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Mohammed Ghaly

# Islamic Ethics and Incidental Findings

Genomic Morality Beyond  
the Secular Paradigm

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Genomic Morality Beyond the Secular Paradigm

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*To Karima, my steadfast muse, whose  
unwavering support always illuminated the  
path of my academic odyssey*

# Acknowledgements

The genesis of this work traces back over a decade to 2013, when I joined the Research Center for Islamic Legislation and Ethics (CILE) at Hamad Bin Khalifa University (HBKU). This is where I embarked on establishing and chairing the Islamic Bioethics research unit. In the same year, the Qatar Genome Programme (QGP) and the Saudi Human Genome Program unfolded their journeys, heralding a new era for genomics across the Gulf region and the broader Arab world. The year marked the initiation of collaborative efforts and inquiries from colleagues at QGP and beyond, seeking ethical insights rooted in the Islamic tradition for their burgeoning research projects and their then emerging field.

The profound questions posed by geneticists in Qatar, Saudi Arabia, and neighboring countries, coupled with their unwavering patience in elucidating the intricate scientific nuances to someone without a biomedical sciences background, were instrumental in the conception and realization of this book.

Distinguished institutions, including the World Innovation Summit for Health (WISH), based in Doha, extended their interest in Islamic bioethical perspectives. WISH graciously accepted my proposal to dedicate a Research Forum in each WISH summit to the intersection of healthcare and Islamic ethics, where the idea of exploring the ethical management of incidental findings took root.

A special acknowledgment also goes to the Qatar Ministry of Public Health (MoPH). Following initial collaborations facilitated by QGP, WISH, Sidra Medicine, Hamad Medical Corporation, Weill Cornell Medicine—Qatar, and kindred institutions, the MoPH Research Governance Department approached me to draft a document on national policies for genomic research. These policies aimed to furnish researchers with robust guidelines grounded in Islamic values and principles. A working draft of this policy document is appended to this book.

In addition to the brilliant minds within the aforementioned institutions, my journey was enriched by the exceptional colleagues at CILE, the College of Islamic Studies, HBKU, and broader Qatar Foundation. Their expertise in Islamic ethics and Islamic studies proved indispensable for this interdisciplinary exploration spanning biomedical sciences and religious ethics.

Last but certainly not least, my heartfelt gratitude extends to my mother, wife, and children—my pillars of strength. Their unwavering support has been the bedrock of every accomplishment in my academic journey. Their love and warmth not only made the writing of this book possible but also rendered every academic milestone unimaginable without their steadfast presence.

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Doha, Qatar  
March 2024

Mohammed Ghaly



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# Chapter 1

## Introduction



**Abstract** This introductory chapter situates the study within the broader context of the genomic revolution catalyzed by the Human Genome Project (HGP). It examines the HGP's profound impact across three pivotal dimensions: its contribution to biomedical sciences by elucidating the human genotype, its facilitation of precision and personalized medicine through extensive genome mapping, and its intersection with ethical inquiries surrounding human nature and morality. The chapter then explores the allure of genomics within the Muslim world, spurred by scientific enthusiasm, the necessity for inclusivity in precision medicine, and the interest in reviving the Islamic civilization's golden age of science. However, it highlights a glaring gap: while Islamic ethical deliberations initially focused on the permissibility of participating in the genomic revolution, practical "how" questions arising from the establishment of national genome projects and biobanks in Muslim-majority countries since 2013 have largely remained unaddressed, particularly regarding the ethical management of incidental findings (IFs). The chapter outlines the study's aim to bridge this gap by constructing a comprehensive Islamic ethical framework for managing IFs, thereby contributing to both secular and Islamic bioethical discourses. It advocates for critical engagement between these discourses, rejecting oversimplified stereotypes and dogmatism, and promoting intercultural dialogue. Furthermore, the chapter delineates the study's structure, comprising two main chapters: the first focuses on constructing a robust moral framework grounded in Islamic metaethics and normative ethics, while the second delves into the ethical evaluation of disclosing various categories of IFs. Appendices include a systematic overview of ethical judgments on IFs and a draft national policy document on Islamic ethics and genomics commissioned by the Qatar Ministry of Public Health, underscoring the study's relevance to healthcare policymaking in Muslim-majority countries.

In the annals of modern biomedical sciences, the Human Genome Project (HGP) stands as a seminal milestone, wielding profound influence over the scientific landscape and catalyzing what has come to be known as the "genomic revolution" (Yudell & DeSalle, 2002). In the context of this study, the exceptional significance of this colossal undertaking unfolds across three dimensions, illustrating its impact

on the genomic revolution, particularly in realms extending beyond the confines of the Western world.

