate in the survey, leading to incomplete plotting of the genetic services in UAE. Additionally, participants did not provide detailed information about their services which hindered the mapping. The websites' lack of data on last updated information and the dynamic nature of the environment of genomic services in UAE are limitations to this mapping.

4.5 Establishing a Stakeholders' Matrix of Power and Interest

Stakeholders in healthcare systems are the major team players and mapping their role, power, interest, and stance is a critical consideration for implementing genomic medicine and pharmacogenomics (Mitropoulou et al., 2020). This will support shaping the roadmap of genomic medicine and pharmacogenomics in the UAE. Supporting standard policies will set up the stage for robust systems in the country.

Role of stakeholders in operationalizing genomic medicine and pharmacogenomics in healthcare and educational systems has been studied extensively. Mitropoulou. et al. (2020) stated that mapping the views of stakeholders paves the road for standardizing national polices. In a recent qualitative study, Best et al. (2020) concluded that pinpointing areas of discrepancies or cohesions among stakeholders will guide them in meeting their needs. The literature review carried out by Roberts et al. (2017) identified the role of stakeholders as a prospect for implementing genomics medicine.

The qualitative nature of the research allowed researcher to dig deep in the stance and interest of stakeholders in UAE. Most of the stakeholders in this research ascertained the clinical demand of genomic medicine in UAE. They aligned this demand with the high prevalence of consanguinity in UAE, the high burden of genetic diseases, the urge

to utilize the genomic technology to personalized medications, and the increased awareness among physicians about the power of genetic services that motivated them to demand genomic medicine. These rationalizations are backed by research conducted in UAE, for instance, Denic et al. (2013) associated consanguinity with the prevalence of β-Thalassemia in Abu Dhabi. Another study by Al-Jasmi et al. (2012) concerning the burden of Lysosomal storage recessive disorder, concluded that UAE had 40-fold higher prevalence compared to western countries and is linked to consanguinity in UAE. Al-Gazali and Ali (2010) reviewed the mutation of single gene disorders and reported that UAE ranked sixth in accordance with the prevalence of birth defects, and they attributed that to the norm of consanguinity.

The positive stance of stakeholders in UAE toward the clinical demand of genomic medicine in UAE is comparable to other stakeholders in the world. In their analysis of stakeholders in Greece, Mitropoulou et al. (2014) reported similar findings; though in their study, the Ministry of Health and public healthcare insurance funds had opposite stances.

Infrastructure is one of the robust pillars for the implementation of genomic medicine and pharmacogenomics (Mitropoulou et al., 2020). Many of the stakeholders in UAE favored building an internal infrastructure in the country over the current norm of sending and processing genetic samples abroad. They expressed the fact that UAE is a wealthy country and can afford building this infrastructure. Interestingly, one of the interviewed stakeholders was responsible for building an internal capacity in UAE and their first project is the Genome Program to sequence Emirati reference genome. The stakeholder agreed that having an internal infrastructure will troubleshoot any issues related to privacy, extra cost, and the delay in receiving the results. Whereas those

stakeholders working as Chief Executive Officers and other administrative roles preferred to wait until a demand is able to bring return on investment. That is in line with the stakeholders in Greece who voiced resources as one of the obstacles and challenges for full implementation of genomic medicine and pharmacogenomics (Mitropoulou et al., 2014).

There has been other projects to sequence the human genome in UAE as well as its neighboring countries: Kuwait, Saudi Arabia, and Qatar (Al-Ali et al., 2018). However, the stakeholders warned that the scattered and fragmented nature of these projects did not add value to the target of having UAE database or even GCC database. Evidence from other studies underscored the issue of fragmentation and recommended having a governance committee with proactive measures (Cornel et al., 2012).

Most of the stakeholders in this sample viewed genomic medicine and pharmacogenomics as cost-effective. One of the stakeholders disclosed that they are in the process of studying this in UAE and has approval from the institutional review board to do so. This demeanor leverages the implementation of genomics medicine and pharmacogenomics in UAE as numerous research provided evidence pertaining the cost-effectives of genomic medicine and pharmacogenomics (Fragoulakis et al., 2019; Girardin et al., 2019; Kasztura et al., 2019; Stark et al., 2019c; Zhang et al., 2019).

However, a stakeholder working in an insurance company had an opposite stance about the cost-effectiveness of genomic medicine and pharmacogenomics in UAE. This attitude raises a red flag. Reimbursement has been identified by Implementing GeNomics In PracTicE (**IGNITE**) network as one of the seven key drivers of

genomic sustainability (Levy et al., 2019). Levy et al. (2019) stated that embracing genomic medicine is challenged by evidence considered necessary for payers to vindicate reimbursement. A study by Hess et al. (2015) was in line with research's findings and they justified the attitude of insurance companies that they are viewing pharmacogenomic tests as experimental not clinical. Further research is needed to analyze this attitude and uncover its explanation to overcome this obstacle in its infancy stage in UAE.

The debate about the best approach for implementing genomic medicine and pharmacogenomics is a hot topic in research (Hart et al., 2019; Leary et al., 2019; Marrero et al., 2020; Nallaseth, 2019). The researcher articulates this in the interview guide. The majority of the stakeholders in UAE favored preemptive approach which seeks testing proactively once in lifetime and having the results of the genetic test ready at time of prescribing over the gene-specific approach. Only the two genetic counselors in the cohort were skewed toward gene-specific approach because they anticipated the dilemma of incidental findings (Lannoy et al., 2019).

On the same theme of genetic testing, most of the stakeholders in UAE are opposing online direct-to-consumer kits. They attributed that to lack of awareness among the community in UAE, lack of regulation and the missing piece of counseling by genetic counselors that are not offered by most direct-to-consumer kits. These attributes had been addressed in research. Schleit et al. (2019) discussed a case of a false negative result and how it poses harm not only for the person taking the test but also to their relatives. Direct-to-consumer is not yet licensed in UAE; however, stakeholders are occupied with health and safety of the UAE community and voiced the need to have regulations in place to protect and educate consumers. Moreover, they proposed the

alternative of accredited clinic-based tests with affordable prices, which are coupled with genetic counseling service (Mitropoulou et al., 2014; Mitropoulou et al., 2020; Schaper et al., 2019; Schleit et al., 2019; Tandy-Connor et al., 2018; Weedon et al., 2019).

On the verge of the implementation of genomic medicine and pharmacogenomics in UAE, some of the stakeholders are occupied with ethical and legal concerns whereas, few stakeholders have not thought about it. These concerns have been consolidated in literature, such as: confidentiality of the results of genetic test in the cloud era, insurance discrimination and employer discrimination (Bélisle-Pipon et al., 2019; Dove et al., 2015; Jooma et al., 2019). These findings are in line with the concerns of stakeholders in Greece (Mitropoulou et al., 2014), and USA (Bélisle-Pipon et al., 2019). One of the stakeholders foresees the need to modify the consent process and adopt a dynamic consent process instead. This is a trajectory that requires enforcing laws and legislation to protect privacy, confidentiality, and autonomy of the patients (Manson, 2019; Meagher et al., 2020; Tindana et al., 2019). Overall, the researcher considers this a pressing need to address before it becomes a barrier (Mitropoulou et al., 2020).

An imperative exploration from the interview of stakeholders is the list of anticipated barriers and challenges for the full implementation of genomic medicine and pharmacogenomics in UAE. Identifying these risk variables gives the stakeholders a vantage point to proactively overcome these barriers. Addressing these risks by the experts will pave the way to the full implementation of genomic medicine and pharmacogenomics in UAE (Rastogi & Trivedi, 2016; Walters & Kitchin, 2009).

Implementing the strategies dictated by the Mendelow's business model will allow the systematic implementation of genomic medicine and pharmacogenomics. It will facilitate saving time and resources by engaging the key players (promoters and defenders) as well as engaging and satisfying the latent stakeholder (Anney, 2014; Elsaid et al., 2017; Gottschalk, 1999; Kuzmin & Khilukha, 2016; Mendelow, 1981).

This research is the first attempt to explore the attitude and stance of the stakeholders in the UAE. The qualitative methodology allowed mapping the power/interest matrix of Mendelow's model which is a substantial footstep for achieving the full implementation of genomic medicine and pharmacogenomics in UAE.

Similar to other qualitative studies, the shortcoming of generalization is the inheritance limitation in this research. However, researcher sets the stage for conducting quantitative studies to satisfy generalization. Another limitation is lack of representation of the media, pharmacists, religious authority, and other stakeholders. Nevertheless, researcher was able to map various stakeholders representing different sectors of the UAE. Researcher insured the credibility, reliability, and quality of the research by ensuring the Lincoln and Guba (1986) evaluation criteria: triangulation, respondent validation reflexivity, peer debriefing and audit trail, as well as using validated tools and models from the business arena.

In summary, the assessment of university curricula resulted in "genetics" being included in the majority of universities syllabus. PGx was taught in six universities but only for Pharmacy majors. The mean knowledge score of the surveyed healthcare providers was 5.2 (± 2.3) out of nine, which shows a fair level of knowledge. However, 92% showed a positive attitude regarding availability of genetic testing. The top

identified barrier for implementation for genomics and PGx was the cost of testing (62%), followed by lack of training or education of genomics and PGx (58%) and lack of health insurance coverage (57%). Moreover, the mean knowledge score for medical and health sciences students was 5.4 (± 2.7). Regarding genetic and genomic services, prenatal testing was the most offered genetic service among the laboratories included in the research, and blood samples was the main sample type for genetic testing followed by saliva. There was no standardization of the accreditation bodies, health insurance coverage. Most of the interviewed stakeholders emphasized the clinical demand for genomic medicine in UAE. However, many were less inclined to articulate the need for PGx at present. Most of stakeholders were in favour of building infrastructure for better genetic services in the country. However, stakeholder from health insurance sector had a contradicting stance about the cost-effectiveness of genomic medicine. The majority were concerned with the legal and ethical aspects of genomic medicine and had an opposing stance on direct-to-consumer kits.

Chapter 5: Conclusion

The conclusion of this research will be presented as a synopsis of what was found in each pillar of the research. Furthermore, the implications of the findings will be presented as the roadmap for the full implementation of genomic medicine and pharmacogenomics in UAE.

5.1 Research Implications

This research set the stage for the stakeholders occupied with implementing genetic testing and PGx in the UAE. Healthcare workers are the front-liners and the champions of the implementation strategies. Therefore, mapping their knowledge, attitudes, and concerns toward genetic testing and PGx will direct the framework for implementation. Crossing and bridging the chasm of knowledge will steer the implementation. Researcher therefore recommends launching Continuing Medical Education (CME) accredited workshops presenting case studies and blended learning for healthcare providers. Researcher urges collaboration between academia and healthcare to utilize experts in the field, seeing as most healthcare workers in the UAE have not studied pharmacogenomics as part of their education. The positive attitude of healthcare workers will facilitate and guide the implementation strategies by identifying multidisciplinary champions. Researcher commends the integration of genetic counselors in the implementation modules to bridge the current gap in knowledge and ability to counsel patients. Researcher urges the stakeholders to declare and implement laws to protect the privacy and confidentiality of genetic test results to avoid discrimination by insurance companies. Researcher proposes streamlining and benchmarking the workflow, algorithms, and guidelines. Researcher advocates better

utilization of technology and attributing the electronic decision support to back up healthcare workers in the UAE.

Moreover, the assessment of the knowledge and attitudes of students of medical and health sciences schools in the UAE captures the gaps and harnesses measures to address these gaps. Students of today are the champions of personalized medicine tomorrow. Stakeholders in the UAE must strive to acquaint their students with up-to-date knowledge of genomic medicine and PGx. Researcher recommends updating the curriculum of the medical and health sciences under the supervision of the experts in the field and in line with accreditation bodies. Researcher proposes stand-alone courses in genomic medicine and pharmacogenomics for both under- and post-graduate medical and health science students. Researcher recommends initiating a rapport between academia and health setting to impute knowledge and translate knowledge into practice.

Mapping the educational environment of genomics and PGx in UAE is a heuristic stage that will galvanize the implementation trajectory. The positive attitude along with the interest of the stakeholders in academia is a well-aimed arrow in the flight of implementation. The researcher recommends the following 11 strategies with regard the educational environment of genomics in UAE:

1. Having a standardized curriculum of genomics and PGx for each health science fields (medicine, pharmacy, nursing, dental, pathology… etc.).

2. Using the blended teaching approach to recruit experts in the field that can teach courses online.

3. Benchmarking with the international universities and organizations for collaboration and accreditations.
4. Blending the laboratory components in the curriculum as literatures prove it efficient.
5. Imputing ethical, legal aspects of genomics and PGx in the curriculum.
6. Adopting “Train the trainer” strategy.
7. Embarking on the basics of genomics and PGx in elementary schools using innovative pedagogy.
8. Fostering the collaboration between academia and healthcare setting to produce research and databases.
9. Spanning the residency and fellowships opportunities to include genomics, PGx, bioinformatics, and genetic counseling.
10. Mandating the stand-alone courses of genomics and PGx in the curriculum for both undergraduates and postgraduates.
11. Establishing national accreditation counsel to train, educate and license healthcare providers.

There has been rapid growth of genetic services in the UAE because of the rapid economic growth and standardization of healthcare; however, the private genetic services appear to lack an appropriate regulatory framework, which is also the case in some European countries including Greece. A wide variety of high-quality certified genetic services are provided by different centers and are mostly directed to clinical

care, but not toward research. These centers are mainly concentrated in Dubai and Abu Dhabi. Some form of counseling (complete/partial) service is provided by 51.8% of the genetic centers. By mapping the data using an internet search, it was clear that most laboratory websites lack critical information, which might be a concern for patients and clinicians. This includes information about legal issues, sample storage, consent forms, standardization of tests, and costs. Researcher believes that written consent and ensuring ethical and legal principles including autonomy, confidentiality, privacy, and equity should be mandatory for all laboratories to protect both parties.

Researcher also recommends that laboratories put some effort into updating and maintaining their websites. We are in an era of wide integration of technology, and researcher thinks that keeping the public informed is a civic duty for everyone in the field of genetic testing. Moreover, the present research highlighted the potential lack of genetic counseling services, bioinformatics analysis, and DNA bio-banking on the market, which is essential for overall genetic profiling and disease prevention.

Researcher foresees these findings as the launching point for establishing a strategy for the implementation of genomic medicine and pharmacogenomics in UAE. This will facilitate the construction of a roadmap for the full implementation of genomic medicine and pharmacogenomics in the UAE with potential applicability to many healthcare systems around the world. The periodic mapping of stakeholders in UAE is a key element in the roadmap. Researcher recommends building on these findings by conducting a quantitative research and replicating it on a different timeline to capture the dynamic stance and interest of stakeholders in UAE.

5.2 Roadmap for the Full Implementation of PGx in UAE

The gathered data from the mixed method approach captivated the root causes of the delay of the implementation of genomic medicine and pharmacogenomics in UAE. These gaps and root causes are presented in the Ishikawa fishbone diagram (Figure 21).

