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Islamic ethics and the healthcare of children in the genetics era

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Islamic ethics and the healthcare of children in the genetics era

WISH 2022 Forum on Islamic Ethics

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FOREWORD

Advancements in genetics and genomics have provided great opportunities for improving children's health and the overall wellbeing of their families. These opportunities, however, are often intertwined with complex ethical questions and challenges that need to be examined in light of people's moral and religio-ethical convictions.

This report focuses on the ethical questions triggered by four main types of genetic testing, namely: premarital; preimplantation; prenatal; and newborn. From the 1990s onward, Muslim religious scholars and biomedical scientists, with the help of transnational Islamic institutions, have been engaged in intensive deliberations on the ethical aspects of genetics and genomics, including these tests. The analyses, recommendations and conclusions provided in this study are based on extensive and critical reading of these deliberations. To put the Islamic bioethical perspectives in their broader context, we also included a multidisciplinary review of the latest biomedical knowledge and the relevant international bioethical discourse.

This report is meant to be accessible to young couples with marriage plans, and their families, who are grappling with tough questions about genetic testing and wish to learn how Islamic morals can help them to address these questions. It is also meant to provide religio-culturally sensitive guidelines for healthcare professionals and policymakers who interact with these groups. Finally, we hope that this report will enhance and diversify the international bioethical discourse on genetics by highlighting the contribution of Islam.

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EXECUTIVE SUMMARY

The genetic tests that can be performed before marriage, before implanting embryos, during pregnancy, or after birth have offered new opportunities to manage the risks of having children with genetic disorders and the associated financial and social burdens. Like other communities worldwide, many Muslims want to pursue the benefits of these tests but in a way that aligns with their religious beliefs and moral convictions. Since the beginning of the 1990s, Muslim religious scholars, in collaboration with biomedical scientists, have been examining the ethical questions surrounding genetic testing.

This report provides an analytical review of these decades-long Islamic bioethical deliberations. It provides a systematic overview of the Islamic perspectives on four main types of genetic testing: premarital; preimplantation; prenatal; and newborn.

Section 1 outlines the related biomedical aspects and key ethical questions, as highlighted in the international bioethical discourse. Section 2 is dedicated to analyzing the Islamic ethical perspectives and how they can be translated into actionable guidelines. Section 3 provides a number of conclusions and policy recommendations, which we hope will aid policymakers, care providers, and couples in navigating these issues from an Islamic ethics perspective.

SECTION 1. PREDICTIVE GENETIC TESTING

Background

By definition, predictive genetic testing is the use of a genetic test in an asymptomatic individual to predict the risk of future disease onset.[1,2] The underlying aim of such technologies is for the early identification of people at high genetic risk of a specific disease that can, in turn, lead to reduced morbidity and mortality. Predictive genetic tests are a relatively new and growing class of medical tests that differ fundamentally from the available conventional medical diagnostic tests. While a conventional diagnostic test defines with reasonable certainty the patient's current condition, in contrast, a predictive genetic test only estimates risk for a future condition that may develop.[3,4] The risks for some conditions always contain a significant component of uncertainty about whether the disease will develop, timing of its onset, and its severity. For these reasons and more, genetic testing can lead to issues of disclosure and discrimination, which confront scientists and clinicians with daunting moral and ethical considerations.[5]

The field of genomics has the potential to revolutionize the health of children. Before conception, genomics offers future parents a suite of options that, until recently, were considered within the realm of science fiction. For example, expanded preconception carrier screening – already in effect at a national level in Australia – empowers parents to make informed reproductive decisions.[6] When prospective parents are found to both carry deleterious variants in genes linked to an autosomal recessive disease (a disease or disorder that is passed on by both biological parents, whereby the affected individual inherits two changed (mutated) genes, one from each parent) or if the potential mother is found to carry a deleterious variant in a gene that has been linked to an X-linked condition, they are at risk of having affected children, unless they pursue options such as preimplantation genetic testing (PGT) to carefully select out the disease-prone embryos.

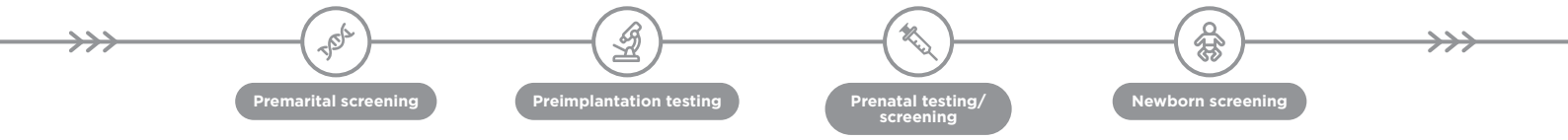
During pregnancy, prenatal testing has also evolved dramatically due to advances in genomics. Maternal blood is tested, from which the fetal component can be isolated and genotyped. Non-maternal blood for fetal DNA testing is now used by millions of pregnant women around the world. Begun as a screening for the three most common chromosomal abnormalities, this testing has now evolved into a much more

comprehensive non-invasive prenatal testing (NIPT) that may soon cover myriad genetic diseases.[7] After birth, many countries maintain newborn screening programs for early detection of select disorders. However, there is a growing interest in supplementing or perhaps replacing these programs with a more comprehensive genome sequencing-based screening to cover all pediatric onset genetic diseases.[8,9]

Types of predictive testing

This section describes four main types of predictive genetic testing (see Figure 1), the conditions they test for, and their use in practice.

Figure 1. Types of predictive testing



Premarital screening

Premarital screening is a genetic carrier screening program that is generally recommended or enforced by government health authorities to prevent specific genetic disorders and sexually transmitted diseases (STDs), and minimize their potential associated burden.[10–12] It is offered to partners before marriage to identify potential carriers of certain genetic diseases, including thalassemia (Mediterranean anemia) and sickle cell disease. Carriers for these diseases of genetic origin are usually asymptomatic but can potentially transmit these diseases to their offspring in the case that both parents are carriers. Premarital screening also covers certain STDs such as hepatitis B and C, and HIV/AIDS. Couples who have results that are considered 'incompatible' are typically offered genetic counseling sessions to discuss associated risks and help them make informed decisions about their marriage.[13] In some cases, this may lead couples to cancel their marriage plans.