The first dimension pertains to its profound contribution to the expansive realm of biomedical sciences. Thanks to the information generated by the HGP and the resulting knowledge, man became able to profoundly identify the human body at the genetic level, a milestone unprecedented in history. Beyond the traditional understanding of the human body as an amalgamation of organs and tissues (phenotype), the genetic composition (genotype) of the body was pinpointed with remarkable precision. This advancement gave rise to compelling arguments supporting the notion that the genotype serves as the foundational framework for the phenotype, exerting influence, and possibly determining its functioning. Leaders of the HGP underscore its multifaceted impact on biomedical sciences, ushering in a new era by facilitating the unraveling of molecular mechanisms underlying myriad diseases, spearheading a revolution in cancer diagnosis and treatment, fostering the maturation of microbiome science, and integrating stem-cell therapies into routine medical practices (Collins, 2003; Green et al., 2015, p. 31).

Closely intertwined with the preceding one, the second dimension delves into the realms of "precision medicine" and "personalized medicine." Thanks to the HGP and advancements in genetics and genomics, a clear understanding emerged that the genetic makeup of the human body varies from one individual to another. This diversity elucidates the distinct responses individuals exhibit to prescribed drugs for treating diseases or recommendations for diet and lifestyle modifications aimed at enhancing overall health. Achieving precision in medicine would thus necessitate customization, tailoring medical approaches to each individual's unique genetic profile. Comprehensive insights into genomic diversity across diverse populations and ethnicities worldwide demand extensive genome mapping and sequencing data. Relying solely on genomic research in the leading countries in biomedical sciences, primarily concentrated in the Western world, proved insufficient. Hence, there is an imperative need to explore the genomes of diverse populations globally (Collins, 2011; Green et al., 2015, p. 30).

The third dimension has to do with the intersection of genomics and morality. The HGP and the genomic revolution unequivocally showcased that genomics transcends being a mere scientific enterprise focused on examining the human body. It holds direct relevance to decades-long discussions on human nature, giving rise to a spectrum of intricate ethical questions. Before the HGP, the conventional trajectory entailed that ethical concerns are to be addressed after substantial scientific advancements had occurred, subsequently triggering dilemmas and challenges.

In the case of the HGP, it became evident from its inception that inevitable challenges and dilemmas would emerge, including the imperative to safeguard people's privacy and protect them from genetic discrimination. These scientific advances also underscored the necessity of reexamining fundamental concepts shaping people's moral worlds, such as health, sickness, well-being, free will vs. determinism, and what distinguishes us as human beings, among others (Hochschild, 2021; Juengst, 1991; Meslin et al., 1997; Peters, 2014; Reardon, 2017). The intertwining of genomics and ethics was explicitly articulated by James Watson, the founding director of the

HGP, who succinctly expressed the project's overarching goal as "to find out what being human is" (Cole-Turner, 1992, p. 161). To grapple with these issues, the HGP established a dedicated ethical arm known as the Ethical, Legal and Social Implications (ELSI) program. Allocated 5% of the NIH budget, the ELSI program stood as the largest public investment in bioethical analysis at that time. The fusion of genomics and ethics, pioneered by the ELSI model of the HGP, gradually became the standard for subsequent research projects conducted in other countries, including Canada and the United Kingdom (Boddington, 2012, pp. 24–25; Green et al., 2015, p. 30; Juengst, 1991, p. 71; Walker & Morrissey, 2012; Wilson, 2004, p. 127).

## **Genomic Allure in the Muslim World**

The three above outlined dimensions of the HGP and the associated genomic revolution forged a compelling connection between the field of genomics and the Muslim world.

The first dimension, in particular, allowed the HGP to cultivate a positive image, widely acclaimed as a monumental and ambitious feat in modern biological research. Right from its inception, the HGP was perceived by many scientists and religious scholars in the Muslim world as the epitome of a scientific revolution that blurred the lines between imagination and reality. In a bid to encourage Muslim-majority countries to participate in this scientific race, the fundamental rationale rested on the strategic significance of not falling behind. There was a prevailing concern that nations lagging in this critical race would risk marginalization and exploitation by more advanced counterparts leading the scientific revolution (Ghaly, 2018, pp. 57–58, 64–66; Khādimī, 2004, pp. 62–63). Beyond the potential of ameliorating the future by combatting prevalent genetic diseases, particularly in Muslim-majority regions like the Gulf region, joining the genomic revolution was also viewed as a strategic step towards reviving the historical golden age of science in Islamic civilization (Ghaly, 2018, pp. 58–59).

The second dimension, emphasizing the imperative to study the genomes of diverse populations for enhanced precision in medicine, positioned the Arab world as an ideal participant in the genomics field. Broadly, this dimension played a pivotal role in the "globalization" of genomic research, evidenced by major funding agencies like the American National Institutes of Health (NIH) and the British Wellcome Trust providing grants to support genomic investigations worldwide, including Africa (Collins, 2011; Green et al., 2015, p. 30). The Arab world held particular allure for human genetics due to the prevalence of some genetic diseases and a high level of genetic diversity shaped by various historical factors, such as the migrations of Semitic tribes from the Arabian Peninsula, the Islamic expansion in the seventh century, the Crusade wars, and contemporary migration dynamics. Consequently, the region emerged as a valuable reservoir for researchers seeking to uncover disease-causing genes and pinpoint causative variants (Teebi & Teebi, 2005; Zayed, 2016). The initiation of the First Arab Genome sequencing project in 2008 exemplified

collaborative efforts within an international consortium led by Saudi Biosciences (Oxford Business Group, 2009). Subsequently, a growing body of scientific research originating from the Arab world, often in collaboration with global partners, has contributed to international genomics journals, enhancing the inclusivity and diversity of populations represented in this field (Al-Ali et al., 2018; Fakhro et al., 2016; Mbarek & Ismail, 2022; Saad et al., 2022; Thareja 2021; Zhou et al., 2022).