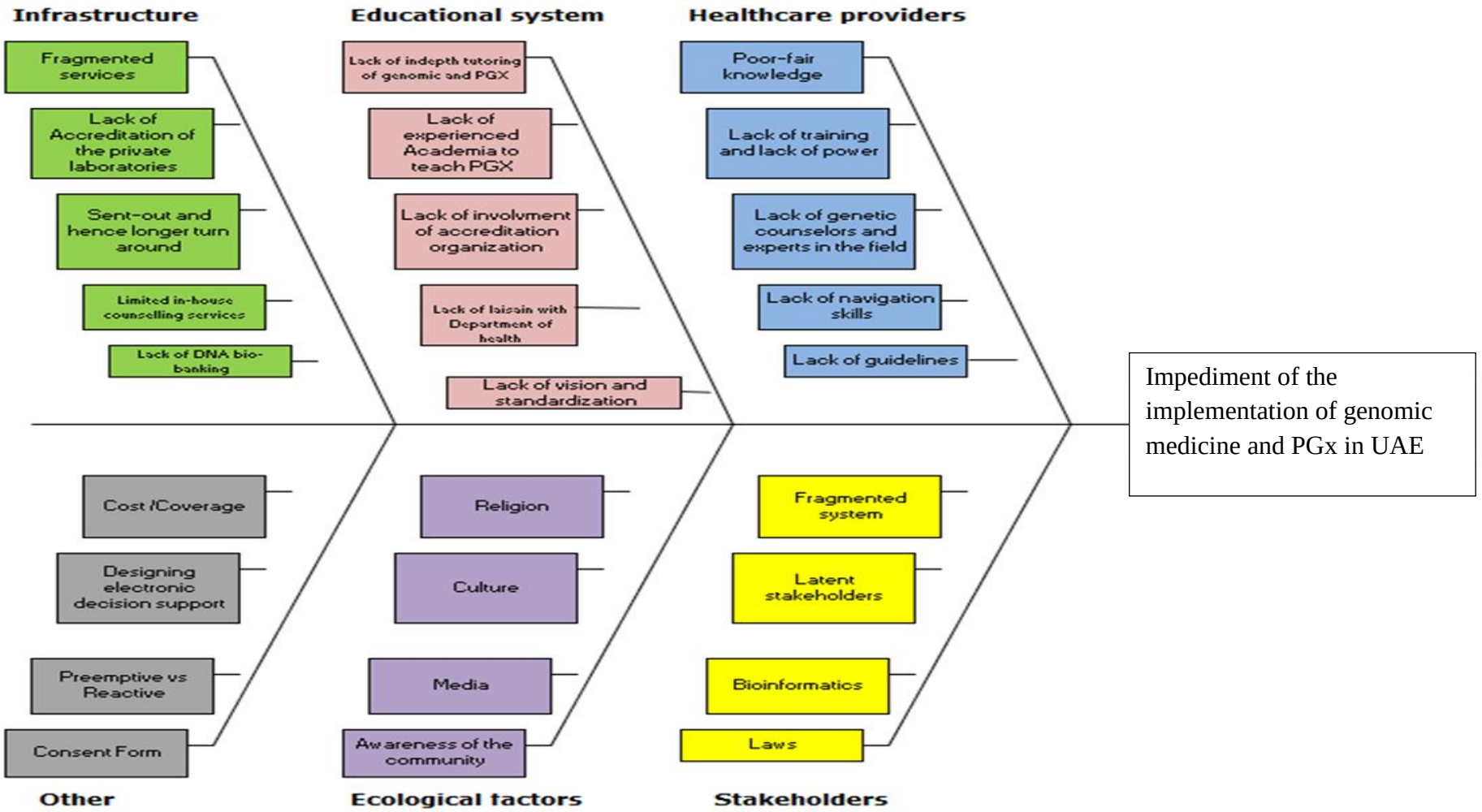


Figure 21: Root causes of the hindered implementation of PGx in UAE

Based on the results tackling the spectrum of public health genomics in UAE, The, researcher declares that the answer to the research questions, is that UAE is in the midway in terms of implementing genomics and PGx. There are fragmented attempts to tackle this field, manifested in the growing interests of adding genomics in the curriculum, offering masters in genetic counseling, building infrastructures, hosting workshops in genomics and pharmacogenomics targeting healthcare providers, starting the Emirati reference genome projects as well as motivating stakeholders to get on board, however solid strategy and clear roadmap is needed to save resources and harvest outcomes. Researcher conceptualized a roadmap for the implementation of genomic medicine and pharmacogenomics in UAE (Figure 22). It was constructed based on all the results and findings of the mixed method approach of this research and based on the bundle of root causes that reside in the infrastructure, educational system, healthcare system, healthcare providers, and stakeholders. It combines both bottom-up and up-bottom approach.

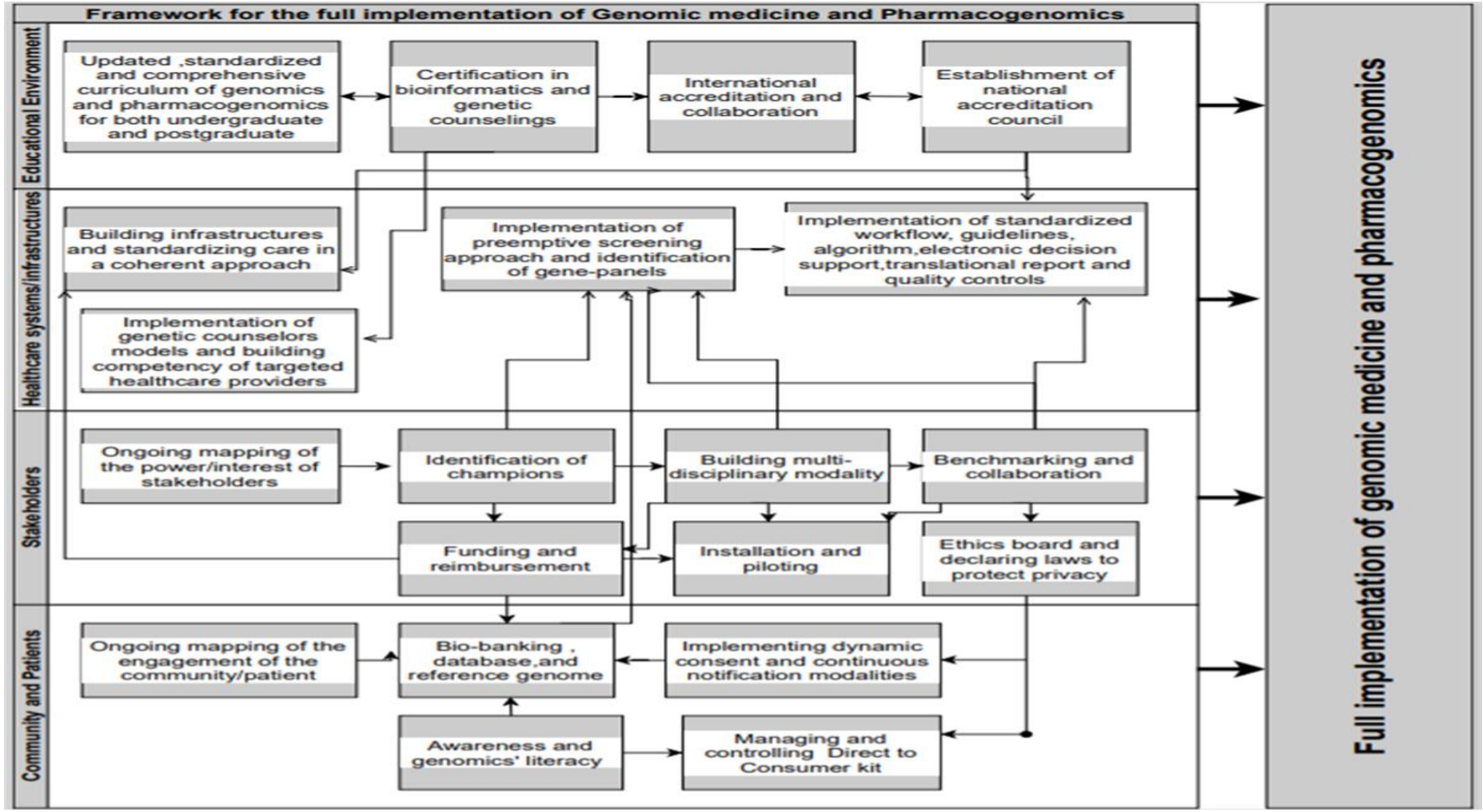


Figure 22: Roadmap for the full implementation of genomic medicine and PGx

This roadmap will facilitate, guide, and strategize the initiatives and proposals to implement genomic medicine and pharmacogenomics not only in UAE but in other neighboring countries as well. It tackles multi-pillars that had been identified by researchers and stakeholders around the world in concordance with the public health aspects. The components of the roadmap span over educational environment, the healthcare systems and infrastructures, the stance of stakeholders and community/patients. This roadmap can be the backbone for all the stages and phases of implementation: exploration, installation and both initial and full implementation of personalized medicine. Moreover, the roadmap can be tailored to meet the objectives, resources, mission, and vision of the stakeholders in UAE or any other country.

The future directions of this research are the continuous and periodic assessment of the pillars of the roadmap in terms of knowledge, attitude, needs, power, and interest. Hence, the findings presented in this research are a baseline that can be a point of reference for the proactive implementation strategy. Additionally, the researcher requests to assess the knowledge, attitude, perception and the genetic literacy of the community and patients in UAE to strategize and assort the implementation resources and approaches. Researcher calls investigators to validate the PGLP framework and the road map for the full implementation of genomic medicine and pharmacogenomics in UAE. Moreover, the researcher anticipates the role of artificial intelligence to bridge the gap between science, knowledge, and application. Artificial intelligence tools will act as a safeguard and safety net for healthcare providers and will streamline the process. Moreover, it will allow up-to-date access and utilization of research. Training local IT experts in bioinformatics will speed the implementation process and ought to be a priority. Additionally, marrying the artificial intelligence with the UAE reference genome and basics of pharmacology will host the discovery of targeted therapy and

will give a face to personalized medicine for UAE nationals and the Arab world. Other disciplines of OMICS like epigenomics, metabolomics must be explored too to ensure a holistic approach to implementation and avoid barriers and wastage of time, money, and resources.

References

Abdela, O. A., Bhagavathula, A. S., Gebreyohannes, E. A., & Tegegn, H. G. (2017). Ethiopian health care professionals' knowledge, attitude, and interests toward pharmacogenomics. *Pharmacogenomics & Personalized Medicine, 10*, 279-285. https://doi.org/10.2147/pgpm.s145336

Abou Tayoun, A., Loney, T., Khansaheb, (…), & AlDabal, L. (2020). Whole genome sequencing and phylogenetic analysis of SARS-CoV-2 strains from the index and early patients with COVID-19 in Dubai, United Arab Emirates, 29 January to 18 March 2020. *bioRxiv*. https://doi.org/10.1101/2020.05.06.080606

Abu Haleeqa, M., Alshamsi, I., Al Habib, A., (…), & Ibrahim, H. (2020). Optimizing Supportive Care in COVID-19 Patients: A Multidisciplinary Approach. *Journal of multidisciplinary healthcare, 13*, 877-880.

Abu-Elmagd, M., Assidi, M., Schulten, H.-J., (…), & Al-Qahtani, M. (2015). Individualized medicine enabled by genomics in Saudi Arabia. *BMC medical genomics, 8*(1), 1-17.

ACMG Board Of Directors (2017). Laboratory and clinical genomic data sharing is crucial to improving genetic health care: a position statement of the American College of Medical Genetics and Genomics. *Genetics in medicine : official journal of the American College of Medical Genetics, 19*(7), 721-722.

Adams, S. M., Anderson, K. B., Coons, J. C., (…), & Empey, P. E. (2016). Advancing pharmacogenomics education in the core PharmD curriculum through student personal genomic testing. *American journal of pharmaceutical education, 80*(1), 3. https://doi.org/10.5688/ajpe8013

Akawi, N. A., Al-Gazali, L., & Ali, B. R. (2012). Clinical and molecular analysis of UAE fibrochondrogenesis patients expands the phenotype and reveals two COL11A1 homozygous null mutations. *Clinical genetics, 82*(2), 147-156.

Akawi, N. A., Ben-Salem, S., Hertecant, J., (…), & Al-Gazali, L. (2016). A homozygous splicing mutation in ELAC2 suggests phenotypic variability including intellectual disability with minimal cardiac involvement. *Orphanet journal of rare diseases, 11*(1), 139. https://doi.org/10.1186/s13023-016-0526-8

Al-Ali, M., Osman, W., Tay, G. K., & AlSafar, H. S. (2018). A 1000 Arab genome project to study the Emirati population. *Journal of human genetics, 63*(4), 533-536.

Al-Gazali, L., & Ali, B. (2010). Mutations of a Country: A Mutation Review of Single Gene Disorders in the United Arab Emirates (UAE) [Review]. *Human Mutation, 31*(5), 505-520. https://doi.org/10.1002/humu.21232

Al-Gazali, L. I., Alwash, R., & Abdulrazzaq, Y. M. (2005). United Arab Emirates: communities and community genetics. *Public Health Genomics, 8*(3), 186-196.

Al-Jaibeji, H. S., John, A., Al-Gazali, L., (…), & Ali, B. R. (2016). Allele and genotype frequencies of the two single nucleotide polymorphisms in the VKORC1 gene that are most important for warfarin treatment among Emiratis. *Hamdan Medical Journal, 212*(3849), 1-10.

Al-Mahayri, Z. N., Al Jaibeji, H. S., Saab, Y., (…), & Ali, B. R. (2019). VKORC1 variants as significant predictors of warfarin dose in Emiratis. *Pharmacogenomics and personalized medicine, 12*, 47-57.

Al-Mahayri, Z. N., Patrinos, G. P., Wattanapokayakit, S., (…), & Ali, B. R. (2020). Variation in 100 relevant pharmacogenes among emiratis with insights from understudied populations. *Scientific Reports, 10*(1), 1-15.

Al-Gazali, L., & Ali, B. R. (2010). Mutations of a country: a mutation review of single gene disorders in the United Arab Emirates (UAE). *Human Mutation, 31*(5), 505-520.

Albassam, A., Alshammari, S., Ouda, G., Koshy, S., & Awad, A. (2018). Knowledge, perceptions and confidence of physicians and pharmacists towards pharmacogenetics practice in Kuwait. *Plos One, 13*(9), Article e0203033. https://doi.org/10.1371/journal.pone.0203033

Alblooshi, H., Al Safar, H., Fisher, H. F., (…), & Tay, G. K. (2019). A case–control genome wide association study of substance use disorder (SUD) identifies novel variants on chromosome 7p14. 1 in patients from the United Arab Emirates (UAE). *American Journal of Medical Genetics Part B: Neuropsychiatric Genetics, 180*(1), 68-79.

AlEjielat, R., Ejielat, Z., Andrawes, S., & Mhaidat, N. M. (2016). An evaluation of the knowledge, opinions, expectations and concerns toward pharmacogenomics among Jordanian pharmacists. *Personalized Medicine, 13*(2), 143-154. https://doi.org/10.2217/pme.15.50

Algahtani, M. (2020). Knowledge, Perception, and Application of Pharmacogenomics Among Hospital Pharmacists in Saudi Arabia. *Risk Management and Healthcare Policy, 13*, 1279-1291.

Alharbi, A. A., Shaqran, T. M., Eltobgy, A. A. E., Albalawi, A. R., & Alnawmasi, W. S. (2019). Physicians' Perspective on Diabetes Mellitus Management within the Context of Personalized Medicine Era in Tabuk Governorate, Saudi Arabia. *Open access Macedonian journal of medical sciences, 7*(10), 1706-1711.

Alsaadi, T., Kassie, S., Mohamed Ali, O., (…), & Ahmed, A. M. (2019). Psychiatric Comorbidity in Neurological Disorders: Towards a Multidisciplinary Approach to Illness Management in the United Arab Emirates. *Frontiers in Psychiatry, 10*, 263. https://doi.org/10.3389/fpsyt.2019.00263

AlSafar, H. S., Al-Ali, M., Elbait, G. D., (…), & Tay, G. K. (2019). Introducing the first whole genomes of nationals from the United Arab Emirates. *Scientific Reports, 9*(1), 1-15.

Altahtooh, U. (2020). Why Take PMP Rather than Prince2 in Project Management in Saudi Arabia?. *European Journal of Business and Management Research, 5*(3). https://doi.org/10.24018/ejbmr.2020.5.3.335

American Society of Health-System, P. (2015). ASHP statement on the pharmacist's role in clinical pharmacogenomics. *Am J Health-Syst Pharm, 72*(7), 579-581.

Aneesh, T. P., Sekhar, S., Jose, A., Chandran, L., & Zachariah, S. M. (2009). Pharmacogenomics: the right drug to the right person. *Journal of clinical medicine research, 1*(4), 191-194.

Anney, V. N. (2014). Ensuring the quality of the findings of qualitative research: Looking at trustworthiness criteria. *Journal of emerging trends in educational research and policy studies, 5*(2), 272-281.

Antoniak, J. (2004). Handwashing compliance. *The Canadian nurse, 100*(7), 21-25.

Arwood, M. J., Chumnumwat, S., Cavallari, L. H., Nutescu, E. A., & Duarte, J. D. (2016). Implementing pharmacogenomics at your institution: establishment and overcoming implementation challenges. *Clinical and Translational Science, 9*(5), 233-245.

Assem, M., Broeckel, U., & MacKinnon, G. E. (2021). Personal DNA Testing Increases Pharmacy Students' Confidence and Competence in Pharmacogenomics. *American Journal of Pharmaceutical Education, 85*(4), 8249. https://doi.org/10.5688/ajpe8249

Bain, K. T., Schwartz, E. J., Knowlton, O. V., Knowlton, C. H., & Turgeon, J. (2018). Implementation of a pharmacist-led pharmacogenomics service for the Program of All-Inclusive Care for the Elderly (PHARM-GENOME-PACE). *Journal of the American Pharmacists Association, 58*(3), 281-289.

Baker, D. W. (2006). The meaning and the measure of health literacy. *Journal of general internal medicine, 21*(8), 878-883.