Premarital testing has been implemented in several countries worldwide, with Cyprus being the first country to implement a mandatory screening in 1973 for β-thalassemia before marriage. Other countries then followed, predominantly Mediterranean and Islamic-majority countries with high rates of consanguineous marriages[14–24] including Saudi Arabia, Qatar, Bahrain, United Arab Emirates (UAE), Palestine and Jordan, which mandate premarital screening programs before the issuance of a marriage certificate (see Table 1).[25]

Table 1. Overview of mandatory premarital testing programs in select countries

Country	Date premarital genetic test was implemented	Program name	Genetic test included	Brief overview of legislation	Availability of additional services such as prenatal diagnosis (PND) and therapeutic abortion
Iran[26,27]	1997	The premarital screening program	β-thalassemia	• Premarital screening is required in order to receive a permit for marriage registration • Screening is performed for the male partner first and eventually for the female, if the male has low blood indices • Genetic counseling is offered for at-risk couples, covering options such as canceling the marriage or continuing with or without having children • If the couple decide to continue and have children, prenatal screening and elective abortion of an affected fetus is offered (available since 2002)	PND and therapeutic abortion are legal at certain times during the pregnancy
Saudi Arabia[28–31]	2004	National Premarital Screening Program (NPSP)	Sickle cell anemia and β-thalassemia	• Couples found to be carriers must attend a counseling session prior to marriage license approval • Couples receive counseling together or separately without any prior appointments • Compliance with the counseling recommendations is voluntary	Abortion is not approved for homozygous thalassemia or sickle cell diseases affected pregnancies

Country	Date premarital genetic test was implemented	Program name	Genetic test included	Brief overview of legislation	Availability of additional services such as prenatal diagnosis (PND) and therapeutic abortion
Jordan[32–34] 	2004	National Premarital Thalassemia Screening Program	β-thalassemia	• Couples found to be carriers must attend a counseling session prior to marriage license approval • Compliance with counseling recommendations is voluntary • If couples get married, no follow-up is required for pregnancies, and undergoing PND is optional • Genetic counseling is provided by general practitioners with minimal or no training in genetic counseling	PND is available but abortion is not approved for homozygous β-thalassemia affected pregnancies
Bahrain[35,36] 	2005	The Premarital Screening and Counseling Program	Sickle cell anemia and β-thalassemia	• Couples found to be carriers must attend a counseling session prior to marriage license approval • Compliance with counseling recommendations is voluntary	PND and therapeutic abortion are legal at certain times during the pregnancy
Kuwait[37,38] 	2008	The Premarital Screening and Counseling Program	Sickle cell anemia and β-thalassemia	• Couples found to be carriers must attend a counseling session prior to marriage license approval • Compliance with counseling recommendations is voluntary	Abortion is not approved for homozygous thalassemia or sickle cell diseases affected pregnancies

Country	Date premarital genetic test was implemented	Program name	Genetic test included	Brief overview of legislation	Availability of additional services such as prenatal diagnosis (PND) and therapeutic abortion
Qatar[39,40] 	2009	The Premarital Screening and Counseling Program	Thalassemia, sickle cell disease, classical homocystinuria, and cystic fibrosis (mandatory) and spinal muscular dystrophy (optional)	• Couples found to be carriers must attend a counseling session prior to marriage license approval • Compliance with counseling recommendations is voluntary	Abortion is not approved for homozygote neonates affected with thalassemia, sickle cell disease, classical homocystinuria, and cystic fibrosis, but approved for homozygous affected pregnancies with spinal muscular dystrophy
UAE[41–43] 	2011	The Premarital Screening and Counseling Program	Sickle cell anemia and β-thalassemia	• Counseling is given to the couple likely to get married or to the male partner and the person representing the female • Couples found to be carriers must attend a counseling session prior to marriage license approval • Compliance with counseling recommendations is voluntary	Abortion is not approved for homozygous β-thalassemia or sickle cell diseases affected pregnancies

While screening programs differ across countries, they are typically designed based on a country's genetic disease prevalence as well as the tests currently available locally and their validity and reliability for accurate detection.[44–46] For example, in Saudi Arabia, premarital screening is mandatory for sickle cell disease, thalassemia, hepatitis B and C and HIV,[47] whereas in Egypt, premarital screening is only obligatory for hemoglobinopathies.[48]

Premarital screening was officially introduced in Qatar in 2009 across several primary healthcare centers and was made mandatory for all Qatari citizens planning to get married. In 2012, it became mandatory for all residents, and services expanded to private clinics and hospitals across the country. The screening covers: infectious diseases (hepatitis B and C, HIV/AIDs, syphilis, and measles, for women only); hereditary blood disorders (sickle cell anemia and thalassemia); genetic diseases (homocystinuria and cystic fibrosis); blood group; and fasting/random blood sugar testing. A further optional screening for spinal muscular atrophy (SMA) can also be offered on request or referral.

Premarital screening accompanied by genetic counseling services have proven effective in reducing the overall incidence of genetic diseases such as β-thalassemia.[49] These services combined have also been shown to prevent the onset of marriages in couples considered at-risk (see Figure 2).[50,51]

Figure 2. Effectiveness of premarital testing in reducing at-risk marriages and at-risk births in the MENA region

Source: Saffi and Howard (2015).[52]

Other factors also play a role in the effectiveness of premarital screening, including perceptions and knowledge about screening programs. People's understanding of the consequences of disease onset also play an important role.[53,54]

In some countries such as Pakistan and Bangladesh, where premarital screening is not mandatory but consanguineous marriages are common, there is a general reluctance for screening due to cultural and social factors.[55] In Pakistan, premarital screening programs tend to be more successful in urban areas due to financial status and accessibility.[56]

Preimplantation genetic testing

Preimplantation genetic testing (PGT) is performed on embryos that are created through *in vitro* fertilization (IVF) prior to transfer.[57] PGT can be helpful in ensuring that the embryo selected for transfer during the IVF process carries the correct number of chromosomes, reducing the chances of miscarriage and failed IVF cycles. PGT has thus become an integral part of the assisted reproductive technology (ART) processes, particularly in the genetic disorders where termination of pregnancy is not allowed or not accepted by the family. After PGT, only embryos free of mutation are implanted, while the remaining embryos are either frozen for future use or discarded. PGT is also used to detect hereditary diseases, particularly in cases of advanced maternal age, the presence of cyto-genetic and molecular diseases in the family, and recurrent miscarriages.[58] It can also be used for gender selection in the case of sex-linked diseases, or for balancing the gender dynamic in families – the latter in particular giving rise to a series of ethical concerns.[59]