The third dimension, underscoring the intimate connection between genomics and ethics, holds particular significance for this study. In contrast to the evident scientific enthusiasm for exploring human genomes in the Arab world, the aforementioned Ethical, Legal, and Social Implications (ELSI) initiatives, despite their initiation in the early 1990s, scarcely delved into or exhibited awareness of religious considerations regarding genomic ethics, not to mention Islamic perspectives in particular.<sup>1</sup> Notably, the absence of religious perspectives on the central theme of this study—namely, the ethical management of incidental findings (IFs)—has been corroborated by existing reviews (Dolan et al., 2022; Elfatih et al., 2021; Ewuoso, 2016; Jackson et al., 2012; Walker & Morrissey 2012). This observation appears to be part of a broader issue within the prevailing secular bioethical discourse in Western academia, where religious discourse, in general, tends to occupy a peripheral or marginal position (Cole-Turner, 1992; Ghaly, 2018a, 2018b, pp. 17–18, 33–34; Guinn 2006).

A striking example in this context was the editorial decision taken by *Developing World Bioethics* in 2018, where the journal opted to significantly restrict the publication of “exclusively religious contributions.” Citing the challenges of defending religion-based arguments within the analytical framework of “public reason-based discourse” and the perceived inadequacy of religious arguments in making substantive or broadly relevant contributions to bioethics discourse, the editor of the journal communicated to readers that such contributions would henceforth be limited (Schuklenk, 2018). In addition to critical responses to this editorial decision (Duijvenbode & Padela, 2019; Wiersma et al., 2019), ongoing discussions keep examining the role, if any, that should be assigned to religious perspectives in modern bioethical discourse (Emmerich, 2019; Evans 2020), where some bioethicists go to the extent of asserting the incompatibility of religion and bioethics. On one hand, they clarify that this incompatibility does not imply that bioethics should exhibit disrespect toward believers of any particular creed or overlook the cultural influence of religion. On the

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<sup>1</sup> Searching the online “ELSI Publications and Products Database” shows the scarcity of available religion-related sources. Searching for terms like “Islam” and “Muslim” returns no results. See <https://www.genome.gov/Funded-Programs-Projects/ELSI-Research-Program/Publications-Products-Database>, accessed 3 January, 2023. Thus, the earlier calls to internationalize and diversify the ELSI research agenda (Henderson et al., 2012, p. 1017; McEwen et al., 2014, pp. 490–491) did not result in serious engagement with the ethical deliberations that have been taking place in the Arab world, with Islamic ethics at the heart of these deliberations. The most recent evaluative reviews of the ELSI legacy still reiterate the need to “engage diverse communities, and the varied personal and cultural influences on the interpretation and use of genetic information” (Dolan et al., 2022, p. 11). It is to be noted that that religious values do play significant roles in different societies around the world when it comes to bioethical issues like those related to the incidental findings. For a systematic review, see Ewuoso, 2016.

other hand, the argument posits that “bioethics should keep its distance from religion because it loses something important when it presumes in advance that religious views occupy any kind of privileged status when it comes to theorizing decisions about health, health care, and biomedical innovation” (Murphy, 2012, p. 3). The contention is that “either bioethics does its work on the assumption of an independently discernible morality or it must attempt to discern relevant divine fiats, which are—so far as human beings can tell—entirely idiosyncratic” (Murphy, 2012, p. 6).<sup>2</sup>

## Understudied Topic

Islamic reflections on genomic ethics trace their origins to the early 1990s, with initial discussions centering around the implications of the Human Genome Project (HGP), which was still in progress at the time. In addition to writings by individual Muslim religious scholars and biomedical scientists, these discussions assumed an interdisciplinary nature through translational Islamic institutions employing the mechanism of collective religio-ethical reasoning (*ijtihad*). The Kuwait-based Islamic Organization for Medical Sciences (IOMS) played a pivotal role in this regard by engaging both Muslim religious scholars and biomedical scientists in symposia addressing various facets of genetic and genomic ethics.<sup>3</sup>

Despite these intensive deliberations spanning over two decades, the ethical questions triggered by the IFs hardly received attention. This can be attributed, in part, to the fact that the foundational and seminal discussions took place during the 1990s. At this time, Muslim religious scholars, and most ethicists worldwide, were primarily focused on addressing what can be termed the “early questions” of genomics, as outlined in the introductory chapter of this study. Ethical implications of IFs were

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<sup>2</sup> The 17th edition of the World Congress of Bioethics (WCB), scheduled for June 2024, will be hosted by the Doha-based Research Center for Islamic Legislation and Ethics (CILE) in collaboration with the World Innovation Summit for Health (WISH). This marks the first occurrence of the WCB in the Arab world and the entire Middle East. To be attuned to the cultural context of WCB2024 and address the perceived oversight of religious dimensions, the chosen theme was “Religion, Culture, and Global Bioethics.” Despite the explicit statements in the call for submissions that both secular and religious perspectives are welcome, some bioethicists, communicating with me in my capacity as the WCB2024 Chair, vehemently opposed the selected theme. Their argument posited that the selected theme “in no way reflects how academic bioethics is actually done. While religion may be a target for academic research, it isn’t typically seen as a source of academic insight, ethical or otherwise.”