Balasopoulou, A., Mooy, F.-M., Baker, D. J., (…), & Patrinos, G. P. (2017). Advancing global precision medicine: An overview of genomic testing and counseling services in Malaysia. *Omics: a journal of integrative biology, 21*(12), 733-740.

Bank, P. C. D., Swen, J. J., Schaap, R. D., (…), & Guchelaar, H.J. (2019). A pilot study of the implementation of pharmacogenomic pharmacist initiated pre-emptive testing in primary care. *European Journal of Human Genetics, 27*(10), 1532-1541.

Barakat-Haddad, C. (2013). Prevalence of high blood pressure, heart disease, thalassemia, sickle-cell anemia, and iron-deficiency anemia among the UAE adolescent population. *Journal of environmental and public health, 2013*. https://doi.org/10.1155/2013/680631

Barh, D., Dhawan, D., & Ganguly, N. K. (2013). *Omics for personalized medicine* (Vol. 2). First edition. New York: Springer. https://doi.org/10.1007/978-81-322-1184-6

Baroncini, A., Calabrese, O., Colotto, M., (…), & Boccia, S. (2015). Knowledge and attitude of general pratictioners towards direct-to-consumer genomic tests: a survey conducted in Italy. *Epidemiology, Biostatistics and Public Health, 12*(4). https://doi.org/10.2427/11613

Basheti, I. A., Armour, C. L., Reddel, H. K., & Bosnic-Anticevich, S. Z. (2009). Long-term maintenance of pharmacists' inhaler technique demonstration skills. *American journal of pharmaceutical education, 73*(2), 32. https://doi.org/10.5688/aj730232

Bayoumi, R. A, Nur-E-Kamal MS, Tadayyon M, (…), & Luzzatto L (1996). Molecular characterization of erythrocyte glucose-6-phosphate dehydrogenase deficiency in Al-Ain District, United Arab Emirates. *Hum Hered, 46*(3), 136-141.

Beamer L.C., and Rosinski A. (2019). Nursing Faculty Knowledge Regarding Genetics, Genomics, and Pharmacogenomics [online], *45th Biennial Convention*, Washington DC, 16-20 November 2019. Retrieved from: http://hdl.handle.net/10755/19013

Bélisle-Pipon, J.-C., Vayena, E., Green, R. C., & Cohen, I. G. (2019). Genetic testing, insurance discrimination and medical research: what the United States can learn from peer countries. *Nature medicine, 25*(8), 1198-1204.

Benzeroual, K. E., Shah, B., & Shinde, S. (2012). Pharmacogenomics: assessing educational exposure, confidence in knowledge and training elements of pharmacists. *Personalized medicine, 9*(4), 387-393.

Berenbrok, L. A., Hart, K. M., McGrath, S. H., (…), & Empey, P. E. (2019). Community pharmacists' educational needs for implementing clinical pharmacogenomic services. *Journal of the American Pharmacists Association, 59*(4), 539-544.

Berlin, D. S., Person, M. G., Mittal, A., (…), & Altman, R. B. (2010). DNATwist: A Web-Based Tool for Teaching Middle and High School Students About Pharmacogenomics. *Clinical Pharmacology & Therapeutics, 87*(4), 393-395.

Bernhardt, B. A., Zayac, C., Gordon, E. S., (…), & Gollust, S. E. (2012). Incorporating direct-to-consumer genomic information into patient care: attitudes and experiences of primary care physicians. *Personalized medicine, 9*(7), 683-692.

Bernstein, S. L., Weiss, J., & Curry, L. (2020). Visualizing implementation: contextual and organizational support mapping of stakeholders (COSMOS). *Implementation Science Communications, 1*, 1-11.

Best, S., Stark, Z., Phillips, P., (…), & Goranitis, I. (2020). Clinical genomic testing: what matters to key stakeholders? *European Journal of Human Genetics, 28*(7), 866-873.

Bonter, K., Desjardins, C., Currier, N., Pun, J., & Ashbury, F. D. (2011). Personalised medicine in Canada: a survey of adoption and practice in oncology, cardiology and family medicine. *BMJ open, 1*(1), e000110. https://doi.org/10.1136/bmjopen-2011-000110

Brown, J. T., Gregornik, D., Kennedy, M. J., Advocacy, & Research, C. (2018). The role of the pediatric pharmacist in precision medicine and clinical pharmacogenomics for children. *The Journal of Pediatric Pharmacology and Therapeutics, 23*(6), 499-501.

Brunette, C. A., Miller, S. J., Majahalme, (…), & Vassy, J. L. (2020). Pragmatic Trials in Genomic Medicine: The Integrating Pharmacogenetics In Clinical Care (I-PICC) Study. *Clinical and Translational Science, 13*(2), 381-390.

Bukini, D., Mbekenga, C., Nkya, S., (…), & Makani, J. (2020). A qualitative study on aspects of consent for genomic research in communities with low literacy. *BMC Medical Ethics, 21*(1), 1-7.

Burke, W., Pinsky, L. E., & Press, N. A. (2001). Categorizing genetic tests to identify their ethical, legal, and social implications. *American journal of medical genetics, 106*(3), 233-240.

Bush, W. S., Bailey, J. N. C., Beno, M. F., & Crawford, D. C. (2019). Bridging the Gaps in Personalized Medicine Value Assessment: A Review of the Need for Outcome Metrics across Stakeholders and Scientific Disciplines. *Public Health Genomics, 22*(1-2), 16-24.

Bush, W. S., Crosslin, D. R., Owusu-Obeng, A., (…), & Crawford, D. (2016). Genetic variation among 82 pharmacogenes: the PGRNseq data from the eMERGE network. *Clinical Pharmacology & Therapeutics, 100*(2), 160-169.

Cameron, L. D., & Reeve, J. (2006). Risk perceptions, worry, and attitudes about genetic testing for breast cancer susceptibility. *Psychology & health, 21*(2), 211-230.

Caraballo, P. J., Hodge, L. S., Bielinski, S. J., (…), & Roger, V. L. (2017). Multidisciplinary model to implement pharmacogenomics at the point of care. *Genetics in Medicine, 19*(4), 421-429.

Carver, R. B., Castéra, J., Gericke, N., Evangelista, N. A. M., & El-Hani, C. N. (2017). Young adults' belief in genetic determinism, and knowledge and attitudes towards modern genetics and genomics: the PUGGS questionnaire. *Plos One, 12*(1), e0169808. https://doi.org/10.1371/journal.pone.0169808

Cavallari, L. H., Beitelshees, A. L., Blake, K. V., (…), & Hicks, J. K. (2017a). The IGNITE Pharmacogenetics Working Group: an opportunity for building evidence with pharmacogenetic implementation in a real-world setting. *Clinical and Translational Science, 10*(3), 143-146.

Cavallari, L. H., Weitzel, K. W., Elsey, A. R., (…), & Franchi, F. (2017b). Institutional profile: University of Florida health personalized medicine program. *Pharmacogenomics, 18*(5), 421-426.

Chair, S. Y., Waye, M. M. Y., Calzone, K., & Chan, C. W. H. (2019). Genomics education in nursing in Hong Kong, Taiwan and Mainland China. *International nursing review, 66*(4), 459-466.

Chanfreau-Coffinier, C., Hull, L. E., Lynch, J. A., (…), & Icardi, M. S. (2019a). Projected prevalence of actionable pharmacogenetic variants and level A drugs prescribed among US veterans health administration pharmacy users. *JAMA network open, 2*(6), e195345-e195345.

Chanfreau-Coffinier, C., Peredo, J., Russell, M. M., (…), & Scheuner, M. T. (2019b). A logic model for precision medicine implementation informed by stakeholder views and implementation science. *Genetics in Medicine, 21*(5), 1139-1154.

Caudle, K. E., Klein, T. E., Hoffman, (…), & Johnson, S. G. (2014). Incorporation of pharmacogenomics into routine clinical practice: the Clinical Pharmacogenetics Implementation Consortium (CPIC) guideline development process. *Current drug metabolism, 15*(2), 209-217.

Chenoweth, M. J., Giacomini, K. M., Pirmohamed, M., (…), & Tyndale, R. F. (2020). Global pharmacogenomics within precision medicine: challenges and opportunities. *Clinical Pharmacology & Therapeutics, 107*(1), 57-61.

Christianson, A., Howson, C. P., & Modell, B. (2006). March of Dimes global report on birth defects: the hidden toll of dying and disabled children [online]. *March of Dimes Birth Defects Foundation.* Retrieved from: http://www.marchofdimes.org/materials/global-report-on-birth-defects-the-hidden-toll-of-dying-and-disabled-children-executive-summary.pdf

Comess, S., Akbay, A., Vasiliou, M., (…), & Kleinstreuer, N. (2020). Bringing Big Data to Bear in Environmental Public Health: Challenges and Recommendations. *Frontiers in Artificial Intelligence, 3*, 31. https://doi.org/10.3389/frai.2020.00031

Corbin, J., & Strauss, A. (2008). *Basics of Qualitative Research (3rd ed.): Techniques and Procedures for Developing Grounded Theory*. Third edition. Thousand Oaks: SAGE Publications. https://doi.org/10.4135/9781452230153

Cornel, M. C., van El, C. G., & Dondorp, W. J. (2012). The promises of genomic screening: building a governance infrastructure. Special issue: genetics and democracy. *Journal of community genetics, 3*(2), 73-77.

Crews, K. R., Hicks, J. K., Pui, C. H., Relling, M. V., & Evans, W. E. (2012). Pharmacogenomics and individualized medicine: translating science into practice. *Clinical Pharmacology & Therapeutics, 92*(4), 467-475.

Crown, N., Sproule, B. A., Luke, M. J., Piquette-Miller, M., & McCarthy, L. M. (2020). A Continuing Professional Development Program for Pharmacists Implementing Pharmacogenomics into Practice. *Pharmacy, 8*(2), 55. https://doi.org/10.3390/pharmacy8020055

Curry, L. (2005). The Future of the Public's Health in the 21st Century. *Generations, 29*(2), 82-84.

De Denus, S., Letarte, N., Hurlimann, T., (…), & Vadnais, B. (2013). An evaluation of pharmacists' expectations towards pharmacogenomics. *Pharmacogenomics, 14*(2), 165-175.

Denic, S., Aden, B., Nagelkerke, N., & Essa, A. A. (2013). β-Thalassemia in Abu Dhabi: consanguinity and tribal stratification are major factors explaining the high prevalence of the disease. *Hemoglobin, 37*(4), 351-358.

Department of Health. (2018, November). Abu Dhabi Health Statistics 2017 [online]. *Department of Health- Abu Dhabi.* Retrieved from: https://www.doh.gov.ae//media/Feature/Resources/AbuDhabiHealthStatistics.ashx

Dodson, C. (2011). Knowledge and attitudes concerning pharmacogenomics among healthcare professionals [Article]. *Personalized Medicine, 8*(4), 421-428. https://doi.org/10.2217/pme.11.28

Dove, E. S., Joly, Y., Tassé, A.-M., & Knoppers, B. M. (2015). Genomic cloud computing: legal and ethical points to consider. *European Journal of Human Genetics, 23*(10), 1271-1278.

Dunnenberger, H. M., Biszewski, M., Bell, G. C., (…), & Khandekar, J. (2016). Implementation of a multidisciplinary pharmacogenomics clinic in a community health system. *American Journal of Health-System Pharmacy, 73*(23), 1956-1966.

Duong, B. Q., Arwood, M. J., Hicks, J. K., (…), & Petry, N. (2020). Development of Customizable Implementation Guides to Support Clinical Adoption of Pharmacogenomics: Experiences of the Implementing GeNomics In pracTicE (IGNITE) Network. *Pharmacogenomics and Personalized Medicine, 13*, 217-226.

El Shanti, H., Chouchane, L., Badii, R., Gallouzi, I. E., & Gasparini, P. (2015). Genetic testing and genomic analysis: a debate on ethical, social and legal issues in the Arab world with a focus on Qatar. *Journal of translational medicine, 13*(1), 1-10.

Elbarazi, I., Devlin, N. J., Katsaiti, M.-S., (…), & Blair, I. (2017). The effect of religion on the perception of health states among adults in the United Arab Emirates: a qualitative study. *BMJ open, 7*(10), e016969. https://doi.org/10.1136/bmjopen-2017-016969

Elewa, H., Alkhiyami, D., Alsahan, D., & Abdel-Aziz, A. (2015). A survey on the awareness and attitude of pharmacists and doctors towards the application of pharmacogenomics and its challenges in Qatar. *Journal of Evaluation in Clinical Practice, 21*(4), 703-709.

Elewa, H., & Awaisu, A. (2019). Pharmacogenomics In Pharmacy Practice: Current Perspectives. *Integrated Pharmacy Research & Practice, 8*, 97-104.

Elsaid, A., Salem, R., & Abdul-Kader, H. (2017). A dynamic stakeholder classification and prioritization based on hybrid rough-fuzzy method. *Journal of Software Engineering, 11*, 143-159.

Esquivel-Sada, D., Lévesque, E., Hagan, J., Knoppers, B. M., & Simard, J. (2019). Envisioning Implementation of a Personalized Approach in Breast Cancer Screening Programs: Stakeholder Perspectives. *Healthcare policy= Politiques de sante, 15*(2), 39-54.

Evans, W. E., Pui, C. H., & Yang, J. J. (2020). The promise and the reality of genomics to guide precision medicine in pediatric oncology: the decade ahead. *Clinical Pharmacology & Therapeutics, 107*(1), 176-180.

Faulkner, E., Holtorf, A.-P., Walton, S., (…), & Shandhu, G. (2020). Being precise about precision medicine: what should value frameworks incorporate to address precision medicine? A report of the Personalized Precision Medicine Special Interest Group. *Value in Health, 23*(5), 529-539.

Feero, W. G., & Green, E. D. (2011). Genomics education for health care professionals in the 21st century. *Jama, 306*(9), 989-990.

Formea, C. M., Nicholson, W. T., McCullough, K. B., (…), & Stollings, J. L. (2013). Development and evaluation of a pharmacogenomics educational program for pharmacists. *American journal of pharmaceutical education, 77*(1), 10. https://doi.org/10.5688/ajpe77110

Fragoulakis, V., Bartsakoulia, M., Díaz-Villamarín, X., (…), & Skoufas, E. (2019). Cost-effectiveness analysis of pharmacogenomics-guided clopidogrel treatment in spanish patients undergoing percutaneous coronary intervention. *The Pharmacogenomics Journal, 19*(5), 438-445.

Freedman, D. A., Bess, K. D., Tucker, H. A., (…), & Wallston, K. A. (2009). Public health literacy defined. *American journal of preventive medicine, 36*(5), 446-451.

Frick, A., Benton, C., Suzuki, O., (…), & Wiltshire, T. (2018). Implementing clinical pharmacogenomics in the classroom: student pharmacist impressions of an educational intervention including personal genotyping. *Pharmacy, 6*(4), 115. https://doi.org/10.3390/pharmacy6040115

Gálvez-Peralta, M., Szklarz, G. D., Geldenhuys, W. J., & Lockman, P. R. (2018). An effective approach to teaching pharmacogenomics in the first year of pharmacy curriculum. *American journal of pharmaceutical education, 82*(8), 6345. https://doi.org/10.5688/ajpe6345

Garten, Y., & Altman, R. B. (2010). Teaching computers to read the pharmacogenomics literature… so you don't have to. *Pharmacogenomics, 11*(4), 515-518.

Geiersbach, K. B., Chen, H., Emmadi, R., (…), & Swisshelm, K. (2020). Current concepts in breast cancer genomics: An evidence based review by the CGC breast cancer working group. *Cancer Genetics, 244*, 11-20.

Girardin, F. R., Poncet, A., Perrier, A., (…), & Villard, J. (2019). Cost-effectiveness of HLA-DQB1/HLA-B pharmacogenetic-guided treatment and blood monitoring in US patients taking clozapine. *The Pharmacogenomics Journal, 19*(2), 211-218.

Giri, J., Curry, T. B., Formea, C. M., Nicholson, W. T., & Rohrer Vitek, C. R. (2018). Education and knowledge in pharmacogenomics: still a challenge? *Clinical Pharmacology & Therapeutics, 103*(5), 752-755.

Goldsmith, L., Jackson, L., O'Connor, A., & Skirton, H. (2013). Direct-to-consumer genomic testing from the perspective of the health professional: a systematic review of the literature. *Journal of community genetics, 4*(2), 169-180.

Gottschalk, P. (1999). Strategic information systems planning: the IT strategy implementation matrix. *European Journal of Information Systems, 8*(2), 107-118.