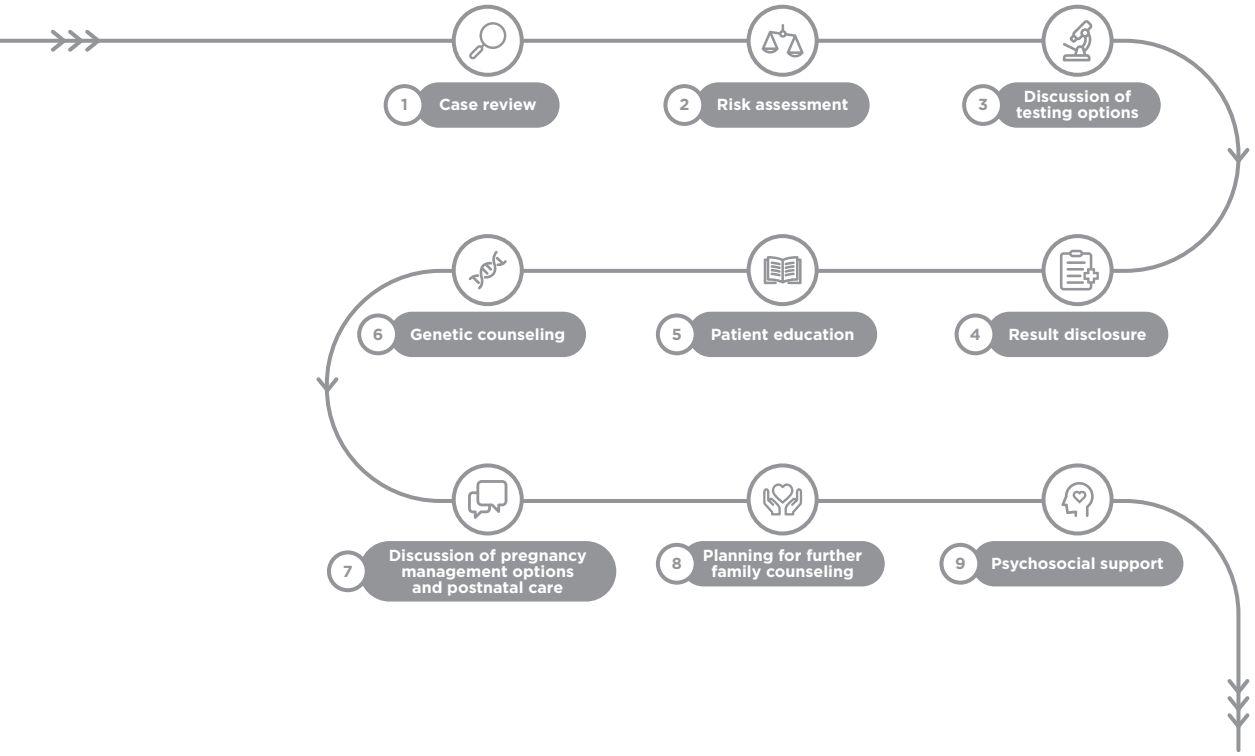
The development of PGT technologies dates back to 1890, originating with scientist Walter Heape's successful embryo transfer in Belgian Hare doe rabbits.[60] After years of experimentation on animals and a few unsuccessful trials in humans, the first successful IVF pregnancy took place in 1978, with the birth of Louise Brown, who became known as the world's first "test tube baby".[61] In 1990, after success in the mouse model, Handyside et al. reported pregnancies after performing PGT for sex-linked diseases and X-linked intellectual disability on human embryos preimplantation.[62] Only a few PGT centers are available in Arab Muslim countries.[63,64] Saudi Arabia, the UAE, Qatar, Malaysia, Iran and Turkey have PGT centers, while others have satellite PGT services with the IVF process performed locally (such as Jordan).[65–67] PGT for preferential sex selection is typically only provided in private hospitals, while sex selection for the prevention of X-linked recessive diseases is provided in some governmental hospitals.[68]

Prenatal testing

Prenatal screening tests can detect whether or not the fetus is likely to have specific birth defects, including genetic disorders.

Noninvasive prenatal testing (NIPT) – also referred to as noninvasive prenatal screening (NIPS) – is a screening tool that uses next-generation sequencing (NGS) technologies to determine the risk that the fetus will carry specific genetic abnormalities. It is considered noninvasive as it requires only a blood sample from the pregnant woman and does not pose risks to the fetus. NIPS can be conducted as early as 9 to 10 weeks' gestation and is more accurate than other traditional forms of prenatal screening.[69–72] During pregnancy, the mother's blood often contains small fragments of DNA that are free-floating rather than cell-bound. These fragments are known as cell-free DNA (cfDNA) and originate from the mother's cells as well as cells from the placenta. The DNA found in placental cells is usually identical to that of the fetus, and so analyzing this placental cfDNA allows for the early detection of certain genetic abnormalities in a noninvasive way. NIPS is generally used to look for chromosomal abnormalities (known as aneuploidy) caused by the presence of an extra chromosome (trisomy) or absence of a chromosome (monosomy), including Down Syndrome (trisomy 21), trisomy 18, trisomy 13, and an extra or missing copy of the X or Y chromosomes.[73,74]

Figure 3. Hamad Medical Corportation (HMC) prenatal genetic testing services



In the Middle East, NGS is only currently available in 16 laboratories which are accredited by the College of American Pathologists. Several countries in the region rely on reference laboratories (most commonly based

in Europe and the USA) to meet the demand of these services.[75] Prenatal genetic testing services were established in Qatar in 2013, as part of the Clinical and Metabolic Genetics division at Hamad Medical Corporation (HMC).[76] Given the high rate of consanguineous marriages in the country, estimated at 54 percent,[77] there has been a high demand for this service. Figure 3 gives a brief overview of the services provided.