<sup>3</sup> For a detailed and analytical overview of these deliberations and resulting publications, see Ghaly, 2016a; Ghaly, 2018.

not yet prominent on the global bioethics agenda for genomics.<sup>4</sup> Post-1990s deliberations in the Muslim world seem to have concentrated on refining and adjusting earlier discussions, rather than responding to new developments and pertinent ethical inquiries in the field.

Available literature, however, shows that geneticists in the Muslim world, along with biomedical scientists in general, have been recognizing ethical challenges arising from IFs since 2015 and have underscored the need to address them.

In an article published in 2015, a number of biomedical scientists based in Qatar demonstrated an awareness of the necessity to tackle these ethical questions within the framework of Muslim-majority countries (Shanti et al., 2015). However, the article did not delve into how this issue could be further fathomed out from an Islamic perspective. Another instance is the Saudi-based epidemiologist Omar Kasule, who briefly addressed this issue in a presentation at the First Annual Saudi Society of Medical Genetics Conference held at King Abdulaziz City for Science and Technology on April 30, 2015. In the presentation's bullet-point outline, which is available on Kasule's website, he argued that genetic researchers "must avoid the complications of IFs by not actively seeking or even noticing them." He also emphasized the importance of proactively addressing any potential ethical dilemmas arising from IFs through the informed consent process in advance (Kasule, 2015). Because of the bullet-point format of the published presentation, no further details were provided.

Another example that is worth mentioning here is the 2016 report on genomics in the Gulf region published by the Qatar-based World Innovative Summit for Health (WISH). The interdisciplinary pool of contributing authors to the report included specialists in genetics, genomics, biomedical sciences, healthcare policymaking, as well as Islamic studies. A distinct section of the report was dedicated to examining the ethical management of IFs from an Islamic perspective (Ghaly et al., 2016a, pp. 35–42). Although that section and the entire report was mainly tailored for an audience with an interest in healthcare policy, this study benefited from the relevant information outlined in that section.<sup>5</sup> As for Arabic publications, there are quite few sources available, such as the book chapter written by Dr. Ayman Şāliḥ, a professor at Qatar University (Şāliḥ, 2020, pp. 252–282), and the article of the late scholar Muḥammad Na'im Yāsīn (d. 2023) (Yāsīn, 2019), whose perspectives will be analyzed in detail in this study.

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<sup>4</sup> According to the report released by the Presidential Commission for the Study of Bioethical Issues in December 2013, the earliest (indirect) recommendations related to incidental and secondary findings were issued in 1998 by the US National Human Genome Research Institute and, outside the United States, in 2001 by the Japanese Ministry of Health, Labour and Welfare (Presidential Commission for the Study of Bioethical Issues 2013, pp. 139, 144).

<sup>5</sup> It is worth mentioning here that the WISH report was utilized by an M.A. thesis on the Islamic ethical perspectives on genomic testing, which was defended in 2019 (Al Shakaki 2019). The preliminary results of the thesis were presented in a conference held in 2018 (Al Shakaki 2019a).



## Bridging the Gaps

This study aims to address substantial voids in existing scholarship within the two domains of mainstream secular bioethics and Islamic bioethics. Given the required brevity of publications in this series, this study concentrates on a specific but pivotal theme within the expansive area of genomics—that is, the ethical governance of Incidental Findings (IFs) from an Islamic perspective. In doing so, it endeavors to provide a nuanced exploration of ethical considerations surrounding IFs, contributing to the broader discourse on genomics and bioethics.

On one hand, the analyses presented in this study serve to create new avenues for interaction between mainstream and predominantly secular bioethical discourses in Western academia and bioethical discussions originating from religious traditions. Islamic values, constituting an integral aspect of the moral framework for millions of Muslims globally, offer a lens through which they seek to comprehend and make sense of their lives.

Authors of prior studies in Islamic bioethics have debunked certain misconceptions, such as the erroneous assumption that science and technology are value-free, devoid of cultural influence, and consequently “immune” to cultural considerations. They have also highlighted the fallacy of the belief that moral solutions derived from the Western secular context universally apply across diverse cultures. This body of literature emphasizes the need for an increased focus on Islamic solutions within predominantly religiously sensitive populations. It underscores the importance for healthcare institutions and professionals to accord greater consideration to individuals’ and societies’ moral and religious sensibilities (Al-Bar & Chamsi-Pasha, 2015, pp. 13–14; Inhorn, 2006; Sachedina 2009, p. 9).