Green, J. S., O'Brien, T. J., Chiappinelli, V. A., & Harralson, A. F. (2010). Pharmacogenomics instruction in US and Canadian medical schools: implications for personalized medicine. *Pharmacogenomics, 11*(9), 1331-1340. https://doi.org/10.2217/pgs.10.122

Green, R. F., Ari, M., Kolor, K., (…), & Khoury, M. J. (2019). Evaluating the role of public health in implementation of genomics-related recommendations: a case study of hereditary cancers using the CDC Science Impact Framework. *Genetics in Medicine, 21*(1), 28-37.

Groenland, E. (2018). Employing the matrix method as a tool for the analysis of qualitative research data in the business domain. *International Journal of Business and Globalisation, 21*(1), 119-134.

Gupta, N., Thiele, C. M., Daum, J. I., (…), & Johnson, C. D. (2020). Building Patient–Physician Trust: A Medical Student Perspective. *Academic Medicine, 95*(7), 980-983.

Gurwitz, D., Lunshof, J. E., Dedoussis, G., (…), & Sheffield, L. J. (2005). Pharmacogenomics education: International Society of Pharmacogenomics recommendations for medical, pharmaceutical, and health schools deans of education. *The Pharmacogenomics Journal, 5*(4), 221-225.

Gurwitz, D., Weizman, A., & Rehavi, M. (2003). Education: teaching pharmacogenomics to prepare future physicians and researchers for personalized medicine. *Trends in pharmacological sciences, 24*(3), 122-125.

Guy, J. W., Patel, I., & Oestreich, J. H. (2020). Clinical application and educational training for pharmacogenomics. *Pharmacy (Basel, Switzerland), 8*(3), 163. https://doi.org/10.3390/pharmacy8030163

Haga, S. B., Burke, W., Ginsburg, G. S., Mills, R., & Agans, R. (2012). Primary care physicians' knowledge of and experience with pharmacogenetic testing. *Clinical genetics, 82*(4), 388-394.

Haga, S. B., Carrig, M. M., O'Daniel, J. M., (…), & Cho, A. (2011). Genomic risk profiling: attitudes and use in personal and clinical care of primary care physicians who offer risk profiling. *Journal of general internal medicine, 26*(8), 834-840.

Hart, M. R., Garrison Jr, L. P., Doyle, D. L., Jarvik, G. P., Watkins, J., & Devine, B. (2019). Projected Cost-Effectiveness for 2 Gene-Drug Pairs Using a Multigene Panel for Patients Undergoing Percutaneous Coronary Intervention. *Value in Health, 22*(11), 1231-1239.

Hawamdeh, S., Almakhzoomy, I., & Hayajneh, Y. (2013). Screening and Correlates of Depression and HbA 1 C in U nited A rab E mirates (UAE) Women With Diabetes. *Perspectives in psychiatric care, 49*(4), 262-268.

Hess, G. P., Fonseca, E., Scott, R., & Fagerness, J. (2015). Pharmacogenomic and pharmacogenetic-guided therapy as a tool in precision medicine: current state and factors impacting acceptance by stakeholders. *Genetics research, 97*, e13. https://doi.org/10.1017/S0016672315000099

Hesse, B. W., Nelson, D. E., Kreps, G. L., (…), & Viswanath, K. (2005). Trust and sources of health information: the impact of the Internet and its implications for health care providers: findings from the first Health Information National Trends Survey. *Archives of internal medicine, 165*(22), 2618-2624.

Hickey, K. T., Taylor, J. Y., Barr, T. L., (…), & Katapodi, M. (2018). Nursing genetics and genomics: The International Society of Nurses in Genetics (ISONG) survey. *Nurse education today, 63*, 12-17.

Hicks, J. K., Stowe, D., Willner, M. A., (…), & Teng, K. (2016). Implementation of clinical pharmacogenomics within a large health system: from electronic health record decision support to consultation services. *Pharmacotherapy: The Journal of Human Pharmacology and Drug Therapy*, *36*(8), 940-948.

Higgs, J. E., Andrews, J., Gurwitz, D., Payne, K., & Newman, W. (2008). Pharmacogenetics education in British medical schools. *Genomic Med, 2*(3-4), 101-105. https://doi.org/10.1007/s11568-009-9032-6

Hoehndorf, R., Dumontier, M., & Gkoutos, G. V. (2012). Identifying aberrant pathways through integrated analysis of knowledge in pharmacogenomics. *Bioinformatics, 28*(16), 2169-2175.

Holtzman N. A. (1999). Promoting safe and effective genetic tests in the United States: work of the task force on genetic testing. *Clinical chemistry*, *45*(5), 732-738.

Jarrar, Y., Mosleh, R., Hawash, M., & Jarrar, Q. (2019). Knowledge And Attitudes Of Pharmacy Students Towards Pharmacogenomics Among Universities In Jordan And West Bank Of Palestine. *Pharmacogenomics and Personalized Medicine, 12*, 247-255.

Jooma, S., Hahn, M. J., Hindorff, L. A., & Bonham, V. L. (2019). Defining and achieving health equity in genomic medicine. *Ethnicity & disease, 29*(Suppl 1), 173-178.

Karas Kuželički, N., Prodan Žitnik, I., Gurwitz, D., (…), & Di Resta, C. (2019). Pharmacogenomics education in medical and pharmacy schools: conclusions of a global survey. *Pharmacogenomics, 20*(9), 643-657.

Karuna, N., Tragulpiankit, P., Mahasirimongkol, S., & Chumnumwat, S. (2020). Knowledge, attitude, and practice towards pharmacogenomics among hospital pharmacists in Thailand. *Pharmacogenetics and Genomics, 30*(4), 73-80.

Kasztura, M., Richard, A., Bempong, N.-E., Loncar, D., & Flahault, A. (2019). Cost-effectiveness of precision medicine: a scoping review. *International journal of public health*, *64*(9), 1261-1271.

Kechagia, S., Mai, Y., Vidalis, T., Patrinos, G. P., & Vayena, E. (2014). Personal genomics in Greece: an overview of available direct-to-consumer genomic services and the relevant legal framework. *Public Health Genomics, 17*(5-6), 299-305.

Keeling, N. J., Rosenthal, M. M., West-Strum, D., Patel, A. S., Haidar, C. E., & Hoffman, J. M. (2019). Preemptive pharmacogenetic testing: exploring the knowledge and perspectives of US payers. *Genetics in Medicine, 21*(5), 1224-1232.

Keen, J. C., & Moore, H. M. (2015). The Genotype-Tissue Expression (GTEx) Project: linking clinical data with molecular analysis to advance personalized medicine. *Journal of Personalized Medicine, 5*(1), 22-29.

Kennedy, M. J. (2018). Personalized medicines–are pharmacists ready for the challenge? *Integrated Pharmacy Research & Practice, 7*, 113-123.

Kim, W.-Y., Kim, H.-S., Oh, M., & Shin, J.-G. (2020). Survey of physicians' views on the clinical implementation of pharmacogenomics-based personalized therapy. *Translational and Clinical Pharmacology, 28*(1), 34-42.

Kizhakkedath, P., Loregger, A., John, A., (…), & Ali, B. R. (2014). Impaired trafficking of the very low density lipoprotein receptor caused by missense mutations associated with dysequilibrium syndrome. *Biochimica et Biophysica Acta (BBA)-Molecular Cell Research, 1843*(12), 2871-2877.

Klein, R. D. (2020). Current policy challenges in genomic medicine. *Clinical Chemistry*, *66*(1), 61-67.

Knapp, K., & Ignoffo, R. (2020). Oncology pharmacists can reduce the projected shortfall in cancer patient visits: Projections for years 2020 to 2025. *Pharmacy (Basel, Switzerland), 8*(1), 43. https://doi.org/10.3390/pharmacy8010043

Knaup, P., Ammenwerth, E., Brandner, R., (…), & Singer, R. (2004). Towards clinical bioinformatics: advancing genomic medicine with informatics methods and tools. *Methods of information in medicine, 43*(03), 302-307.

Knowles, L., Luth, W., & Bubela, T. (2017). Paving the road to personalized medicine: recommendations on regulatory, intellectual property and reimbursement challenges. *Journal of Law and the Biosciences, 4*(3), 453-506.

Kochan, D. C., Winkler, E., Lindor, (…), & Sharp, R. R. (2020). Challenges in returning results in a genomic medicine implementation study: the Return of Actionable Variants Empirical (RAVE) study. *NPJ Genomic Medicine, 5*(1), 1-7.

Komara, M., John, A., Suleiman, J., Ali, B. R., & Al-Gazali, L. (2016). Clinical and molecular delineation of dysequilibrium syndrome type 2 and profound sensorineural hearing loss in an inbred Arab family. *American Journal of Medical Genetics Part A, 170*(2), 540-543.

Korf, B. R., Berry, A. B., Limson, M., (…), & Tsongalis, G. J. (2014). Framework for development of physician competencies in genomic medicine: report of the Competencies Working Group of the Inter-Society Coordinating Committee for Physician Education in Genomics. *Genetics in Medicine, 16*(11), 804-809.

Kudzi, W., Addy, B. S., & Dzudzor, B. (2015). Knowledge of pharmacogenetics among healthcare professionals and faculty members of health training institutions in Ghana. *Ghana medical journal, 49*(1), 50-56.

Kuzmin, O., & Khilukha, O. (2016). Regulation of stakeholders' interests in corporate governance through negotiations. *Економічний часопис-XXI*(161), 56-60.

Landry, L. G., Ali, N., Williams, D. R., Rehm, H. L., & Bonham, V. L. (2018). Lack of diversity in genomic databases is a barrier to translating precision medicine research into practice. *Health Affairs, 37*(5), 780-785.

Lannoy, N., Lambert, C., Van Damme, A., & Hermans, C. (2019). Incidental finding of unreported large duplication in F8 gene during prenatal analysis: Which management for genetic counselling? *Thrombosis research, 182*, 39-42.

Lappalainen, T., Scott, A. J., Brandt, M., & Hall, I. M. (2019). Genomic analysis in the age of human genome sequencing. *Cell*, *177*(1), 70-84.

Laskey, S. L., Williams, J., Pierre-Louis, J., (…), & Robin, N. H. (2003). Attitudes of African American premedical students toward genetic testing and screening. *Genetics in Medicine, 5*(1), 49-54.

Lauschke, V. M., & Ingelman-Sundberg, M. (2020). Emerging strategies to bridge the gap between pharmacogenomic research and its clinical implementation. *NPJ Genomic Medicine, 5*(1), 1-7.

Leary, E., Brilliant, M., Peissig, P., & Griesbach, S. (2019). Preliminary outcomes of preemptive warfarin pharmacogenetic testing at a large rural healthcare center. *American Journal of Health-System Pharmacy, 76*(6), 387-397.

LeBlanc, M. D., & Dyer, B. D. (2003). Teaching together: A three-year case study in genomics. *Journal of Computing Sciences in Colleges, 18*(5), 85-95.

Lee, K. C., Ma, J. D., Hudmon, K. S., & Kuo, G. M. (2012). A train-the-trainer approach to a shared pharmacogenomics curriculum for US colleges and schools of pharmacy. *Am J Pharm Educ, 76*(10), 193. https://doi.org/10.5688/ajpe7610193

Lesko, L. J., & Johnson, J. A. (2012). Academia at the crossroads: education and training in pharmacogenomics. *Personalized medicine, 9*(5), 497-506.

Leventhal, H., Phillips, L. A., & Burns, E. (2016). The Common-Sense Model of Self-Regulation (CSM): a dynamic framework for understanding illness self-management. *Journal of behavioral medicine, 39*(6), 935-946.

Levy, K. D., Blake, K., Fletcher-Hoppe, C., (…), & Musty, M. D. (2019). Correction: Opportunities to implement a sustainable genomic medicine program: lessons learned from the IGNITE Network. *Genetics in Medicine, 21*(7), 1670-1670.

Lincoln, Y. S., & Guba, E. G. (1986). But is it rigorous? Trustworthiness and authenticity in naturalistic evaluation. *New directions for program evaluation, 1986*(30), 73-84.

Lopes-Júnior, L. C., Carvalho Junior, P. M., de Faria Ferraz, V. E., (…), & Flória-Santos, M. (2017). Genetic education, knowledge and experiences between nurses and physicians in primary care in Brazil: A cross-sectional study. *Nursing & health sciences, 19*(1), 66-74.

Lucas, J. S., Davis, S. D., Omran, H., & Shoemark, A. (2020). Primary ciliary dyskinesia in the genomics age. *The Lancet Respiratory Medicine, 8*(2), 202-216.

Mai, Y., Mitropoulou, C., Papadopoulou, X. E., (…), & Patrinos, G. P. (2014). Critical appraisal of the views of healthcare professionals with respect to pharmacogenomics and personalized medicine in Greece. *Personalized Medicine, 11*(1), 15-26.

Manda, V., Sreedharan, J., Muttappallymyalil, J., Das, R., & Hisamatsu, E. (2012). Foot ulcers and risk factors among diabetic patients visiting Surgery Department in a University Teaching Hospital in Ajman, UAE. *International Journal of Medicine and Public Health, 2*(3), 34-38.

Manolio, T. A., Chisholm, R. L., Ozenberger, B., (…), & Eng, C. (2013). Implementing genomic medicine in the clinic: the future is here. *Genetics in Medicine, 15*(4), 258-267.

Manson, N. C. (2019). The biobank consent debate: Why 'meta-consent'is not the solution? *Journal of medical ethics, 45*(5), 291-294.

Marrero, R. J., Cicali, E. J., Arwood, M. J., (…), & Cooper-DeHoff, R. M. (2020). How to Transition from Single-Gene Pharmacogenetic Testing to Preemptive Panel-Based Testing: A Tutorial. *Clinical pharmacology and therapeutics*, *108*(3), 557-565.

Martins, A., Fonseca, M. J., Lemos, M., Lencastre, L., & Tavares, F. (2020). Bioinformatics-Based Activities in High School: Fostering Students' Literacy, Interest, and Attitudes on Gene Regulation, Genomics, and Evolution. *Frontiers in microbiology*, *11*, 578099. https://doi.org/10.3389/fmicb.2020.578099

Mason-Suares, H., Sweetser, D. A., Lindeman, N. I., & Morton, C. C. (2016). Training the future leaders in personalized medicine. *Journal of Personalized Medicine, 6*(1), 1. https://doi.org/10.3390/jpm6010001

Mavroidopoulou, V., Xera, E., & Mollaki, V. (2015). Awareness, attitudes and perspectives of direct-to-consumer genetic testing in Greece: a survey of potential consumers. *Journal of human genetics, 60*(9), 515-523.

McClaren, B. J., Crellin, E., Janinski, M., (…), & Gaff, C. L. (2020a). Preparing medical specialists for genomic medicine: continuing education should include opportunities for experiential learning. *Frontiers in Genetics, 11*, 151. https://doi.org/10.3389/fgene.2020.00151

McClaren, B. J., King, E. A., Crellin, E., (…), & Nisselle, A. (2020b). Development of an Evidence-Based, Theory-Informed National Survey of Physician Preparedness for Genomic Medicine and Preferences for Genomics Continuing Education. *Frontiers in Genetics, 11*, 59. https://doi.org/10.3389/fgene.2020.00059

McCullough, K. B., Formea, C. M., Berg, K. D., (…), & Nicholson, W. T. (2011). Assessment of the pharmacogenomics educational needs of pharmacists. *American journal of pharmaceutical education, 75*(3). https://doi.org/10.5688/ajpe75351

McMahon, T., & Tucci, J. (2011). Percepciones de los farmacéuticos en Victoria, Australia sobre la farmacogenética y sus implicaciones. *Pharmacy Practice (Internet), 9*(3), 141-147.

Meagher, K. M., Curtis, S. H., Gamm, K. O., (…), & Sharp, R. R. (2020). At a Moment's Notice: Community Advisory Board Perspectives on Biobank Communication to Supplement Broad Consent. *Public Health Genomics, 23*(1-2), 1-13.

Mendelow, A. L. (1981). Environmental Scanning-The Impact of the Stakeholder Concept. In *Proceedings of the International Conference on Information Systems*, Cambridge, MA 7-9 December, 1981. Retrieved from: https://aisel.aisnet.org/icis1981/20/

Mills, R., & Haga, S. B. (2013). Clinical delivery of pharmacogenetic testing services: a proposed partnership between genetic counselors and pharmacists. *Pharmacogenomics, 14*(8), 957-968.

Mitropoulos, K., Al Jaibeji, H., Forero, D. A., (…), & Llerena, A. (2015). Success stories in genomic medicine from resource-limited countries. *Human Genomics, 9*(1), 1-7.