Amniocentesis, usually performed between the fifteenth and twentieth weeks of pregnancy, is a procedure where amniotic fluid is extracted from the uterus for testing. Risks can include miscarriage in approximately 0.5 percent of cases and is therefore only indicated where initial testing suspects a high risk of a genetic anomaly. The test analyzes genes from the fetal cells found in the amniotic fluid, which are then tested for aneuploidies.[78] In addition, amniocentesis can detect and diagnose inherited disorders caused by gene mutations, such as sickle cell disease, Tay-Sachs disease, and cystic fibrosis. It can also detect neural tube defects such as spina bifida by measuring levels of alpha-fetoprotein present in the amniotic fluid.[79]

Chorionic villus sampling (CVS) is a prenatal test where the chorionic villi are removed from the placenta and tested as early as 10 weeks of pregnancy. CVS can detect the presence of chromosomal abnormalities and is often performed to confirm or rule out a diagnosis if the result of a previously conducted NIPT is positive or worrisome. It can also be performed if a previous pregnancy was affected by a chromosomal condition, if the pregnant woman is 35 or older, or there is a family history of a specific genetic condition.[80]

Newborn genetic screening

The main aim of newborn genetic screening is to detect serious, treatable disorders in newborns, thereby enabling medical or lifestyle interventions to avoid or ameliorate unfavorable outcomes.[81] These tests, typically based on biochemical assays, are usually performed on a dried blood spot sample from the newborn. However, researchers are actively investigating a genomics-based screening program and the additional health benefits such an approach will carry.

Mass testing of newborns started in the 1960s with the introduction of the screening for phenylketonuria, a rare inborn metabolic disorder. Screening for congenital hypothyroidism and a few more rare disorders were gradually introduced after this.[82] As part of the 'Recommended Uniform Screening Panel', the US Government recommends screening for 35 core conditions and 26 secondary conditions.[83] The benefit of such screening programs is not easily demonstrated and also requires very large, longitudinal pilot studies. In the future, two things will impact the development

of newborn screening: technologies that drive the advancement of new testing strategies; and the development of new, effective treatments for previously untreatable disorders.

Newborn screening is common in the Middle East and North Africa (MENA) region, with national newborn screening programs in Bahrain, Kuwait, Saudi Arabia, Egypt, UAE and Qatar. In addition, pilot programs have been completed in Lebanon, Jordan, Tunisia and Oman.[84,85]

In Saudi Arabia, the first national newborn screening program was established in 1989 and specifically targeted congenital hypothyroidism.[86] This was expanded in 2005 to screen for 16 inborn errors of metabolism and endocrine disorders, and in 2016 to include hearing loss and congenital heart defects. Available data suggest that Saudi Arabia faces one of the world's highest burdens of genetic conditions covered in the program.[87]

Qatar established its newborn screening program in 2003 in partnership with Heidelberg University Children's Hospital in Germany. Similar to other programs in the region, these services continue to improve and evolve as science develops, technology advances, and as scientific knowledge of high-risk genetic conditions with available interventions increases.[88] The genetic newborn screening program is free of charge and is considered one of the most successful preventative public healthcare programs in Qatar. Within 36 to 72 hours of birth, all newborns are screened for vision, hearing, and metabolic and endocrine diseases, as part of Qatar's National Newborn Screening Program. A heel prick test is performed to screen for more than 80 disorders and diseases. Should the blood sample detect any illness, early treatment is provided for the diagnosed condition. As of 2021, the newborn heel prick test has been administered to more than 300,000 babies across the country.[89]

Ethical challenges

Premarital genetic screening

Some patient advocacy groups have been vocal in criticizing preconception screening efforts as trivializing the lives of individuals with genetic disorders. By focusing on 'prevention', they argue, these programs imply that individuals with genetic disorders are not worth bringing to this world, and this will stigmatize those who live with these conditions.[90] Others, however, argue that it may even be an ethical imperative for parents to ensure that their future children are free from conditions that lead to a great deal of suffering if this is possible through use of current technology. Another potential issue is defining the severity of conditions that are screened for and subsequently 'prevented'. The decision against the inclusion of deafness and disorders of sex development is an example.[91]

These decisions are not necessarily driven by cost, because today's genomic technology allows for a comprehensive look at all genes at once. Rather, they are ethics-driven, due to a perceived notion that hearing loss and disorders of sex development are within the range of 'normal' instead of 'diseases' per se; yet this perception varies between cultures and societies. One can also argue that it is up to future parents to make a choice for which disorders they choose to eliminate during or before pregnancy, and that the genomics community should not paternalistically dictate this. Finally, there are ethical issues related related to the termination of pregnancy in treatable disorders where the treatment is not easily accessible.

While there is no doubt that the prevention of serious childhood conditions such as cystic fibrosis is of extreme value, results of carrier screening must be handled with caution. This is particularly the case in a premarital context, as this can influence and impact the decision to move forward with marriage plans.[92] The inclusion of milder phenotypes, as well as conditions that have their onset in adulthood, presents an ethical dilemma. In addition, respect of confidentiality and autonomous decision-making are also important ethical considerations.[93] There is an urgent need for debate on whether relatives of someone with a positive predictive genetic test should be notified of the results and risks. The result must balance the moral obligations of the diagnosing physician with the needs of the patient. The decision to inform or not will vary depending on what moral theory is used. The principles of justice and nonmaleficence also play an important role.

Preimplantation genetic testing (PGT)

PGT has been a tremendous tool to countless couples who choose to have children free of a specific familial genetic disease. However, with our growing ability to also test for common diseases (for example, diabetes) and non-disease related traits (such as IQ) much is to be said about where we draw the line when it comes to testing and selecting embryos. This could also potentially increase the gap between those with the means to access such costly technologies and the rest of the public, which is another cause for concern.[94] In addition, PGT for sex selection purposes could lead to inherent gender discrimination, as well as control over characteristics of children that are considered non-essential and not clinically advised. This increases unnecessary medical burdens, costs and wasted resources.

Prenatal testing

The ethical challenges associated with prenatal testing mainly revolve around the availability of results at an early stage in pregnancy. Having results at this stage may influence the decision to continue or terminate the pregnancy, given the presence of a certain medical condition,

or for sex selection purposes.[95] This presents a delicate balance between reproductive autonomy and other values and principles, including disability rights, human dignity and the duty of healthcare professionals.[96] More complex issues arise when termination is considered based on the identification of genes related to localized impairments, such as deafness or blindness, as well as termination based on adult-onset conditions such as Huntington's disease.[97,98] In addition, NIPT is expensive and, unlike traditional prenatal testing, is not typically covered by insurance; therefore, ethical issues related to cost and access must also be considered.