Moreover, these religious values permeate public morality in many Muslim-majority countries, influencing not only mainstream scholarly and intellectual discourse but also the legal and regulatory aspects of numerous bioethical issues. Studies demonstrate the interest of legal specialists in engaging with religious discourse on various bioethical matters, including reproductive genetics (Sharaf al-Dīn, 2001).

Drawing on first-hand experience and more than a decade-long involvement in the healthcare sector in the Muslim world, it is evident that decision-makers in the healthcare sector consistently strive to ensure alignment between to-be-codified laws or to-be-adopted policies and the religious values embraced by society. Ministries of health routinely seek input from Muslim religious scholars and experts in Islamic bioethics to verify the compatibility of existing and future policies and regulations on diverse bioethical issues. As a concrete example of how Islamic ethics contributes to national policymaking in genomics, the full text of the most recent draft of a national policy document on the interplay of Islamic ethics and genomics, written by the author of this study and commissioned by the Qatar Ministry of Public Health, is provided in Appendix B.

On the flip side, this study seeks to make a substantial contribution to the field of Islamic bioethics by addressing existing gaps. Academic publications examining

Islamic ethical considerations in genomics are relatively scarce. Moreover, these publications typically concentrate on how Muslim religious scholars and biomedical scientists debated the overarching theoretical question of whether it is religiously permissible for individual scientists and governments of Muslim-majority countries to participate in the genomic revolution. As elucidated in previous studies, this yes/no question dominated Islamic deliberations on genomics from 1993 to 2013 (Ghaly, 2018b).

However, with the initiation of national genome projects and the establishment of biobanks in various Muslim-majority countries, particularly in the Gulf region, since 2013, a myriad of other intricate “how” questions has surfaced. The active involvement of these institutions in the continuously evolving field of genomics has given rise to practical and applied questions, many of which are novel and unprecedented in the field of Islamic ethics. These questions create gaps that necessitate addressing through increased publications in the domain of Islamic bioethics. Through long-term engagement and consultation with institutions dedicated to genomics in the Gulf region, it is evident that the ethical management of Incidental Findings (IFs) takes precedence among their critical concerns. This aligns with the conclusions drawn in recent studies (Elfatih et al., 2021, p. 373; Qoronfleh et al., 2020, p. 13).

While this study aims to contribute to and address gaps in both secular and Islamic bioethical discourses, it does not view these two discourses as inherently competitive, opposing, or mutually exclusive. On the contrary, the intention is to illustrate that both are essential for the development of a truly international discourse. The study does not seek to defend the superiority of one approach over the other but rather promotes constructive and critical engagement between them. Therefore, the target audience extends beyond the Muslim community to encompass the broader scholarly community of bioethicists and geneticists worldwide. The study is particularly relevant to those interested in intercultural communication and the cross-fertilization of ideas and perspectives.

An additional note is also due on some methodological aspects of this study. While the primary focus remains on Islamic bioethics, the study will incorporate references to parallel secular perspectives and insights whenever pertinent. Secular bioethicists occasionally adopt oversimplified stereotypes, assuming that religious bioethical discourse is inherently dogmatic, lacking space for rational reasoning, and consequently unwilling to verify its logical consistency and coherence. Using Islam as an example, this study aims to illustrate that religious bioethical discourse can be grounded in rigorous reasoning, synthesizing scriptural evidence-based systems and rational thinking, each with its verifiable and measurable coherence and logic.

To delve deeper into this aspect, a dedicated chapter will expound on the related theoretical dimensions in a manner accessible to non-specialists in Islamic studies. In acknowledging the diversity of perspectives within the Islamic moral tradition, this study will meticulously examine dissenting positions, the arguments put forth by proponents of each stance, and a wide array of authoritative sources spanning both classical and modern scholarship. This comprehensive approach aims to provide a nuanced and thorough understanding of Islamic bioethics, fostering dialogue and mutual understanding across diverse perspectives.

A final note is warranted regarding the sources cited in this study, all of which are written in Arabic or English, the two languages mastered by the author. To avoid potential misunderstandings regarding the assumption that the use of Arabic sources implies an exclusively “Arab” perspective, it is crucial to provide a general note about the field of Islamic bioethics. As extensively detailed in my previous publications (Ghaly, 2010, 2012, 2015, 2018a, 2018b), the primary contributions shaping this emerging field originate from three transnational Islamic institutions: the Kuwait-based Islamic Organization for Medical Sciences (IOMS), the Jeddah-based International Islamic Fiqh Academy (IIFA), and the Mecca-based Islamic Fiqh Academy (IFA). While the publications of these three institutions, heavily quoted in this study, are predominantly in Arabic, the contributing scholars hail from across the Muslim world, representing a diverse spectrum of Islamic doctrines, including Sunni, Shia, Ibadi, and others. The list of contributing scholars includes renowned figures from various regions, such as ‘Alī al-Taskhīrī and Ḥasan al-Jawharī from Iran in the Persian-speaking part of the Muslim world and Taqī Usmani from Pakistan in the Urdu-speaking world, among others. Given these developments that have blurred the lines between different Muslim-majority countries, it becomes challenging to delineate a distinctively “Arab” versus “Persian” or “Urdu” perspective. Nevertheless, it remains necessary to delve into the works published in the various languages spoken in Muslim-majority countries through academic studies authored by researchers proficient in these languages.