Mitropoulou, C., Mai, Y., Van Schaik, R. H., Vozikis, A., & Patrinos, G. P. (2014). Stakeholder analysis in pharmacogenomics and genomic medicine in Greece. *Public Health Genomics, 17*(5-6), 280-286.

Mitropoulou, C., Politopoulou, K., Vozikis, A., & Patrinos, G. P. (2020). Assessing the Stakeholder Landscape and Stance Point on Genomic and Personalized Medicine. In G.P Patrinos, *Applied Genomics and Public Health* (pp. 211-223). First edition. Cambridge: Academic Press. https://doi.org/10.1016/B978-0-12-813695-9.00011-X

Monaghan, K. G., Leach, N. T., Pekarek, D., Prasad, P., & Rose, N. C. (2020). The use of fetal exome sequencing in prenatal diagnosis: a points to consider document of the American College of Medical Genetics and Genomics (ACMG). *Genetics in Medicine, 22*(4), 675-680.

Monte, A. A., Vasiliou, V., & Heard, K. J. (2012). Omics screening for pharmaceutical efficacy and safety in clinical practice. *Journal of pharmacogenomics & pharmacoproteomics, S5,* 001. https://doi.org/10.4172/2153-0645.s5-001

Morash, M., Mitchell, H., Beltran, H., Elemento, O., & Pathak, J. (2018). The role of next-generation sequencing in precision medicine: a review of outcomes in oncology. *Journal of Personalized Medicine, 8*(3), 30. https://doi.org/10.3390/jpm8030030

Morganti, S., Tarantino, P., Ferraro, E., (…), & Curigliano, G. (2019). Next generation sequencing (NGS): a revolutionary Technology in Pharmacogenomics and Personalized Medicine in cancer. *Translational Research and Onco-Omics Applications in the Era of Cancer Personal Genomics,* 9-30.

Murphy, J. E., Green, J. S., Adams, L. A., (…), & McKay, A. (2010, Feb). Pharmacogenomics in the curricula of colleges and schools of pharmacy in the United States. *Am J Pharm Educ, 74*(1), 7. https://doi.org/10.5688/aj740107

Murray, M. F., Kenny, E. E., Ritchie, M. D., (…), & Abul-Husn, N. S. (2020). COVID-19 outcomes and the human genome. *Genetics in Medicine, 22*(7), 1175-1177.

Mustapa, M. A. C., Amin, L., & Mahadi, Z. (2020). Determinants of stakeholders' intention to adopt pharmacogenomic. *The Pharmacogenomics Journal, 20*(6), 801-812.

Muzoriana, N., Gavi, S., Nembaware, V., Dhoro, M., & Matimba, A. (2017). Knowledge, Attitude, and Perceptions of Pharmacists and Pharmacy Students towards Pharmacogenomics in Zimbabwe. *Pharmacy (Basel, Switzerland), 5*(3), 36. https://doi.org/10.3390/pharmacy5030036

Nagy, M., Lynch, M., Kamal, S., (…), & Aquilante, C. L. (2020). Assessment of healthcare professionals' knowledge, attitudes, and perceived challenges of clinical pharmacogenetic testing in Egypt. *Personalized Medicine, 17*(4), 251-260.

Najafzadeh, M., Lynd, L. D., Davis, (…), & Marra, C. A. (2012). Barriers to integrating personalized medicine into clinical practice: a best-worst scaling choice experiment. *Genetics in medicine : official journal of the American College of Medical Genetics, 14*(5), 520-526.

Nallaseth, F. S. (2019). Shifting the therapeutic paradigm in medicine from post mutational (& pathological) intervention to preemption–a synopsis of the 'nuts and bolts'. *MOJ Proteomics Bioinform, 8*(2), 41-43.

Neill, S. G., Hauenstein, J., Li, M. M., (…), & Ligon, A. H. (2020). Copy number assessment in the genomic analysis of CNS neoplasia: An evidence-based review from the cancer genomics consortium (CGC) working group on primary CNS tumors. *Cancer Genetics, 243*, 19-47.

Nelson, D.E., Hesse, B. W., & Croyle, R. T. (2009). *Making Data Talk: Communicating Public Health Data to the Public, Policy Makers, and the Press*. New York: Oxford University Press. http://dx.doi.org/10.1093/acprof:oso/9780195381535.001.0001

Nembaware, V., Mulder, N., Abidi, O., (…), & Fadlelmola, F. M. (2019). The African genomic medicine training initiative (AGMT): showcasing a community and framework driven genomic medicine training for nurses in Africa. *Frontiers in Genetics, 10*, 1209. https://doi.org/10.3389/fgene.2019.01209

Nicholson, W. T., Formea, C. M., Matey, E. T., (…), & Moyer, A. M. (2021). Considerations When Applying Pharmacogenomics to Your Practice. *Mayo Clinic proceedings*, *96*(1), 218-230. https://doi.org/10.1016/j.mayocp.2020.03.011

Nishant, T., Bindu, H. K., Kumar, S. D., & Kumar, A. R. (2012). Pharmacogenomics-Personalized treatment of cancer, diabetes and cardiovascular diseases. *J Pharmacogenom Pharmacoproteomics, 3*(107), 2153-0645.

Nyika, A. (2009). Ethical and practical challenges surrounding genetic and genomic research in developing countries. *Acta Tropica, 112*, S21-S31.

O'Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for reporting qualitative research: a synthesis of recommendations. *Academic Medicine, 89*(9), 1245-1251.

Olwi, D., Merdad, L., & Ramadan, E. (2016). Knowledge of genetics and attitudes toward genetic testing among college students in Saudi Arabia. *Public Health Genomics, 19*(5), 260-268.

Osman, W., Tay, G. K., & Alsafar, H. (2018). Multiple genetic variations confer risks for obesity and type 2 diabetes mellitus in arab descendants from UAE. *International Journal of Obesity, 42*(7), 1345-1353.

Osman, W. M., Jelinek, H. F., Tay, G. K., (…), & Alsafar, H. S. (2019). Genetics of diabetic kidney disease: A follow-up study in the Arab population of the United Arab Emirates. *Molecular genetics & genomic medicine, 7*(12), e985. https://doi.org/10.1002/mgg3.985

Owen, J. A. (2011). Integrating pharmacogenomics into pharmacy practice via medication therapy management: American Pharmacists Association. *Journal of the American Pharmacists Association, 51*(6), e64-e74. https://doi.org/10.1331/JAPhA.2011.11543

Owusu-Obeng, A., Weitzel, K. W., Hatton, R. C., (…), & Johnson, J. A. (2014). Emerging roles for pharmacists in clinical implementation of pharmacogenomics. *Pharmacotherapy: The Journal of Human Pharmacology and Drug Therapy, 34*(10), 1102-1112.

Owusu Obeng, A., Fei, K., Levy, K. D., (…), & Horowitz, C. R. (2018). Physician-reported benefits and barriers to clinical implementation of genomic medicine: a multi-site IGNITE-network survey. *Journal of Personalized Medicine, 8*(3), 24. https://doi.org/10.3390/jpm8030024

Palacios, R., & Collado-Vides, J. (2007). Development of genomic sciences in Mexico: a good start and a long way to go. *PLoS computational biology, 3*(9), 1670-1673.

Pang, T. (2009). Pharmacogenomics and personalized medicine for the developing world-too soon or just-in-time? A personal view from the World Health Organization. *Current Pharmacogenomics and Personalized Medicine (Formerly Current Pharmacogenomics), 7*(3), 149-157.

Papastergiou, J., Tolios, P., Li, W., & Li, J. (2017). The innovative canadian pharmacogenomic screening initiative in community pharmacy (ICANPIC) study. *Journal of the American Pharmacists Association, 57*(5), 624-629.

Patrinos, G. P., Baker, D. J., Al-Mulla, F., Vasiliou, V., & Cooper, D. N. (2013). Genetic tests obtainable through pharmacies: the good, the bad, and the ugly. *Human Genomics, 7*(1), 17. https://doi.org/10.1186/1479-7364-7-17

Patrinos, G. P., & Katsila, T. (2016). Pharmacogenomics education and research at the Department of Pharmacy, University of Patras, Greece. *Pharmacogenomics, 17*(17), 1865-1872.

Perkmann, M., & Schildt, H. (2015). Open data partnerships between firms and universities: The role of boundary organizations. *Research Policy, 44*(5), 1133-1143.

Perry, C. G., Maloney, K. A., Beitelshees, (…), & Blitzer, M. G. (2016). Educational innovations in clinical pharmacogenomics. *Clinical Pharmacology & Therapeutics, 99*(6), 582-584.

Petersen, K. E., Prows, C. A., Martin, L. J., & Maglo, K. N. (2014). Personalized medicine, availability, and group disparity: an inquiry into how physicians perceive and rate the elements and barriers of personalized medicine. *Public Health Genomics, 17*(4), 209-220.

Peterson-Clark, G., Aslani, P., & Williams, K. A. (2010). Pharmacists' online information literacy: an assessment of their use of Internet-based medicines information. *Health Information & Libraries Journal, 27*(3), 208-216.

Pisanu, C., Tsermpini, E.-E., Mavroidi, (…), & Squassina, A. (2014). Assessment of the pharmacogenomics educational environment in Southeast Europe. *Public Health Genomics, 17*(5-6), 272-279.

Plunkett-Rondeau, J., Hyland, K., & Dasgupta, S. (2015). Training future physicians in the era of genomic medicine: trends in undergraduate medical genetics education. *Genetics in Medicine, 17*(11), 927-934.

Potnis, D. D., & Gala, B. (2020). Managing the "backend" of LIS research projects: A project management perspective. *Library & Information Science Research, 42*(1), 100996. https://doi.org/10.1016/j.lisr.2019.100996

Powell, K. P., Cogswell, W. A., Christianson, C. A., (…), & Henrich, V. C. (2012). Primary care physicians' awareness, experience and opinions of direct-to-consumer genetic testing. *Journal of genetic counseling, 21*(1), 113-126.

Qiang, Z. (2003). Internationalization of higher education: Towards a conceptual framework. *Policy futures in education, 1*(2), 248-270.

Quenzel, G., & Hurrelmann, K. (2013). The growing gender gap in education. *International journal of adolescence and youth, 18*(2), 69-84.

Qumsieh, R. Y., Ali, B. R., Abdulrazzaq, Y. M., (…), & Bastaki, S. M. A. (2011). Identification of new alleles and the determination of alleles and genotypes frequencies at the CYP2D6 gene in Emiratis. *Plos One, 6*(12), e28943. https://doi.org/10.1371/journal.pone.0028943

Rahawi, S., Naik, H., Blake, K. V., (…), & Scott, S. A. (2020). Knowledge and attitudes on pharmacogenetics among pediatricians. *Journal of human genetics, 65*(5), 437-444.

Rahma, A. T., Elbarazi, I., Ali, B. R., (…), & Al Maskari, F. (2020a). Genomics and Pharmacogenomics Knowledge, Attitude and Practice of Pharmacists Working in United Arab Emirates: Findings from Focus Group Discussions—A Qualitative Study. *Journal of Personalized Medicine, 10*(3), 134. https://doi.org/10.3390/jpm10030134

Rahma, A. T., Elsheik, M., Ali, B. R., (…), & Al Maskari, F. (2020b). Knowledge, Attitudes, and Perceived Barriers toward Genetic Testing and Pharmacogenomics among Healthcare Workers in the United Arab Emirates: A Cross-Sectional Study. *Journal of Personalized Medicine, 10*(4), 216. https://doi.org/10.3390/jpm10030134

Rahma, A. T., Elsheik, M., Elbarazi, I., (…), & Al Maskari, F. (2020c). Knowledge and Attitudes of Medical and Health Science Students in the United Arab Emirates toward Genomic Medicine and Pharmacogenomics: A Cross-Sectional Study. *Journal of Personalized Medicine, 10*(4), 191. https://doi.org/10.3390/jpm10040191

Rahmani, A., & Afandi, B. (2015). Improving neonatal complications with a structured multidisciplinary approach to gestational diabetes mellitus management. *Journal of neonatal-perinatal medicine, 8*(4), 359-362.

Randhawa, G. S., Soltysiak, M. P. M., El Roz, H., (…), & Kari, L. (2020). Machine learning using intrinsic genomic signatures for rapid classification of novel pathogens: COVID-19 case study. *Plos One, 15*(4), e0232391. https://doi.org/10.1371/journal.pone.0232391

Rastogi, N., & Trivedi, M. K. (2016). PESTLE technique–a tool to identify external risks in construction projects. *International Research Journal of Engineering and Technology (IRJET), 3*(1), 384-388.

Relling, M. V., Altman, R. B., Goetz, M. P., & Evans, W. E. (2010). Clinical implementation of pharmacogenomics: overcoming genetic exceptionalism. *The lancet oncology, 11*(6), 507-509.

Relling, M. V., Gardner, E. E., Sandborn, W. J., (…), & Klein, T. E. (2011). Clinical Pharmacogenetics Implementation Consortium guidelines for thiopurine methyltransferase genotype and thiopurine dosing. *Clinical Pharmacology & Therapeutics, 89*(3), 387-391.

Reydon, T. A. C., Kampourakis, K., & Patrinos, G. P. (2012). Genetics, genomics and society: the responsibilities of scientists for science communication and education. *Personalized Medicine, 9*(6), 633-643.

Riggs, E. R., Andersen, E. F., Cherry, A. M., (…), & Thorland, E. C. (2020). Technical standards for the interpretation and reporting of constitutional copy-number variants: a joint consensus recommendation of the American College of Medical Genetics and Genomics (ACMG) and the Clinical Genome Resource (ClinGen). *Genetics in Medicine, 22*(2), 245-257.

Rigter, T., Jansen, M., Groot, J. d., (…), & Cornel, M. C. (2020). Implementation of pharmacogenetics in primary care: a Multi-stakeholder perspective. *Frontiers in Genetics, 11*, 10. https://doi.org/10.3389/fgene.2020.00010

Roberts, J. S., Dolinoy, D. C., & Tarini, B. A. (2014). Emerging issues in public health genomics. *Annual review of genomics and human genetics, 15*, 461-480.

Roberts, J. S., Gornick, M. C., Carere, D. A., (…), & Green, R. C. (2017). Direct-to-consumer genetic testing: user motivations, decision making, and perceived utility of results. *Public Health Genomics, 20*(1), 36-45.

Roederer, M. W., Van Riper, M., Valgus, J., Knafl, G., & McLeod, H. (2012). Knowledge, attitudes and education of pharmacists regarding pharmacogenetic testing. *Personalized Medicine, 9*(1), 19-27.

Rogausch, A., Prause, D., Schallenberg, A., Brockmöller, J., & Himmel, W. (2006). Patients' and physicians' perspectives on pharmacogenetic testing. *Pharmacogenomics, 7*(1), 49-59.

Romagnoli, K. M., Boyce, R. D., Empey, P. E., Adams, S., & Hochheiser, H. (2016). Bringing clinical pharmacogenomics information to pharmacists: a qualitative study of information needs and resource requirements. *International journal of medical informatics, 86*, 54-61.

Rowland-Jones, R. (2012). The EFQM concepts of excellence approach to management development within the UAE healthcare industry utilizing action modalities. *Human Resource Development International, 15*(4), 501-514.

Sabatello, M., Chen, Y., Sanderson, S. C., Chung, W. K., & Appelbaum, P. S. (2019). Increasing genomic literacy among adolescents. *Genetics in Medicine, 21*(4), 994-1000.

Sagia, A., Cooper, D. N., Poulas, K., Stathakopoulos, V., & Patrinos, G. P. (2011). Critical appraisal of the private genetic and pharmacogenomic testing environment in Greece. *Personalized medicine, 8*(4), 413-420.

Schaper, M., Wöhlke, S., & Schicktanz, S. (2019). "I would rather have it done by a doctor"—laypeople's perceptions of direct-to-consumer genetic testing (DTC GT) and its ethical implications. *Medicine, Health Care and Philosophy, 22*(1), 31-40.

Schleit, J., Naylor, L. V., & Hisama, F. M. (2019). First, do no harm: direct-to-consumer genetic testing. *Genetics in Medicine, 21*(2), 510-511.

Schuh, M. J., & Crosby, S. (2019a). Description of an Established, Fee-for-Service, Office-Based, Pharmacist-Managed Pharmacogenomics Practice. *The Senior Care Pharmacist, 34*(10), 660-668.

Schuh, M. J., & Crosby, S. (2019b). Methotrexate Central Nervous System Toxicity Identified in a Pharmacogenomics Pharmacist Consult Patient. *The Senior Care Pharmacist, 34*(9), 595-599.