Newborn genetic screening

Genomic tests for children present ethical challenges, particularly when it comes to uncovering 'secondary' findings that are not related to the primary indication of the test.[99] This is especially problematic when they reveal adult-onset conditions, which ideally should only be disclosed at the discretion of the individual once they reach the age of consent.[100] Another problem, particularly faced in the MENA region, is the general resistance of parents to accept the international norm of refraining from disclosing carrier status for pathogenic variants that are only relevant when these children are at an age to make reproductive choices. They argue that failure to disclose these results to parents will deprive their children from ever knowing about these results if they are not recorded in the child's chart.[101]

Other harms related to testing minors include future implications for insurance, employment, academic and educational opportunities, and adoption. Children diagnosed through newborn screening may be subject to social as well as intrafamilial stigmatization, whereby children who test positive for mutations are treated differently than their siblings.

SECTION 2. ISLAMIC ETHICAL PERSPECTIVES

Overview of relevant Islamic bioethical deliberations

Muslim religious scholars agree that taking care of children's overall well-being, including their health, is a religious obligation. Early scholars have already highlighted the parental duty to secure the best possible treatment for one's child when they get sick.[102] From the 1990s onwards, the ethical questions triggered by modern genetics and genomics have been the subject of intensive Islamic bioethical deliberations.

As explained in previous reports published by the World Innovation Summit for Health (WISH), many of the authoritative and impactful modern Islamic bioethical discussions have been facilitated by transnational Islamic institutions, especially the Islamic Organization for Medical Sciences (IOMS) based in Kuwait, the Islamic Fiqh Academy (IFA) based in Mecca, and the International Islamic Fiqh Academy (IIFA) based in Jeddah, Saudi Arabia. In addition to the contributions of individual religious scholars, these institutions facilitated interdisciplinary discussions involving religious scholars and biomedical scientists.[103–105] Below, we analyze these discussions relating to children's healthcare across the development cycle of (prospective) children.

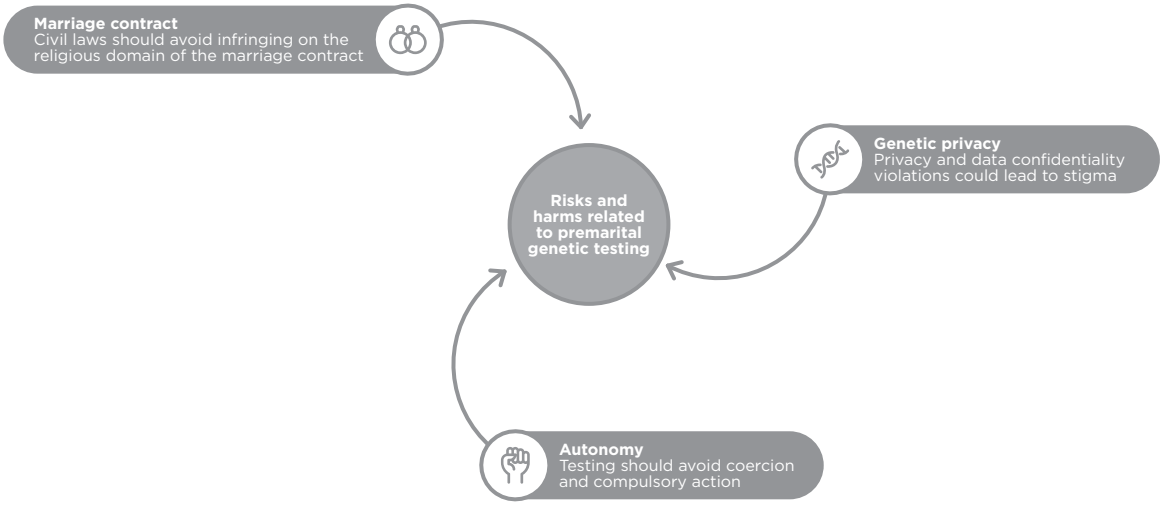
Premarital genetic testing

Early discussions within the Islamic tradition stressed that children's overall wellbeing starts with parents choosing a good partner to marry, to guarantee good future parenting. Within these discussions, some early Muslim jurists touched on ideas with relevance to the modern discussions on genetics. Especially within the Shāfiʿī and Ḥanbalī juristic schools, some scholars held that marriage among close relatives, such as cousins, is not recommended. Besides non-medical arguments, some of these scholars based their standpoint on a Prophetic tradition, whose authenticity was disputed by others, which indicates that such marriages would produce children with poor health.[106,107]

Against this background, the great majority of modern religious scholars recognized that prospective married couples' genetic structure could influence their children's health conditions. Only a few scholars expressed reservations against the very idea of undergoing genetic

tests, questioning the credibility of the predictive information provided by the field of genetics. They preferred, instead, to trust in God's omnipresent knowledge.[108,109] Beyond this small group, the mainstream position adopted by both transnational Islamic institutions and individual scholars held that premarital genetic testing was either permissible or even strongly recommended because of its health benefits to children. Strong support was given to establish a wide network of genetic counseling programs and public awareness campaigns in Muslim communities about the significance and benefits of genetic testing, via media, public seminars, mosque-related activities, and so on.[110–112] Besides the expected health-related benefits, these bioethical deliberations also highlighted the need to address possible risks and harms, as outlined below and in Figure 4.

Figure 4. Risks and harms related to premarital genetic testing



Genetic privacy

The risk that genetic information revealed by premarital genetic testing could eventually undermine a couple's genetic privacy and data confidentiality was one of the main ethical concerns. In response, respecting people's genetic privacy was introduced as a strict condition for permitting this testing. This stipulation is also part of the agreed healthcare professionals' general obligation of not disclosing their patients' confidential information.[113,114]

Recommended approach

We, the authors, after reviewing national guidelines and the ethical discourse, do not support the perspective that the principal prohibition of sharing people's genetic information with any third party should indiscriminately apply to the case of premarital genetic testing.[115] Because

of its special nature, both partners undergo premarital genetic testing with the expectation that their results will inform them about the possible genetic risk of their future marriage. Additionally, a set of interrelated moral values rooted in the Islamic tradition is at stake in this particular context, and the path to striking a good balance is not always obvious. After reviewing the available Islamic bioethical deliberations, we suggest the following process of communication with the engaged couple.