In terms of classical sources, the situation is notably straightforward. Virtually all well-established contemporary Muslim scholars across the globe are proficient in Arabic, routinely drawing upon many of the classical Arabic sources cited in this study. Arabic, given its status as the language of classical Islamic texts, acts as a unifying medium that facilitates scholarly discourse and engagement with traditional Islamic scholarship, underscoring its enduring significance in the realm of Islamic Studies.

## Overall Structure of the Study

Given the identified gaps in the existing academic literature and the commitment to delivering in-depth analyses that remain accessible to a broad readership with diverse backgrounds and specializations, the subsequent portion of this study will be organized into two main chapters. Each of these chapters will, in turn, encompass various sections, structured as follows.

**Chapter 2**, titled “Constructing a Comprehensive Moral Discourse,” delves into the question of devising a robust and well-structured moral framework. This framework is designed to be robust in theory and adaptable in practice, ensuring its reliable application to a diverse array of concrete issues and cases. So, the chapter endeavors to illuminate the process of creating a moral discourse that seamlessly combines theoretical solidity with practical flexibility, facilitating its consistent application across a broad spectrum of ethical dilemmas.

This chapter consists of three sections. The first section, “Theoretical level: Metaethics and normative ethics,” presents a succinct overview of pertinent metaethical discussions within the Islamic tradition, particularly as delineated in the scholarly disciplines of Islamic theology and legal theory. It elucidates the significance of aligning human actions with God’s will so that they can be deemed morally good. Addressing normative ethics, this section delves into the process of religio-ethical reasoning (*ijtihād*) and how it can be employed to discern God’s will in specific situations, particularly those pertaining to the field of bioethics.

Expanding upon the established metaethical framework, the second section, “Practical level: Fivefold classification of human acts,” delves into the widely acknowledged and centuries-old fivefold scheme for categorizing human actions according to their ethical value. After outlining the details and subtleties of this fivefold classification, known as *al-aḥkām al-khamsa*, this section further elaborates on how the IFs could be situated within one of these categories.

**Chapter 3**, titled “Ethical judgment of what (not) to be disclosed,” examines the intricacies of managing incidental findings (IFs). By way of setting the stage, the chapter starts with elucidating the technical term IFs within the context of this study. The chapter unfolds further across four sections, each dedicated to specific examples of IFs aligning with the categories of human actions outlined in the preceding chapter.

The first section, “(A) Obligatory,” undertakes an analysis of two instances of IFs where disclosure is deemed obligatory. This involves forewarning the patient or research participant about the likelihood of encountering IFs during genome sequencing and disclosing life-saving information.

The second section, “(B) Prohibited,” tackles one of the most contentious and ethically challenging categories of IFs—specifically, those revealing “misattributed” paternity. This section delves into the diversity of perspectives within the Islamic tradition. Initially, the standpoint asserting that the disclosure of these IFs is prohibited, is delineated, accompanied by a comprehensive presentation of key arguments supporting this position. Subsequently, an opposing viewpoint, asserting that disclosure is obligatory, is explored. This also involves a thorough exposition and analysis of relevant arguments and counter-arguments.

The third section “(C) Recommended” discusses IFs whose disclosure would help prevent, treat, or improve one’s health condition and explains why their disclosure should be judged as a recommended act. To defend this position, the section analyzes the Islamic perspectives on the concepts of seeking medical treatment (*tadāwī*) and providing medical care (*taḥbīb*). Then the so-called “minimum gene list”, developed by the American College of Medical Genetics (ACMG) is examined as a concrete example of these IFs whose disclosure should in principle be encouraged.

The fourth section “(D) Reprehensible” discusses the disclosure of IFs related to possible misattributed distant lineage, particularly tribal filiation. We argue that it is in principle reprehensible to disclose these IFs to the person whose gene/genome has been sequenced. To defend this position, the section elaborates on the concept of distant lineage (*nasab ba’īd*) in Arab culture and religious normativity and the parallel concept of genetic ancestry.

The final part of this study comprises two appendices and a glossary. Appendix A, titled “Ethical judgments on incidental findings (IFs): A Systematic overview”, provides a highly condensed summary of all analyzed IFs, their corresponding ethical judgments, and supporting key arguments. Appendix B, titled “Islamic Ethics and Genomics: Drafting National Policy” features the author’s draft of a national policy document commissioned by the Qatar Ministry of Public Health (MoPH). This document emphasizes the intricate interplay between genomics and Islamic ethics and is currently under review by the MoPH and various stakeholders in Qatar. The inclusion of this document serves to illustrate the significance of Islamic ethical perspectives in shaping national healthcare policies in a Muslim-majority country like Qatar. Lastly, the glossary is included to enhance the accessibility of the book to a diverse readership, extending beyond specialists in Islamic bioethics to encompass researchers and healthcare professionals from different backgrounds.