Schwartz, E. J., & Issa, A. M. (2017). The role of hospital pharmacists in the adoption and use of pharmacogenomics and precision medicine. *Personalized Medicine, 14*(1), 27-35.

Shaffer, C. D., Alvarez, C., Bailey, C., (…), & Du, C. (2010). The Genomics Education Partnership: successful integration of research into laboratory classes at a diverse group of undergraduate institutions. *CBE—Life Sciences Education, 9*(1), 55-69.

Shah, S. N., & Shaheen, S. (2016). Artificial Intelligence (AI), Genomics and Personalized Medicine. *Biotechnological Research, 2*(4), 173-175.

Sharoff, L. (2020). A pilot assessment: Integrating a cystic fibrosis simulation scenario to enhance pre-licensure educational understanding of genomics. *Journal of Nursing Education and Practice, 10*(1), 24. https://doi.org/10.5430/jnep.v10n1p24

Shaya, B., Al Homsi, N., Eid, K., (…), & Akl, E. A. (2019). Factors associated with the public's trust in physicians in the context of the Lebanese healthcare system: a qualitative study. *BMC health services research, 19*(1), 525. https://doi.org/10.1186/s12913-019-4354-0

Shendure, J., Findlay, G. M., & Snyder, M. W. (2019). Genomic medicine–progress, pitfalls, and promise. *Cell, 177*(1), 45-57.

Shuster, M., Glazewski, K., & Villa, C. (2020). Design, Development, and Evaluation of a Teacher Workshop Enhanced with DNA Instructional Cases to Impact Content Knowledge and Confidence. *Interdisciplinary Journal of Problem-Based Learning, 14*(1), 28724. https://doi.org/10.14434/ijpbl.v14i1.28724

Singh D. B. (2020). The Impact of Pharmacogenomics in Personalized Medicine. *Advances in biochemical engineering/biotechnology*, *171*, 369-394.

Snyder, S. R., Mitropoulou, C., Patrinos, G. P., & Williams, M. S. (2014). Economic evaluation of pharmacogenomics: a value-based approach to pragmatic decision making in the face of complexity. *Public Health Genomics, 17*(5-6), 256-264. https://doi.org/10.1159/000366177

Squiers, L., Peinado, S., Berkman, N., Boudewyns, V., & McCormack, L. (2012). The health literacy skills framework. *Journal of health communication, 17*(sup3), 30-54.

Stanek, E. J., Sanders, C. L., Taber, K. A., (…), & Frueh, F. W. (2012). Adoption of pharmacogenomic testing by US physicians: results of a nationwide survey. *Clin Pharmacol Ther, 91*(3), 450-458. https://doi.org/10.1038/clpt.2011.306

Stark, Z., Dolman, L., Manolio, T. A., (…), & Lawler, M. (2019a). Integrating genomics into healthcare: a global responsibility. *The American Journal of Human Genetics, 104*(1), 13-20.

Stark, Z., Nisselle, A., McClaren, B., (…), & Gaff, C. L. (2019b). Attitudes of Australian health professionals towards rapid genomic testing in neonatal and paediatric intensive care. *European journal of human genetics : EJHG, 27*(10), 1493-1501.

Stark, Z., Schofield, D., Martyn, M., (…), & White, S. M. (2019c). Correction: Does genomic sequencing early in the diagnostic trajectory make a difference? A follow-up study of clinical outcomes and cost-effectiveness. *Genetics in medicine: official journal of the American College of Medical Genetics, 21*(2), 516-516.

Swan, M. (2012). Health 2050: The realization of personalized medicine through crowdsourcing, the quantified self, and the participatory biocitizen. *Journal of Personalized Medicine, 2*(3), 93-118.

Syurina, E. V., Brankovic, I., Probst-Hensch, N., & Brand, A. (2011). Genome-based health literacy: a new challenge for public health genomics. *Public Health Genomics, 14*(4-5), 201-210.

Ta, R., Cayabyab, M. A. S., & Coloso, R. (2019). Precision medicine: a call for increased pharmacogenomic education. *Personalized Medicine, 16*(3), 233-245.

Taber, K. A. J., & Dickinson, B. D. (2014). Pharmacogenomic knowledge gaps and educational resource needs among physicians in selected specialties. *Pharmacogenomics and Personalized Medicine, 7*, 145-162.

Tai, C. G., Harris-Wai, J., Schaefer, C., Liljestrand, P., & Somkin, C. P. (2018). Multiple Stakeholder Views on Data Sharing in a Biobank in an Integrated Healthcare Delivery System: Implications for Biobank Governance. *Public Health Genomics, 21*(5-6), 207-216.

Talwar, D., Chen, W.-J., Yeh, Y.-L., (…), & Chen, L.-S. (2019). Characteristics and evaluation outcomes of genomics curricula for health professional students: a systematic literature review. *Genetics in Medicine, 21*(8), 1675-1682.

Tandy-Connor, S., Guiltinan, J., Krempely, K., (…), & Davis, B. T. (2018). False-positive results released by direct-to-consumer genetic tests highlight the importance of clinical confirmation testing for appropriate patient care. *Genetics in Medicine, 20*(12), 1515-1521.

Thomas, S. M. (2004). Society and ethics–the genetics of disease. *Current opinion in genetics & development, 14*(3), 287-291.

Thorn, C. F., Klein, T. E., & Altman, R. B. (2013). PharmGKB: the Pharmacogenomics Knowledge Base. In J.M. Walker , *Methods in molecular biology,* Vol. 1015, (pp. 311-320). Second edition. Totowa, NJ: Humana Press. https://doi.org/10.1007/978-1-62703-435-7_20

Thornberg, R., Perhamus, L. M., & Charmaz, K. (2015). Grounded theory. In O. N. Saracho, *Handbook of research methods in early childhood education: Review of research methodologies,* Vol. 1, (pp. 405-439). Charlotte, NC: IAP Information Age Publishing. http://dx.doi.org/10.4135/9781473983953.n18

Tindana, P., Molyneux, S., Bull, S., & Parker, M. (2019). 'It is an entrustment': Broad consent for genomic research and biobanks in sub-Saharan Africa. *Developing world bioethics, 19*(1), 9-17.

Tsai, Y.-S., Perrotta, C., & Gašević, D. (2020). Empowering learners with personalised learning approaches? Agency, equity and transparency in the context of learning analytics. *Assessment & Evaluation in Higher Education, 45*(4), 554-567.

Tuteja, S., Haynes, K., Zayac, C., (…), & Pyeritz, R. (2013). Community pharmacists 'attitudes towards clinical utility and ethical implications of pharmacogenetic testing. *Personalized medicine, 10*(8), 793-800.

Uddin, M., Mustafa, F., Rizvi, T. A., (…), & Stefanini, C. (2020). SARS-CoV-2/COVID-19: Viral genomics, epidemiology, vaccines, and therapeutic interventions. *Viruses, 12*(5), 526. https://doi.org/10.3390/v12050526

United Arab Emirates Population 2021 (Demographics, Maps, Graphs). (2021) [online]. *World Population Review*. Retrived from: https://worldpopulationreview.com/countries/united-arab-emirates-population

Van Bavel, J., Schwartz, C. R., & Esteve, A. (2018). The reversal of the gender gap in education and its consequences for family life. *Annual Review of Sociology, 44*, 341-360.

van den Boom, D., Wjst, M., & Everts, R. E. (2013). MALDI-TOF mass spectrometry. In J.M. Walker, *Methods in molecular biology*, Vol. 1015, (pp. 71-85). Totowa, NJ: Humana Press. http://dx.doi.org/10.1007/978-1-62703-435-7_4

van der Wouden, C. H., Bank, P. C. D., Özokcu, K., Swen, J. J., & Guchelaar, H.-J. (2019). Pharmacist-initiated pre-emptive pharmacogenetic panel testing with clinical decision support in primary care: record of PGx results and real-world impact. *Genes, 10*(6), 416. https://doi.org/10.3390/genes10060416

Visvikis-Siest, S., Gorenjak, V., Stathopoulou, M. G., (…), & Boerwinkle, E. (2018). The 9th Santorini Conference: Systems Medicine, Personalised Health and Therapy."The Odyssey from Hope to Practice", Santorini, Greece, 30 September–3 October 2018. *Journal of Personalized Medicine, 8*(4), 43.

Walters, G., & Kitchin, P. J. (2009). Stakeholder Management and Sport Facilities: A Case Study of the Emirates Stadium*. *Birkbeck Sport Business Centre Case Study Series*, *1*(2), 1-23.

Ward, K. M., Taubman, D. S., Pasternak, A. L., (…), & Parikh, S. V. (2020). Teaching psychiatric pharmacogenomics effectively: Evaluation of a novel interprofessional online course. *Journal of the American College of Clinical Pharmacy 4*(2), 176-183.

Wauters, A., & Van Hoyweghen, I. (2018). Concerns about genetic discrimination after regulation: A qualitative study of the situation regarding BRCA and Huntington's disease in Belgium. *Laws, 7*(2), 17.

Weedon, M. N., Jackson, L., Harrison, J. W., (…), & Wright, C. F. (2019). Very rare pathogenic genetic variants detected by SNP-chips are usually false positives: implications for direct-to-consumer genetic testing. *bioRxiv*, 696799. https://doi.org/10.1101/696799

Weir, M., Morin, K., Ries, N., & Castle, D. (2010). Canadian health care professionals' knowledge, attitudes and perceptions of nutritional genomics. *British journal of nutrition, 104*(8), 1112-1119.

Weitzel, K. W., McDonough, C. W., Elsey, A. R., (…), & Johnson, J. A. (2016). Effects of using personal genotype data on student learning and attitudes in a pharmacogenomics course. *American journal of pharmaceutical education, 80*(7), 122. https://doi.org/10.5688/ajpe807122

Whitley, K. V., Tueller, J. A., & Weber, K. S. (2020). Genomics education in the era of personal genomics: Academic, professional, and public considerations. *International journal of molecular sciences, 21*(3), 768. https://doi.org/10.3390/ijms21030768

World Health Organization. (2018). United Arab Emirates [online]. *World Health Organization - Noncommunicable Diseases (NCD) Country Profiles*. Retrieved from: https://www.who.int/nmh/countries/are_en.pdf

Williams, M. S. (2019). Early lessons from the implementation of genomic medicine programs. *Annual review of genomics and human genetics, 20*, 389-411.

Wonkam, A., & Hurst, S. (2014). A call for policy action in sub-Saharan Africa to rethink diagnostics for pregnancy affected by sickle cell disease: differential views of medical doctors, parents and adult patients predict value conflicts in Cameroon. *Omics: a journal of integrative biology, 18*(7), 472-480.

Wonkam, A., Njamnshi, A. K., & Angwafo, F. F. (2006). Knowledge and attitudes concerning medical genetics amongst physicians and medical students in Cameroon (sub-Saharan Africa). *Genetics in Medicine, 8*(6), 331-338.

Woolhouse, N. M., Qureshi, M. M., Bastaki, S. M., (…), & Bayoumi, R. A. (1997). Polymorphic N-acetyltransferase (NAT2) genotyping of Emiratis. *Pharmacogenetics, 7*(1), 73-82.

Wurcel, V., Cicchetti, A., Garrison, L., (…), & Oortwijn, W. (2019). The Value of Diagnostic Information in Personalised Healthcare: A Comprehensive Concept to Facilitate Bringing This Technology into Healthcare Systems. *Public Health Genomics, 22*(1-2), 8-15.

Yau, A., Abd Aziz, A. B., & Haque, M. (2015). Knowledge, attitude and practice concerning pharmacogenomics among pharmacists: a systematic review. *Journal of Young Pharmacists, 7*(3), 145-154.

Zarei, S., Costas, Y., Orozco, G., (…), & Gonzalez Cardona, A. R. (2020). A Web-Based Pharmacogenomics Search Tool for Precision Medicine in Perioperative Care. *Journal of Personalized Medicine, 10*(3), 65. https://doi.org/10.3390/jpm10030065

Zayed, H., & Ouhtit, A. (2016). Accredited genetic testing in the Arab Gulf region: reinventing the wheel. *Journal of human genetics, 61*(7), 673-674.

Zgheib, N. K., Patrinos, G. P., Akika, R., & Mahfouz, R. (2020). Precision Medicine in Low-and Middle-Income Countries. *Clinical Pharmacology & Therapeutics, 107*(1), 29-32.

Zhang, H., & Li, P. (2014). On the globalization and standardization of medical genetics and genomics as clinical and laboratory specialties. *North American Journal of Medicine and Science, 7*(4), 194-198.

Zhang, L., Bao, Y., Riaz, M., (…), & Lacaze, P. (2019). Population genomic screening of all young adults in a health-care system: a cost-effectiveness analysis. *Genetics in medicine : official journal of the American College of Medical Genetics, 21*(9), 1958-1968.

Zhao, X., Wang, P., Tao, X., & Zhong, N. (2013). Genetic services and testing in China. *Journal of community genetics, 4*(3), 379-390.

Ziegelstein, R. C. (2015). Personomics. *JAMA internal medicine, 175*(6), 888-889.

Ziegelstein, R. C. (2017). Personomics: The missing link in the evolution from precision medicine to personalized medicine. *Journal of Personalized Medicine, 7*(4), 11. https://doi.org/10.3390/jpm7040011

List of Publications

Rahma, A. T., Elbarazi, I., Ali, B. R., Patrinos, G. P., Ahmed, L. A., & Al Maskari, F. (2020). Genomics and Pharmacogenomics Knowledge, Attitude and Practice of Pharmacists Working in United Arab Emirates: Findings from Focus Group Discussions—A Qualitative Study. *Journal of Personalized Medicine*, *10*(3), 134. https://doi.org/10.3390/jpm10030134

Rahma, A. T., Elsheik, M., Elbarazi, I., Ali, B. R., Patrinos, G. P., Kazim, M. A., ... & Al Maskari, F. (2020). Knowledge and Attitudes of Medical and Health Science Students in the United Arab Emirates toward Genomic Medicine and Pharmacogenomics: A Cross-Sectional Study. *Journal of Personalized Medicine*, *10*(4), 191. https://doi.org/10.3390/jpm10040191

Rahma, A. T., Elsheik, M., Ali, B. R., Elbarazi, I., Patrinos, G. P., Ahmed, L. A., & Al Maskari, F. (2020). Knowledge, Attitudes, and Perceived Barriers toward Genetic Testing and Pharmacogenomics among Healthcare Workers in the United Arab Emirates: A Cross-Sectional Study. *Journal of Personalized Medicine*, *10*(4), 216. https://doi.org/10.3390/jpm10040216

Rahma, A. T., Elbarazi, I., Ali, B. R., Patrinos, G. P., Ahmed, L. A., & Al-Maskari, F. (2021). Stakeholders' Interest and Attitudes toward Genomic Medicine and Pharmacogenomics Implementation in the United Arab Emirates: A Qualitative Study. *Public Health Genomics*, 1-11. https://doi.org/10.1159/000513753

Rahma, A. T., Ahmed, L. A., Elsheik, M., Ali, B. R., Elbarazi, I., Patrinos, G. P., & Al Maskari, F. (2021). Mapping the Educational Environment of Genomics and Pharmacogenomics in the United Arab Emirates: A Mixed Method Triangulated Design. *OMICS*, *25*(5), 285-293. https://doi.org/10.1089/omi.2021.0029

Appendices

Appendix A: Participant Information Sheet

Study Title: Assessing the knowledge, Attitude and perception of Genomic Medicine and Pharmacogenomics among healthcare providers and patients in the UAE"

Invitation to Participate:

Dear Participant…

We are seeking your kind participation in filling in a questionnaire to help us identify the current status and future needs for genetic testing, genomic medicine and pharmacogenomics in the UAE. The questionnaire is short and will not take more than 15 minutes. We appreciate your support and cooperation. Please note that this is an anonymous questionnaire where at no stage your name and identity will be revealed to anyone.

We greatly appreciate your time and support

Purpose of the study:

Public health genomics is a recent interdisciplinary aspect in public health comprising the use of genetic epidemiology, biostatistics, health policy, health education, and state-funded programs focused on surveillance and prevention of heritable disorders as well as provide the necessary set up needed to achieve the ultimate aim of improving population health. The underlying driving force behind this discipline is the phenomenal improvement in our understanding of the human genome and its relevance to human health and disease. This understanding led to numerous medical and public health applications including in diagnosis, therapy and prevention of ill health. In this proposal, we aim to evaluate the current status of the knowledge and facilities for utilizing genomic medicine and pharmacogenomics in the UAE and construct a roadmap to implementing genomic medicine in the clinic with the aim of improving the public health of the UAE nation.