- When genetic testing reveals that the planned marriage will entail risks for the resulting offspring, then the first step is to communicate only this general piece of information, without providing further details about how each partner contributes to this risk, as long as this is technically possible. This is to avoid the consensually prohibited practice of slander and backbiting (*ghība*), where people's shortcomings, especially physical defects or flaws (*'uyūb*), are revealed without a compelling reason.[116,117]

- If the couple insist on receiving detailed information to make an informed decision, and they consent to sharing each other's information, the next step is to check if the prospective genetic risks have to do with one or both partners.

- If the risks are linked to only one partner, then the detailed information shall be first shared with him/her only. If sharing these details does not make this partner end the marriage plan, then he/she shall be informed that these details will be shared with the other partner in his/her presence, to avoid the abovementioned unethical practice of 'backbiting' and also to avoid any misunderstanding about what will be shared. If this partner changes his/her mind and does not want to share this genetic information with the other partner, then healthcare professionals can explain this situation to the other partner, but again without revealing genetic details.

- If the prospective risks have to do with both future partners, then joint counseling sessions shall be arranged to provide them with the necessary details. Disclosing the genetic information in this case is exceptionally permitted because it will be the only possible way to achieve the legitimate objective of providing beneficial advice (*naṣīḥa*), especially for those who explicitly request advice about the suitability of a future marriage partner.[118] By involving both partners in the counseling session, the moral harm of revealing people's defects *in absentia* will also be avoided. To minimize the risk that such confidential information will be spread further, both partners shall sign a binding non-disclosure document, where they both pledge that they will not share this information with others.

All these nuances and detailed measures, we argue, should be meticulously implemented to prevent the stigma that the future partners, and by extension their families, may experience if their genetic privacy was violated. The seriousness and magnitude of such harm becomes clear when we realize that marriage, within the dominant religio-moral world in Muslim communities, is the only possible way to have children and establish a family, and that extramarital relations are categorically prohibited in Islam.[119,120]

Autonomy

One of the agreed ethical principles that apply to all genetic tests is that informed consent should be obtained first. Therefore, no one should be coerced to undergo such tests, and the results of these tests should not lead to further compulsory measures. Thus, the decision to undergo the premarital test and what to do with its results should be voluntary and autonomous.[121–123]

However, different countries in the Arab world, including some member countries of the Gulf Cooperation Council (GCC), codified laws that made premarital testing for specific genetic disorders mandatory. As per these laws, the to-be-married couple will not receive an officially registered marriage contract until they demonstrate that they have performed the required premarital testing.[124–128] The legal enforcement of this genetic testing stirred heated discussions among Muslim religious scholars, resulting in differing perspectives.

Recommended approach

After studying these discussions and examining the arguments for or against such legal enforcement, we propose a nuanced position to minimize the harm of undermining people's autonomy. In principle, enforcement is incompatible with the due respect for people's autonomy to choose their future partner, and decide about their body and health, which God entrusted them with. Because of one's authority over his/her body in the capacity as God's trustee, the opponents explained, it is not permissible to enforce medical treatment for actual symptomatic diseases, nor predictive genetic tests.[129] Thus, legal enforcement of premarital genetic testing should not be the first option, but the last resort, and it should never function as an alternative to public awareness campaigns.

Legal enforcement of this testing should be premised on strong justifications, which cumulatively create the case of public interest (*maṣlaḥa ʿāmma*) that otherwise cannot be achieved. For instance, this would apply to testing for specific genetic conditions whose prevalence in society entails heavy financial costs and social burdens on prospective parents,

families, and the healthcare sector, as well as other possible stakeholders. Many early and modern Muslim jurists tolerate entitling the ruler (*waliyy al-amr*), or the respective governmental authorities, to narrow the scope of individual freedoms when this is indispensable to protecting public interests. The legitimacy of this position is supported by various agreed maxims in Islamic jurisprudence (*fiqh*) – for example, "the lesser of the two evils shall be chosen", "private harm shall be tolerated to dispel public harm", and "the authority of the ruler over the ruled is contingent upon interest".[130–132] Once the justifications related to the public interest case are dismissed, or once this interest can be achieved by less controversial means, such as raising public awareness, then the legal enforcement of genetic testing will be unjustified from an Islamic ethical perspective. That is why these codified laws should be subject to regular and rigorous reviews to make sure that they meet the requirements that justify limiting individual autonomy.

Marriage contract

The legal enforcement of genetic testing was implemented by making it a condition for the official registration of the marriage contract. This procedure raised concerns related to the marriage contract's religious nature in Islam. This concern was articulated in the resolution adopted in 2003 by the IFA and it was cited as the main reason for this form of legal enforcement being unacceptable from an Islamic perspective. The marriage contract, it was explained, has a particularly religious character because it is God, in the capacity of Lawgiver, who determined its terms, together with the resulting rights and obligations. Opening the door for humans to modify the terms that God Himself has specified, by adding the condition of undergoing premarital genetic testing, is thus impermissible.[133]

To explain how this concern can be addressed, we look at the nature of legally binding orders issued by the ruler (*waliyy al-amr*), represented by the respective governmental authorities. Muslim jurists agreed that the ruler is sometimes entitled to legally enforce certain practices in the name of judicious policy or good governance (*siyāsa*), rather than in the name of the Islamic religio-moral system (*Sharī'a*).[134,135] Such government-imposed obligations do not necessarily have the same religious character as the obligations commanded by God, such as ritual prayers and fasting during the month of Ramadan. Early discussions within Islamic jurisprudence (*fiqh*) include similar examples, where a distinction was made between the religious and non-religious character of certain ethical judgments. For instance, using sun-heated water was judged as reprehensible (*makrūh*) because of available medical information about its potential

harm. Because this judgment was based on a medical assessment, some jurists argued that the reprehensible nature in this instance had a medical rather than a religious character.[136,137]

Against this background, these codified laws need to avoid infringing on the religious domain of the marriage contract. Thus, the legal obligation to undergo genetic testing should not affect the validity of the marriage contract which has fulfilled the normal religious conditions. So, the spouses who concluded a religiously valid marriage contract without undergoing the mandatory test should not be judged by the law as engaging in an adulterous relationship. Also, the future spouses whose testing shows that their planned marriage may entail genetic risks should not be prevented from ending their marriage contract as long as they voluntarily decided to move forward with their plans.