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## Chapter 2

# Constructing a Comprehensive Discourse



**Abstract** Chapter two constructs a comprehensive ethical framework to facilitate the analysis of intricate bioethical issues like incidental findings (IFs) in genomics. Drawing from both secular and Islamic traditions, it synthesizes Robert Veatch’s multi-layered approach to bioethics and the recommendation by Muslim ethicists to engage diverse scholarly disciplines. The “Theoretical Level” section explores Islamic metaethics rooted in theology and legal theory, centering on aligning human actions with God’s will to achieve benefit and avert harm. It examines the process of religio-ethical reasoning (ijtihad) employed by Muslim scholars to discern divine guidance on novel issues. The “Practical Level” section outlines the fivefold classification scheme for categorizing human acts based on their moral value within the Islamic tradition: prohibited, obligatory, reprehensible, recommended, and permissible. Distinct from secular schemes, this classification’s theological foundations, definitions, and moral dimensions are elucidated. Bridging theory and practice, the chapter proposes utilizing this fivefold scheme as a nuanced tool to evaluate the ethical management of IFs. It advocates a dynamic approach, acknowledging how evolving scientific understanding may shift the categorization of specific IFs over time. The chapter lays the groundwork for the subsequent analysis, where representative cases illustrating each ethical category are examined through the synthesized Islamic ethical lens, fostering constructive dialogue between religious and secular bioethical discourses on this complex issue.

The ethical questions related to the proper management of incidental findings (IFs) in the context of genomic research or clinical testing are often complex and multi-layered. Dealing with this genre of intricate bioethical issues, like genetic engineering and reproductive technologies, necessitates developing a comprehensive and consistent ethical framework. The delineation of such a framework is crucial to illustrate that the moral assessment of a particular course of action, whether deemed acceptable or unacceptable, is founded on robust and consistent reasoning rather than subjective biases. Moreover, such a framework plays an indispensable role in bridging gaps between diverse moral traditions, aligning with a primary objective of this study—fostering constructive dialogue. This approach aligns with the advocacy of

Muslim ethicists who emphasize the imperative to evolve a comprehensive discourse in contemporary Islamic bioethics transcending mere legal boundaries (Sachedina, 2008, p. 244). Thus, the ethical management of IFs serves as an exemplar to show how discerning the theoretical underpinnings of a governing framework can facilitate the systematic and consistent evaluation of specific and concrete bioethical issues.

Against this background, the main question to be addressed reads: What features make an ethical framework comprehensive enough to effectively address intricate bioethical issues such as incidental findings (IFs), genetic engineering, and reproductive technologies? In mainstream secular bioethical discourse, the late bioethicist from Georgetown University Robert Veatch (d. 2020) offered a well-reasoned proposition in his seminal work, *The Basics of Bioethics*. Veatch argued that a thorough and consistent bioethical analysis should encompass four main levels of moral discourse:

- **Metaethics (First Level):** This is the most abstract level that delves into the fundamental questions of ethics and their ultimate grounding, exploring issues such as the sources of ethics and the methodologies for ascertaining correct answers. Veatch noted that religious traditions often exhibit a particular interest in this level, and most of them have developed standard approaches to address such metaethical questions.
- **Normative Ethics (Second Level):** Here, the examination extends to broad norms of behavior and character. Lists of moral principles and values are articulated within this level, serving as ethical criteria for evaluating actions. Additionally, lists concerning character traits judged as morally praiseworthy are considered.
- **Rules and Maxims (Third Level):** This level involves the formulation of general rules, rights, and maxims which are applicable to a wide range of cases. Occasionally, specific groups of these rules and maxims are consolidated into codes of ethics.
- **Casistry (Fourth Level):** At the most granular level, the focus shifts to concrete and individual case problems. This involves seeking morally appropriate behavior in a particular situation. Agreements on the morally acceptable course of action in a specific situation (fourth level) may be reached even when consensus is lacking at other levels, especially the first one (Veatch, 2012, pp. 2–9).<sup>1</sup>

As far as the Islamic moral tradition is concerned, the extent of comprehensiveness in contemporary bioethical discourse is typically gauged by its level of engagement with diverse scholarly disciplines and genres both inside and outside the Islamic tradition (Moosa, 2007, pp. 47–59; Padela, 2021, pp. 227–234; Sachedina, 2008a, 2008b, 2009, pp. 7–14; Setia, 2022, pp. 79–109).<sup>2</sup> Given the nature of this study, which aims to forge connections between various bioethical discourses, a synesthetic

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<sup>1</sup> The fourth edition of *The Basics of Bioethics*, co-authored by Laura Guidry-Grimes (University of Arkansas for Medical Sciences), was published in 2020. The new edition included various updates but with no major changes in Veatch's ideas, as outlined in the third edition of the book, on the four levels of moral discourse. See Veatch and Guidry-Grimes (2020, pp. 3–14).