Why have I been chosen?

This study aims to survey health care workers, medical related students as well as the public

Do I have to take part?

It is absolutely voluntary to take part in this study. You to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. You can withdraw your participation at any time and even after you have given the consent. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What will happen to me if I take part?

This is a one off 5-10 minutes survey through questionnaire, all information obtained will be handled with the utmost degree of confidentiality.

Principal Researchers Contact details:

Azhar Talal , PhD candidate UAEU ,Institute of public health , Tawam Hospital, Pharmacy Department, 0501126098

Definitions

GENETIC TESTING: The use of genetic material (DNA) for we diagnosis of genetic and other human conditions

GENOMIC MEDICINE: The use of genetic information of an individual for their diagnosis, treatment and other relevant applications

PHARMACOGENOMICS: The use of genetic and genomic information of the individual for the prescription of their medications.

You will be given a copy of the information sheet and a signed consent form to keep.

Appendix B: Consent Form

UAEU

جامعة الإمارات العربية المتحدة
United Arab Emirates University

Please read carefully the information sheet and consent form before signing

Project title: Assessing the knowledge, Attitude and perception of Genomic Medicine and Pharmacogenomics among healthcare providers and patients in the UAE"

Researchers:

Miss. Azhar Talal Al-Rahma, PhD Student at the Institute of Public Health, College of Medicine and Health Sciences. Telephone: 0501126098. Email: 201280026@uaeu.ac.ae

You will be asked to provide or deny consent after reading the information sheet.

1	I confirm that I have read and understand the information sheet dated (Version) for the above study and have had the opportunity to ask questions.
2	I understand that my participants is voluntary and that I am free to withdraw
3	I understand that if I withdraw from the study it will not adversely affect my healthcare or employment
4	I understand that my data will be kept confidential and in a safe place
5	I agree to take part in the above study

Name of Participant	Date	Signature

Name of Researcher Taking Consent	Date	Signature

Appendix C: Questionnaire for Healthcare Providers

We are seeking your kind participation in filling in the below questions about genomic medicine and pharmacogenomics. The questionnaire is short and will not take more than 15 minutes. We appreciate your support and cooperation. Please note that this is an anonymous questionnaire where at no stage your name and identity will be known to anyone.

As an INCENTIVE you are given a chance to get a FREE registration for the third workshop of GENOMIC MEDICINE and Pharmacogenomics organized by Golden Helix Foundation and UAEU next February 2019 , all you have to do is to send me an e-mail, which will appear in the space at the end of this survey

Do you agree to participate ?

- ○ Yes
- ○ No

Gender:

- ○ Male
- ○ Female

Your nationality

_____

Your facility is operated by:

- ○ Government
- ○ Private
- ○ Semi-government

Location of your facility :

- ○ Abu Dhabi
- ○ Al-Ain
- ○ Ajman
- ○ Fujairah
- ○ Ras al-Khaimah
- ○ Sharjah
- ○ Umm al-Quwain
- ○ Dubai

Type of facility:

- ○ Tertiary care Hospital
- ○ Secondary care Hospital
- ○ Health Clinic
- ○ Other _____

How old are you? (Age in years)

_____

Total years of experience:

_____

Your occupation is:

- ○ Consultant
- ○ Hospitalist
- ○ Surgeon
- ○ Specialist
- ○ Attending Physician
- ○ Primary Physician
- ○ Resident
- ○ Nurse
- ○ Dentist
- ○ Inpatient Pharmacist
- ○ Pharmacy Technician
- ○ Outpatient Pharmacist
- ○ Pharmacy supervisor
- ○ Clinical Pharmacist
- ○ Other: (please specify)

_____

Location of Facility:

- ○ Rural
- ○ Urban

Did you practice outside United Arab Emirates ?

- ○ No
- ○ Yes, please name countries you practice in _____

Choose the best answer that suits your qualifications (you can choose more than one answer)

- ○ Bachelor
- ○ Master
- ○ PhD
- ○ Board certified
- ○ Diploma
- ○ Other _____

In general, to what extent are your opinions and decisions influenced by religion?

- ○ Greatly influenced
- ○ Somewhat influenced
- ○ Not influenced

How much your decision to go for genetic testing would be affected by your traditions and cultural customs ?

- ○ Greatly influenced
- ○ Somewhat influenced
- ○ Not influenced

Have you or anyone close to you ever had any experience with genetic issues? For example, having a heritable disease in the family, or taking a genetic test?

- ○ YES
- ○ NO

Have you completed Pharmacogenomics/ Pharmacogenetics related training or education?

- ○ Yes
- ○ No

Type of the course:

- ○ Stand alone course on Pharmacogenomics /Pharmacogenetics
- ○ As part of other course
- ○ Online course
- ○ Other _____

Choose the correct answer for the following statements about genetics & Pharmacogenomics:

	True	False	Do Not Know
Humans have 48 chromosomes?	○	○	○
Adenine (A) only pairs with cytosine (C) and Thymine (T) only pairs with Guanine (G)?	○	○	○
Pharmacogenomics seeks to individualize therapy based on patient's genetic profile?	○	○	○
Genetic changes can cause adverse reactions?	○	○	○
Pharmacogenomics testing is recommended by FDA for certain drugs?	○	○	○
Genetic changes can affect the patient's response to certain drug?	○	○	○
Genes can be activated or deactivated by other genes?	○	○	○
Every cell of the body contains the whole genome?	○	○	○
Environmental factors, such as cigarette smoke, can affect gene activity?	○	○	○

On a scale from strongly disagree to strongly agree, to what extent do you agree with the following statements?

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
At some point in my life, I might consider having a genetic test to find out my risk of developing various genetic diseases	○	○	○	○	○
I am glad that genetic tests can be ordered on the internet	○	○	○	○	○
I am glad that genetic tests are available so that people with a family history of serious genetic disease can find out if they are at risk	○	○	○	○	○
The availability of genetic tests for insurance companies and future employers is problematic.	○	○	○	○	○
I am generally positive towards genetic testing and think the government should invest more money into its development	○	○	○	○	○
I would like to participate in genetic research	○	○	○	○	○

On a scale from strongly disagree to strongly agree, to what extent do you agree with the following statements?

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
I would like to donate my genetics materials for bio-bank	○	○	○	○	○
If I were diagnosed with cancer, I would consider having my genes analysed in order to help chose a cancer treatment with the fewest side effects	○	○	○	○	○
If I had a family history of diabetes I would consider having my genes analysed in order to help me make lifestyle choices and decisions about interventions that may prevent diabetes from developing	○	○	○	○	○
I would NOT be willing to get my whole genome analysed, because I worry about issues of confidentiality	○	○	○	○	○
I am skeptical toward pharmacogenomics because of the possibility of getting information about my genes that is unrelated to the treatment	○	○	○	○	○

On a scale from strongly disagree to strongly agree, to what extent do you agree with the following statements?

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
I believe that, in the future, medicine will be more personalized	○	○	○	○	○
I think that more time should be devoted for the teaching of pharmacogenomics in the course of study	○	○	○	○	○
I would you be interested in attending a pharmacogenomics course and/or educational seminar	○	○	○	○	○
I believe that pharmacogenomics could be exploited by employers, insurance companies..etc to discriminate certain population groups or patients	○	○	○	○	○
I would like only to know my susceptibility to diseases that have current intervention for protection	○	○	○	○	○
Genetics and Genetic tests are involved in my current work.	○	○	○	○	○

On a scale from strongly disagree to strongly agree, to what extent do you agree with the following statements?

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
Pharmacogenomics and it' tests are involved in my current work.	○	○	○	○	○
The results of genetic tests will affect the medical care of my patients in terms of medications, diagnosis, appointments…etc.)	○	○	○	○	○
The expense of genetic & pharmacogenomics tests should be covered by insurance companies.	○	○	○	○	○
I could explain the results of genetics and pharmacogenomics tests to my patients without translation.	○	○	○	○	○
My undergraduate studies at the University provided me with sufficient knowledge on genetics & pharmacogenomics.	○	○	○	○	○
Policy and procedures as well as legal framework do exist in the field of genetic tests in UAE.	○	○	○	○	○

Which type of education do you prefer to learn about Pharmacogenomics/ Pharmacogenetics? Please tick all that apply

- ○ Workshops or seminars
- ○ Internet based learning activities
- ○ Self-directed learning
- ○ blended learning (joint e-learning and onsite training)
- ○ Other _____

Which of the following do you think are barriers for the implementation of pharmacogenetic /Pharmacogenomics testing in U.A.E ? Please tick all that apply

- ○ Shortage of personnel
- ○ Lack of clinical guidelines on Pharmacogenomics/ Pharmacogenetics practice
- ○ Lack of testing services
- ○ Lack of training or education
- ○ Cost of testing
- ○ No clinical need
- ○ Insurance coverage
- ○ No law for confidentiality of results
- ○ Other _____

Which of the following sample you may provide for Pharmacogenomics/ Pharmacogenetics testing ? Please tick all that apply

- ○ Blood
- ○ Saliva
- ○ Buccal Swap

Have you ever advised any of your patients to undertake a genetic test?

- ○ Yes
- ○ No
- ○ Not Applicable

Choose which test (Check all that applies):

- ○ A genetic test (e.g. to control a hereditary disease).
- ○ A cytogenetic test (e.g. for dysmorphology and or mental retardation syndromes).
- ○ A pharmacogenomic test (e.g. to reduce significantly the chances of developing side effects and or to control response to a medication).
- ○ Other _____

Have you had any patients who asked about undertaking a genetic test in the last two years?

- ○ Yes
- ○ No
- ○ Not Applicable

Have you had any patients who asked your advice about the results of a genetic test in the last two years?

- ○ Yes
- ○ No
- ○ Not Applicable

What is the most reliable source of information regarding genetics & pharmacogenomics? (you can choose more than one answer)

- ○ Databases
- ○ The leaflet of the medication
- ○ Scientific Journals
- ○ Google
- ○ YouTube
- ○ Lexicomp
- ○ Up to Date
- ○ Micromedx
- ○ Other _____

Who do you think should provide counseling to genetic/pharmacogenetic testing and results?

- ○ Physician
- ○ Pharmacist
- ○ Genetic counselor
- ○ Nurse
- ○ Other _____

The present state of Genomic Medicine and Pharmacogenomics in UAE is:

- ○ Very good
- ○ Good
- ○ Adequate
- ○ Poor
- ○ I do not know

If you wish to get a FREE registration to the third Genomic medicine and Pharmacogenmic workshop organized by GoldenHelix foundation and UAEU in February 2019 , please put your email here or you can simply email me at 201280026@uaeu.ac.ae

_____

Thank you for your valuable time, you really helped me and helped the future of health in UAE.

Appendix D: Questionnaire for the Medical and Health Sciences Students

We are seeking your kind participation in filling in the below questions about genomic medicine and pharmacogenomics . The questionnaire is short and will not take more than 5 minutes . We appreciate your support and cooperation. Please note that this is an anonymous questionnaire where at no stage your name and identity will be known to anyone.

As an INCENTIVE you are given a chance to get a FREE registration for the third workshop of GENOMIC MEDICINE and Pharmacogenomics organized by Golden Helix Foundation and UAEU next February 2019 , all you have to do is to send me an e-mail in the space at the end of this survey

Do you agree to participate ?

- ○ Yes
- ○ No

Gender:

- ○ Male
- ○ Female

Your nationality

_____

Type of your University:

- ○ Government
- ○ Private
- ○ Semi-government

Location of your university:

- ○ Abu Dhabi
- ○ Al Ain
- ○ Fujairah
- ○ Sharjah
- ○ Umm al Quwain
- ○ Ajman
- ○ Ras Al Khaimah
- ○ Dubai

You are studying for which degree?

- ○ Bachelor
- ○ Master
- ○ PhD
- ○ Other (please specify)_____

Your year of study?

- ○ First Year (1)
- ○ Second Year (2)
- ○ Third Year (3)
- ○ Forth year (4)
- ○ Fifth year (5)
- ○ Sixth Year (6)
- ○ Other (7) _____

Your main field of study:

- ○ Medicine (1)
- ○ Pharmacy (2)
- ○ Laboratory (3)
- ○ Nursing (4)
- ○ Other (5) _____

How old are you? (Age in years)

_____

Did you complete an internship training abroad OR study any course abroad?

- ○ Yes
- ○ No

Can you please specify which COUNTRY

_____

Can you please specify what was the COURSE or type of internship?

_____

In general, to what extent are your opinions and decisions influenced by religion?

- ○ Greatly influenced
- ○ Somewhat influenced
- ○ Not influenced

How much your decision to go for genetic testing would be affected by your traditions and cultural customs

- ○ Greatly influenced
- ○ Somewhat influenced
- ○ Not influenced

Have you or anyone close to you ever had any experience with genetic issues? For example, having a heritable disease in the family, or taking a genetic test?

- ○ Yes
- ○ No

Have you completed Pharmacogenomics /Pharmacogenetics related training or education?

- ○ Yes
- ○ No

Type of the course:

- ☐ Stand alone course on Pharmacogenomics /Pharmacogenetics
- ☐ As part of other course
- ☐ Online course

Choose the correct answer for the following statements about genetics & pharmacogenomics:

	True	False	Do Not know
Humans have 48 chromosomes?	○	○	○
Adenine (A) only pairs with cytosine (C) and Thymine (T) only pairs with Guanine (G)?	○	○	○
Pharmacogenomics seeks to individualize therapy based on patient's genetic profile?	○	○	○
Genetic changes can cause adverse reactions?	○	○	○
Pharmacogenomics testing is recommended by FDA for certain drugs?	○	○	○
Genetic changes can affect the patient's response to certain drug?	○	○	○
Genes can be activated or deactivated by other genes?	○	○	○
Every cell of the body contains the whole genome?	○	○	○
Environmental factors, such as cigarette smoke, can affect gene activity?	○	○	○

On a scale from strongly disagree to strongly agree, to what extent do you agree with the following statements?

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree
At some point in my life, I might consider having a genetic test to find out my risk of developing various genetic diseases	○	○	○	○	○
I am glad that genetic tests can be ordered on the internet	○	○	○	○	○
I am glad that genetic tests are available so that people with a family history of serious genetic disease can find out if they are at risk	○	○	○	○	○
The availability of genetic tests for insurance companies and future employers is problematic	○	○	○	○	○
I am generally positive towards genetic testing and think the government should invest more money into its development	○	○	○	○	○
I would like to participate in genetic research	○	○	○	○	○

On a scale from strongly disagree to strongly agree, to what extent do you agree with the following statements?

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewat disagree	Strongly disagree
I would like to donate my genetics materials for bio-bank	○	○	○	○	○
If I were diagnosed with cancer, I would consider having my genes analysed in order to help chose a cancer treatment with the fewest side effects	○	○	○	○	○
If I had a family history of diabetes I would consider having my genes analysed in order to help me make lifestyle choices and decisions about interventions that may prevent diabetes from developing	○	○	○	○	○
I would NOT be willing to get my whole genome analysed, because I worry about issues of confidentiality	○	○	○	○	○

On a scale from strongly disagree to strongly agree, to what extent do you agree with the following statements?

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewat disagree	Strongly disagree
I am skeptical toward pharmacogenomics because of the possibility of getting information about my genes that is unrelated to the treatment	○	○	○	○	○
I believe that, in the future, medicine will be more personalized	○	○	○	○	○
I think that more time should be devoted for the teaching of pharmacogenomics in the course of study	○	○	○	○	○
I would you be interested in attending a pharmacogenomics course and/or educational seminar	○	○	○	○	○
I believe that pharmacogenomics could be exploited by employers, insurance companies..etc to discriminate certain population groups or patients	○	○	○	○	○

On a scale from strongly disagree to strongly agree, to what extent do you agree with the following statements?