Preimplantation genetic testing (PGT)

Based on the PGT results, the tested embryo can be classified into three broad categories: (a) free: not having any of the tested genetic conditions; (b) carrier: carrying a mutated gene but remaining unaffected; or (c) affected: already affected by the mutated gene and thus will be born with the tested genetic disorder.

Two groups of Muslim religious scholars maintained that these categories do not imply morally significant differences, although each of the two groups reached a different conclusion. One group held that PGT is outright prohibited, mainly because of their contention that the preimplantation embryo has the moral status of a human being, and thus cannot be discarded because of the results of such testing.[138–140] The other group judged PGT as almost unconditionally permissible, mainly because of the argument that the preimplantation embryo has no human dignity or sanctity whatsoever.[141–143]

Recommended approach

In this study, we do not support either of these two extreme positions and argue instead for a subtle position, which captures the technical and moral nuances brought forth by this type of testing.

PGT cannot be done without *in vitro* fertilization (IVF), which is permitted under certain conditions. We explained this in a previous study – *Islamic Ethics and Infertility Treatment*.[144] In addition to other conditions, what is particularly relevant to the PGT context is that the married couple can use IVF only in the case of necessity, or even extreme necessity (*ḍarūra quṣwā*), according to some scholars.[145] Thus, when PGT or the history

of the couple's families show that the likelihood of having a child with genetic disorders is not higher than the normal average, then there is no case of necessity that would justify these additional procedures.

Another related condition is that the number of fertilized eggs in the IVF process should be kept to a minimum to reduce the chance of having surplus embryos.[146] So, PGT should be used within the limit of medical needs to achieve the legitimate target of having the embryo without the tested genetic disorder, but not as an excuse to produce as many embryos as possible to maximize the chance of choosing the embryo with the 'strongest genes'. If the PGT test shows that the available embryos are either carriers or affected, then the carriers should be chosen, without repeating the IVF cycle again and again until we obtain the sought-after 'ideal' embryo.

Additionally, the pool of tested disorders should be limited to the prevalent diseases in a society or to those that persistently show up in the couple's families, whose prevention represents a societal/familial urgency or priority. If the genetic condition is linked to a specific sex, then this will be viewed as a 'medical necessity', permitting sex selection in this particular case. We reiterate our previously published position that using PGT to select a specific favorable sex is not permitted from an Islamic perspective.[147]

One of the inaccurate generalizations that needs to be addressed here is the claim that PGT can be a legitimate reason to dissolve a marriage (*faskh al-nikāḥ*) when it reveals the risk of an autosomal dominant genetic disorder being inherited from one of the spouses.[148] Unlike the supposedly analogous list of actual and symptomatic diseases mentioned in the classical juristic works, the genetic risks revealed by PGT can usually be minimized or mitigated by choosing a non-affected embryo. As confirmed by the geneticists who were consulted in this study, this situation also holds true to the great majority of cases where one partner carries the gene mutation of an autosomal dominant disorder.

Prenatal testing

Theoretically speaking, results of prenatal testing can help in exploring the options of doing fetal surgery or using the modern techniques of gene editing and gene therapy to repair birth defects inside the womb. Most of these options are part of emerging techniques, whose safety, efficacy and success rates still need rigorous evaluation. That is why the Islamic institutions expressed their reservations against the premature permission of these emerging interventions, especially when this involves germline

cells.[149,150] These options fall outside the scope of this study, which focuses on predictive rather than therapeutic genetics. Besides the abovementioned options, the results of prenatal genetic testing are mainly used to decide whether the revealed genetic risks would justify aborting the tested embryo/fetus. Besides considering the usual conditions related to the safety of the test for both the unborn baby and the mother – and the accuracy of its results – the perception of the moral status of the embryo/fetus is also crucial to determining the positions adopted by the Muslim religion in this regard.

Recommended approach

With modern biomedical knowledge about the nature of the embryo and its development inside the uterus, contemporary Muslim religious scholars and biomedical scientists agree almost unanimously that the embryo has life. This has moral implications because it is higher in status than that of the preimplantation embryo, and so should be protected from the beginning of pregnancy. The other agreed position is that the human soul is breathed into the unborn baby at the age of 120 days, calculated from the moment of fertilization or implantation. From this moment of 'ensoulment' (*nafkh al-rūḥ*), aborting the ensouled fetus will be permissible only if the continuation of pregnancy will put the mother's life at risk.[151–155] Therefore, the mainstream position is that pregnancy, from its beginning and up to the maximum of 120 days, cannot be terminated unless there is a religiously valid reason (*'udhr shar'ī*). As we see below, genetic risks related to the unborn baby, which are revealed by prenatal testing, can be one of these valid reasons, but only under certain conditions. After the lapse of 120 days – some scholars would push this ultimatum back to 40 days or less – no genetic risks or any other reasons can legitimize abortion, except the above-mentioned risk related to the mother's life.[156]

One of the most well-known fatwas with particular relevance to prenatal testing is the one issued by the IFA in 1990. With support from the majority of IFA voting members, it was held that aborting the fetus before the lapse of 120 days will be permissible under two main conditions:

- A medical committee drafts a report confirming that that the fetus is "seriously malformed" (*mushawwah tashwīhan khaṭīran*), the diagnosed disorder is incurable, and that the unborn baby is expected to have a difficult and painful life after birth, with distress for both the individual and the family.

- The prospective parents submit a request to abort that fetus.[157]

Despite the authoritative character of IFA's fatwa and its agreement with other individual and institutional fatwas,[158] it should be noted that some of the participating religious scholars in the IFA discussions disagreed with this position.[159] A large number of religious scholars in Saudi Arabia, where IFA is based, also do not agree with the fatwa.[160] Additionally, the fatwa restricted permissible abortion only to the case of having a "seriously malformed fetus", without specifying *how* the "seriousness" of the disorder can be measured, and *which* genetic conditions would fit under this category. This intentional 'vagueness' can create more flexibility. Some individual scholars went as far as recommending the recommending the mandatory screening of pregnant women for specific disorders, such as achondroplasia, thalassemia (Mediterranean anemia), muscular dystrophy, and phenylketonuria.[161] Others named conditions that would not justify aborting the fetus, such as blindness, deafness or losing one of the two hands.[162]

We argue that these different perspectives are based on acceptable reasoning within the Islamic scholarly tradition, and so they provide flexibility. To avoid undue medicalization of the entire process, we stress the need for examining the results of prenatal testing on a case-by-case basis by a multidisciplinary ethics committee, where healthcare professionals are represented, but also those with expertise in other fields, including Islamic studies and social sciences.