	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewat disagree	Strongly disagree
I would like only to know my susceptibility to diseases that have current intervention for protection	○	○	○	○	○
I would prefer that the PHARMACIST to explain to me my genome report	○	○	○	○	○
I would prefer that the PHYSICIAN to explain to me my genome report	○	○	○	○	○

Which type of education do you prefer to learn about Pharmacogenomics /Pharmacogenetics? Please tick all that apply

○ Workshops or seminars

○ Internet based learning activities

○ Self-directed learning

○ During internship year

○ Other _____

Which of the following do you think are barriers for the implementation of Pharmacogenomics /Pharmacogenetics testing in U.A.E ? Please tick all that apply

- ○ Shortage of personnel
- ○ Lack of clinical guidelines on Pharmacogenomics /Pharmacogenetics practice
- ○ Lack of testing services
- ○ Lack of training or education
- ○ Cost of testing
- ○ Other _____

Which of the following sample you may provide for Pharmacogenomics /Pharmacogenetics testing? Please tick all that apply

- ○ Blood (1)
- ○ Saliva (2)
- ○ Buccal Swap (3)

As an INCENTIVE you are given a chance to get a FREE registration for the third workshop of GENOMIC MEDICINE and Pharmacogenomics organized by Golden Helix Foundation and UAEU next February 2019 , all you have to do is to send me an e-mail at 201280026@uaeu.ac.ae

_____

Appendix E: Onsite Laboratories Questionnaire

Name of the laboratory : ……

Location: ……

1. Are you providing a genetic service in your lab?
   A. Yes B. No

2. What type of genetic service do you offer?

1. Paternity test	8. Molecular microbiology analysis
2. Family tree analysis	9. Immunologic microbiology
3. Ancestry analysis	10. Cytogenetics (FISH/Chromosomal breakage)
4. Prenatal testing	11. Mitochondrial DNA
5. Pharmacogenomic testing	12. Health and wellness (fitness, skin care)
6. Whole Genome sequencing	13. Other: ……
7. Genomic screening	

3. What are the DNA sources used in your lab?

1. Blood	12. Urine
2. Plasma	13. CSF
3. Serum	14. Nasal swabs
4. Saliva/ sputum	15. Throat/pharyngeal swabs
5. Buccal swab	16. Rectal swab
6. Tissue (bone/bone marrow/ placenta/embryo)	17. Genital swab
7. Seminal stains/semen	18. Bronchoalveolar lavage fluid (BAL)
8. Cigarette butts	19. Other: ……
9. Hair	
10. Items of everyday use	
11. Stool	
12. Amniotic fluid	

4. Do you have a genomic bank?
A. Yes B. No

5. Do you have bioinformatics analysis?
A. Yes B. No

6. Who are your stakeholders?
A. Only directly to clients
B. Only through medical referrals (Hospitals/ clinics/doctors)
C. Both A & B

7. Is genetic counseling available at your center?
A. Yes B. No

8. If genetic counseling is available at your center, is it limited or complete?
A. Limited B. complete

9. Regarding the genetic counseling service – if available-:
A. The counselor is available at the center
B. We refer the patients to an outside counselor

10. Do you consider the information on you website complete and representative of your service?
A. Yes B. No C. I don't know

11. How frequent do you update the information on your website?
A. Every few months (less than six months)
B. Every 6 months – 1 year
C. Every 1-2 years
D. More than that

12. Do you have a personal who is responsible for updating your website?

A. Yes B. No

13. Are the services costs available on your website?
A. Yes B. No C. I don't know

14. Do you have information about the legal issues on your website?
A. Yes B. No C. I don't know

15. Do you have information regarding the privacy of each case on your website?
A. Yes B. No C. I don't know

16. Do you have information about the sample storage available on your website?
A. Yes B. No C. I don't know

17. Do you have information regarding the consent available on your website?
A. Yes B. No C. I don't know

18. Is your lab covered by health insurance?
A. Fully covered B. Partially covered C. No

19. Is your lab accredited?
A. Yes B. No

20. If your lab is accredited, please list the accreditation parties
A.
B.
C.
D.

21. Where does the processing of your specimens take place?
A. Local
B. Samples are sent abroad

Pharmacogene selection:

22. How are the genes aggregated for testing?

A. Single gene

B. Disease specific panel

C. Broad panel testing

D. I do not know

23. Can the laboratory provide customized panel of genes?

A. Yes

B. No

C. I do not know

Logistics:

24. What is the turnaround time?

25. Are samples used for research purposes?

A. Yes

B. No

C. I do not know

26. Is there any KPI in your lab?

A. Yes

B. No

C. I do not know

Reporting of results:

27. How are the results returned to a provider/patient?

A. Through system

B. Through written report

C. Through website

D.I do not know.

E.Other : specify please : ……

28. Are the results easy to interpret for a provider/patient?

A. Yes

B. No

C. I don't know

29. Is their evidence for each recommendation available in the report?

A. Yes

B. No

C. I don't know

30. What type of evidence you use to support your recommendations?

A. American guidelines.
B. Canadian guidelines.
C. Dutch guidelines.
D. Other: specify……
E. I don't know

31. What educational materials are available to aid in discussion of the results? (You can choose more than one answer)

A. Brochures

B. Videos

C. Posters

D. Online resources

Test cost and reimbursement:

32. Does the laboratory bill patient insurance directly?

A. Yes

B. No

C. I do not know.

D. Other: ……

33. What patient financial assistance programs does the laboratory provide?

34. Does the laboratory provide a maximum cost for the patient?

A. Yes

B. No

C.I Do not know

Thank you so much for your time and help

Appendix F: Topic Guide for Pharmacists' Focus Group Discussion

Introduction:

Welcome to UAEU and thank you for accepting the invitation to participate in this first focus group in UAE to address Pharmacogenomics and genomic medicine. Your opinions and thoughts are valuable and will help us construct the road map to the implementation of genomic medicine and pharmacogenomics in UAE.

My name is Azhar Talal and this is/are my colleague(s) ……..

The aims of the focus group:

In the coming 2 hours we will discuss:

1- Your Knowledge toward Genomic medicine and pharmacogenomics
2- Your experiences and attitude with Pharmacogenomics/genetics training/education and its application in your practice.
3- Your perceived barriers of implementation of genomic medicine and pharmacogenomics in UAE.

Can I get your permission to tape the discussion, so I can get to it later for the transcribing and analysis? (If yes, switch it on)

I want to emphasis that there is no right or wrong answers, you can disagree with each other, and you can change your mind. Please feel comfortable saying what you want.

Discuss procedure:

My colleague will be taking notes, so I do not oversight anything you have to say, because your opinion matters.

Anonymity:

In spite of being recorded, I would like to promise you that the discussion will be anonymous. The tapes will be locked and once transcribed will be erased. The transcribing will not allow linkage to you or to the name of the area of your practice.

The participants of this focus group and I would appreciate if you refrain from discussing what we will bring on the table today to other members outside the focus group.

Ground rules:

The only rule here is that ONE person speaks at a time. You may feel that you want to interrupt to say something important, though I value all your inputs, but I will be thankful if you please wait until he/she finishes. You can write your comment in a piece of paper so you don not forget it, and discuss it when no one is talking.

As I said there is no right or wrong answers, you can disagree with each other, and you can change your mind. You do not have to speak in any particular order. Please feel comfortable saying what you want.

Your opinion matters to me and will help shape the future of genomic medicine and pharmacogenomics in UAE.

Does anyone have any questions?

OK, let us begin.

Participant introduction:

I would like everyone to introduce themselves. Can you tell us your name?

Topics for discussion:

We will discuss the following topics:

1- Your Knowledge toward Genomic medicine and pharmacogenomics

2- Your experiences and attitude with Pharmacogenomics/genetics training/education and its application in your practice.

3- Your perceived barriers of implementation of genomic medicine and pharmacogenomics in UAE.

Appendix G: Interview Guide for Pharmacists

Research Title: Knowledge, attitudes of registered pharmacists in UAE toward genomic medicine and pharmacogenomics and their perceived barriers of its implementation

1. Demographic questions	✓ Gender ✓ Year of Graduation ✓ Nationality ✓ In which Emirates you work? ✓ In which section/setting you work? ✓ Type of employer (Government, private, university, retail) ✓ How many years have you been in practice? ✓ Are you studying for board or degree? and what are you studying? Did you study in UAE or abroad?
Knowledge of registered pharmacists in UAE toward Genomic medicine and pharmacogenomics	
2. Can you explain genomic medicine and/ or pharmacogenomics?	2.a. Is it true or false that: patient's genetic profile may influence response to drug therapy? 2.b. Do you know that the package insert for warfarin includes a warning about altered metabolism in patients who have specific genetic variants? 2.c. Do you agree that Genetic determinants of drugs response change over a person's lifetime? 2.d. Is it true or false that: pharmacogenomics can identify drug-drug interactions? 2.e. Is it true or false that: pharmacogenetics testing is currently available for most medications? 2.f. Is it true or false that: Human has 24 chromosomes? 2.g. Is it true or false that: Adenine (A) only pairs with cytosine (C) and Thymine (T) only pairs with Guanine (G)? 2.h. Is it true or false that: Pharmacogenomics testing is recommended by FDA for certain drugs? 2.i. What does a poor metabolizer phenotype indicate? -Lower drug safety because of poor metabolism. -Good drug efficacy because of poor metabolism 2.j. Is it true or false that: Every cell of the body contains the whole genome? 2.k. Is it true or false that: Environmental factors, such as cigarette smoke, can affect gene activity? 2.l. Is it true or false that: Genetic determinants of drug response change over a person's lifetime?
Pharmacogenomics/genetics training/education and application in practice	
3.a Did you study Genomic medicine or pharmacogenomics? 3.b. Did you apply pharmacogenomics (drug selection, dosing, monitoring, counselling) for a patient in your practice setting? 3.c. As far as you know, do you have pharmacogenomics testing at your work? 3.d. Did you attend any conference or workshop about pharmacogenomics? 3.e. How would you rate your current understanding of pharmacogenomics (poor, fair, good, very good, excellent)? 3.f. Where do you obtain information on genomic and pharmacogenomics? 3.g. Are you competent to interpret the warning in Warfarin leaflet about altered metabolism in patients who have specific genetic variants if a patient asks you? 3.h. Which type of education do you prefer to learn about pharmacogenomics ? workshop? E-Learning? University? Scientific articles? 3.i.Do you think that more time should be devoted for the teaching of pharmacogenomics in the course of study?	

Attitudes of registered pharmacists in UAE toward genomic medicine and pharmacogenomics	
4.Tell me about your attitude toward genomic medicine and pharmacogenomics:	4.a. In your opinion, how likely is it that pharmacogenomics testing will help to decrease the number of adverse drug reactions? 4.b. In your opinion how likely is it that pharmacogenomics will help to decrease the cost of developing new drugs? 4.c. Do you know anyone with genetic condition? 4.d. Do you feel that you are adequately informed about the availability of genetic testing and its application in the context of drug therapy? 4.e. Do you think that the pharmacist should be the one who counsel patients about genomic testing? Or we are not equipped to do so and should leave it to the physician or genetic counsellor? 4.f. Do you rely on package leaflet (inserts) for information regarding genetic testing and the prediction of response to drugs? 4.g. Do you think that pharmacogenomics test will benefit patients by: -improving drug effectiveness. -Reducing drug toxicity. -Increasing patient's understanding of their therapy. -Improving patient's adherence to therapy. -Control drug therapy expenditures. -Will not benefit the patients at all. 4.h. Do you think that insurance companies should cover the cost of pharmacogenomics tests? Or you think there should be criteria for coverage based on age, comorbidities and type of insurance card? 4.i. As a pharmacist, do you think that all pharmacists should be required to have some knowledge of pharmacogenomics? 4.j. In your opinion , who should counsel the patient about their DNA reports ? pharmacist ? physician? Genetic counselors? 4.k. Do you think there is a need to have laboratory facilities in UAE that can do and analyze DNA analysis? 4.l. In general, to what extent are your opinions and decisions influenced by religion? 4.m. Have you or anyone close to you ever had any experience with genetic issues? For example, having a heritable disease in the family, or taking a genetic test? 4.n. Will you consider having a genetic test to find out your risk of developing various genetic diseases? 4.o. Are you glad that genetic tests can be ordered on the internet? 4.p. would like to participate in genetic research or donate to biobank?
5. Perceived barriers of implementation of genomic medicine and pharmacogenomics in UAE	
5.Tell me what are the barriers for adopting genomic medicine and pharmacogenomics in UAE	5.a. How concerned are you that unauthorized persons may gain access to the results of genetic test or pharmacogenomics testes? 5.b How concerned are you that the results of genetic test or pharmacogenomics testes can cause discrimination by employers and or insurance companies? 5.c. How do you think the community in UAE will react to pharmacogenomics and genomic medicine? 5.d. In your opinion what are barriers for the implementation of pharmacogenomics in your practice setting? -Shortage of personnel -Lack of guidelines -Lack of testing services -Lack of training or education -Cost of Testing
Comments	

Questions for the Retail Pharmacist

6.Views on DTC KIT
6.a. Do you sell DTC? 6.b. Do you think that DTC need FDA approvals? 6.c. Do you imagine that one day in the future each patient coming to your pharmacy will have his /her pharmacogenomics analysis uploaded in an electronic chip , so it can be guide your choice of the right medications and dose ?

Concluding question:

Of all the points that we addressed today, what is the most important point you would like to highlight about constructing a road map for the implementation of Pharmacogenomics and genomic medicine in UAE?

Is there any other information that you think would be beneficial for me to know?

Conclusion:

My colleague and I cannot thank you enough for coming today and for opening up and sharing your valuable opinions. I hope you found the discussion interesting.

If there is anything you are un satisfied with, please let me know either now or later.

I would like to emphasis again that all your comments and opinions will be anonymous.

Before you leave, please hand in your completed demographic questionnaire.

Text of e-mail invitation:

Dear Esteemed Pharmacist:

You are invited to participate in a focus group for a research project on the Implementation of Genomic medicine and pharmacogenomics in UAE.

The project is called *Establishing the Roadmap for Genomic Medicine and Pharmacogenomics in the UAE*

It is part of my PhD studies at United Arab Emirates University and has been approved by their Ethics committee.

I am asking you to take part in this focus group because you have valuable insight and experience that will help shape the future of pharmacogenomics in UAE.I have asked nine other pharmacists to join us in the discussion and I will be assisted by 1-2 colleagues.

DATE: Saturday 15 December 2018

TIME: 11:00 AM

DURATION: 2 hours

LOCATION: UAEU, CMHS, the campus near Tawam hospital, male entrance, ground floor, institute of public health, Room: IPH-GE108.

You will need to sign at the entrance to gain visitor access, and there will be signs to guide you to the venue as well as refreshments.

Confidentiality

Please note that your name and any identifying information you share with us will remain confidential. Your responses will be summarized along with other responses and used collectively to help guide decision-making. No names or identifying information will be used when compiling this information.

Consent

There is no obligation to participate in this focus group. You may refuse to participate or withdraw at any time and it will not affect your practice in any way.

I do very much hope that you will agree to take part and looking forward to seeing you on Saturday 15 December 2018.

Please email me back or call me on my mobile (0501126098) to confirm your attendance.

Yours,

Azhar Talal

Appendix H: Interview Guide for Stakeholders

Q1. Can you tell me about yourself? Your qualifications and area of practice

Q2. Do you apply GENETIC testing in your practice setting?

Q3. Do you apply GENOMIC testing in your practice setting?

Q4. Do you apply pharmacogenomics (drug selection, dosing, monitoring, counseling) for a patient in your practice setting?

Q5. As far as you know, do the testing carried at your hospital lab or abroad?

Q6. Do you think there is a need to have laboratory facilities in UAE that can do and analyze DNA ?

Q7. Do you know how to read genome sequencing report?

Q8. Do you think that more time should be devoted for the teaching of Genomic medicine and /or pharmacogenomics in the course of study?

Q9. In your opinion how likely it is that pharmacogenomics will help to decrease the cost of treatment?

Q10. Do you think that the pharmacist should be the one who counsel patients about genomic testing? Or you think the physician should counsel the patient?

Q11. Do you see a future were genetic counselor set with patients and their families and discuss susceptibility for diseases and life style modifications based on genome sequencing?

Q12. How do you think that pharmacogenomics test will benefit patients?

Q13. Do you think that insurance companies should cover the cost of pharmacogenomics and or genomic tests?

Q14. Are you going to depend on pharmacists to intervene based on pharmacogenomics?

Q15. Have you or anyone close to you ever had any experience with genetic issues? For example, having a heritable disease in the family, or taking a genetic test?

Q16. Will you consider having a genetic test to find out your risk of developing various genetic diseases?

Q17. Are you glad that genetic tests can be ordered on the internet? Why?

Q18. Do you like to participate in genetic research or donate to biobank?

Q19. How concerned is you that unauthorized persons may gain access to the results of genetic test or pharmacogenomics testes?

Q20. How concerned is you that the results of genetic test or pharmacogenomics testes can cause discrimination by employers and or insurance companies?

Q21. How do you think the community in UAE will react to pharmacogenomics and genomic medicine?

Q22. In your opinion what are barriers for the implementation of pharmacogenomics in your practice setting?

Q23. Of all the points that we addressed today, what is the most important point you would like to highlight about constructing a road map for the implementation of Pharmacogenomics and genomic medicine in UAE?

Q24. Can you share with me an experience in which you used genomic medicine or pharmacogenomics?