Newborn genetic screening

Available Islamic deliberations give the impression that newborn genetic screening hardly raises any complex ethical dilemmas and that its permissibility is relatively straightforward. Many of the publications that examined the Islamic ethical dimensions of genetic tests did not touch on this type of genetic screening.[163–165] Other publications only briefly noted its permissibility as long as conventional stipulations are fulfilled, such as safety and not violating people's genetic privacy.[166–168] In its 2013 resolution, the IIFA went even further by stating that newborn genetic screening should be made obligatory in the case of curable genetic conditions, to facilitate early intervention.[169]

Recommended approach

Building on this generally positive position, it should not be permissible to abort embryos/fetuses for having genetic disorders that can be discovered using newborn genetic screening, and so which could be treated after birth. However, there are important ethical aspects that should be considered. Determining a list of the to-be-screened genetic disorders should be tied to available technology as well as other important

factors for consideration. For instance, the screened disorders should be part of the public health concern, an affordable, safe and accurate test should be available, and an effective curative or preventive intervention should be available.

As for adult-onset disorders, we do not recommend including them in the newborn screening programs to avoid the ethical complexities of obtaining informed consent. From an Islamic perspective, each accountable person (*mukallaf*) in Islam has the exclusive right to provide informed consent about their body. However, newborn babies do not fall into this category.[170] In this context, the consent to be provided by their parents or legally representative guardian remains problematic. Because of their late-onset nature, such disorders do not necessitate taking decisions before the children reach the age of maturity (*bulūgh*), as they will naturally fall into the category of *mukallaf* and will be entitled to make autonomous decisions about their bodies. Available information about the genetic disorder, while they are newborn babies, may considerably change by the time they are adults. Therefore, there is no guarantee that the proxy consent provided at the time of their childhood won't later be classified as 'misinformed' consent.[171]

SECTION 3. CONCLUSION AND POLICY RECOMMENDATIONS

This report shows the wide range of options that Islamic perspectives offer. We have outlined the rationale behind these perspectives. We have seen how they can be used to develop nuanced positions that are faithful to the rich Islamic tradition and actionable to produce clear guidelines for involved stakeholders. Below, we summarize the key conclusions and recommendations from this report.

1. **Using genetic testing to contain genetic risks is, in principle, a commendable act in Islam and can sometimes be viewed as a religious obligation.**
   Most Muslim religious scholars agree that there is no inherent moral harm or unsurmountable ethical obstacle in using genetic tests as a tool to reduce the risk of having children with genetic disorders. Some argue further that undergoing these tests can be a religious obligation under certain circumstances.

2. **The legal enforcement of premarital genetic testing should not be the first option, but the last resort, and should be subject to regular and rigorous review.**
   The legal enforcement of premarital genetic testing raises serious ethical concerns, especially the religiously protected authority of autonomous individuals to decide what do with one's body and to choose their marriage partner. Thus, priority should be given to more acceptable means to raise public awareness about the significance of these genetic tests. Additionally, these laws and related executive orders should be reviewed on a regular basis to see if they are effective, if certain modifications are needed, or if these laws are still needed.

3. **The process of premarital genetic testing should be meticulously managed to minimize the risk of violating genetic privacy.**
   Involving both future partners in premarital genetic testing to inform them about possible genetic risks is part of the commendable marriage-related advice (*naṣīḥa*) in Islam. However, this does not automatically justify giving both partners open access to each other's genetic information. The genetic information should be restricted to what is necessary for the future spouses to make an informed decision about their planned marriage.

4. **Making premarital genetic testing a legal condition for the official registration of marriage contract should not infringe on the religious aspects of this contract.**
   The validity of a marriage contract in Islam is a legal issue as well as a religious one. To avoid the complexities of the possible overlap between the legal and religious domains, the codified laws should be clear that the disciplinary measures that can apply to the couples who have a religiously valid marriage contract, but did not undergo the premarital genetic testing, will not eventually mean considering them involved in an adulterous relationship.

5. **Conducting preimplantation genetic testing (PGT) to avoid implanting an embryo with the tested genetic disorders is, in principle, permissible.**
   The majority of Muslim religious scholars either permit or recommend PGT for married couples, as long as the preceding *in vitro* fertilization (IVF) process fulfills certain requirements. Although the mainstream position among these scholars is that the preimplantation embryos do not have the status of human being, we argue that such embryos should be treated with due respect because they have the potential of becoming human.

6. **Before reaching the age of 120 days, calculated from the moment of fertilization or implantation, preimplantation genetic testing (PGT) can, in principle, legitimize aborting an embryo/fetus with a genetic disorder.**
   Many Muslim religious scholars agree that pregnancy can be terminated before the lapse of 120 days as long as there is a religiously acceptable reason, including the risk of having a child with genetic disorders. To do justice to the different perspectives and nuances in the Islamic tradition, the suggested optimal approach is the case-by-case evaluation by a multidisciplinary ethics committee, comprising healthcare professionals and also experts in other fields, including Islamic studies and social sciences.

7. **The openness within the Islamic tradition towards using genetic advances to improve children's health should not be misinterpreted as accepting the geneticization of 'good childhood'.**
   The Holy Qur'an recommends supplicating God to have "good" children (Q. 03:38*). 'Goodness' here is, religiously speaking, a multidimensional concept that cannot be reduced to just having good genes. Besides good health, this concept also involves good manners and ethics and a good relationship with the Creator, fellow humans and other creatures in the universe. If children are born with genetic disorders, they

* "O My Lord! Grant me–by your grace–good offspring (*dhurriyya ṭayyiba*)".

should never be seen as of 'less value' than other children. In the end, it is God who decides who will be born and all children should be seen as part of God's destiny that Muslims should graciously accept.

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