<sup>2</sup> The question of interdisciplinarity is also gradually being incorporated into initiatives to teach Islamic bioethics. For instance, the famous platform for online education, EdX, has now a course on Islamic Bioethics. In this course, a distinct module is dedicated to explaining how different

and hybrid ethical framework will be introduced. This proposed framework seeks to amalgamate Veatch's multi-layered structure and the recommendation of Muslim ethicists to involve different disciplines.

Consequently, the first three levels of Veatch's multi-layered framework—metaethics, rules, and normative ethics—will be consolidated under the heading “Theoretical level: Metaethics and normative ethics.” The fourth level, casuistry, will be explored independently under the heading “Practical level: Fivefold classification of human acts.” Each of the two sections dedicated respectively to the theoretical and practical levels will incorporate pertinent insights from various Islamic scholarly disciplines and genres. These disciplines include theology (*'aqīda*), legal theory (*uṣūl fiqh*), jurisprudence (*fiqh*), and Sufism. Additionally, a diverse array of scholarly genres will be consulted, encompassing works on regulating public morality through the institution of *ḥisba* (professional accountability), etiquettes of the physician (*adab al-ṭabīb*), and more.<sup>3</sup>

## Theoretical Level: Metaethics and Normative Ethics

### *Metaethics*

The grand metaethical questions are primarily examined within two main scholarly disciplines in the Islamic tradition: theology (*'aqīda*) and legal theory (*uṣūl al-fiqh*). The foundational premise revolves around an individual's deeply ingrained conviction and belief in the existence of One God, characterized by flawless attributes and reflected in His names—attributes that encompass omniscience, omnipotence, justice, wisdom, mercy, and more.<sup>4</sup> This recognition of God's immaculate character, compared to the inherently limited cognitive capacity of humans, leads to the acknowledgment of humanity's need for divine guidance. This guidance is perceived as essential for achieving success in this life and salvation in the hereafter.

The divine guidance necessary for human conduct is conveyed to humans through scriptures revealed to prophets and messengers. These chosen individuals are entrusted with the task of elucidating to humanity what God desires—referred to as God's will (*murād Allāh*)—and providing guidance on how individuals should comport themselves in alignment with this divine will.

In their pursuit to comprehend the overarching philosophy underlying God's will and the ways to distinguish between good/benefit and bad/harm, Muslim scholars

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scholarly disciplines and genres can contribute to Islamic bioethical deliberations. See <https://www.edx.org/course/islamic-bioethics>, retrieved 11 February 2023.

<sup>3</sup> An accessible overview of these disciplines and genres is provided in the Glossary.

<sup>4</sup> Such questions were mainly discussed within the broad theme of God-related issues (*ilāhiyyāt*), which has been one of the central themes of Islamic theology. See Baydāwī (1991, pp. 161–205), Ījī (1997, vol. 8, pp. 3–240). Some works were dedicated to the more specific theme of God's names and attributes, e.g., Ghazālī (1987).



endeavored to formulate a list of objectives for both God's creation and God's legislation. Concerning the former, scholars articulated three objectives for which humans were created by God: the cultivation of the earth (*'imārat al-ard*), worshipping God (*'ibāda*), and functioning as God's trustee and vicegerent on earth (*khilāfa*). The closer an individual aligns with these objectives, the more morally upright they become (Aṣṣāhānī, 2007, pp. 82–83). Regarding the latter, scholars held that an examination of the religio-ethical system of Islam reveals five higher objectives of Sharia (*maqāṣid al-Sharī'a*): safeguarding religion, life, wealth, intellect, and offspring. A number of modern studies have explored the relevance of these higher objectives to the field of bioethics (Ghaly, 2016; Rafī', 2012; Shīwa, 2020; Zūzū, 2002, pp. 167–201).

Within this broad theological framework, Muslim legal theorists and jurists formulated the concept of *khiṭāb Allāh*, loosely translated as God's address, which is primarily conveyed through the Quran and Sunna, both integral to understanding this divine communication. The Quran is believed to be the literal word of God and the Sunna comprises statements, deeds, and approvals attributed to the Prophet of Islam, who God has assigned the task of explaining His revelation to humanity.<sup>5</sup> All religious commandments, encapsulated in the comprehensive term *taklīf*, establish the relationship between God, as the divine addressor (*mukhāṭib*), and man, as the human addressee (*mukhāṭab*).

In God's justice toward the human addressee, certain senses, faculties, and capacities have been provided to enable humans to comprehend and fulfill God's commandments. The extent and magnitude of these obligations are intricately linked to an individual's mental capacity (*istiṭā'a 'aqliyya*), enabling comprehension of the divine address's meaning, and physical capacity (*qudra badaniyya*), facilitating the execution of commandments. Full functionality of mental and physical powers entitles individuals to the complete package of religious obligations and duties (*taklīf*), as these powers constitute the foundational elements of legal capacity (*ahliyya*). The scope of religious obligations and duties automatically diminishes when either of these two types of power is deficient or malfunctions (Ghaly, 2019, pp. 259–260; Sarakhsī, n.d., vol. 2, p. 340; Sam'ānī, 1999, vol. 2, p. 373).

Against this background, the overarching question that Muslim scholars grapple with, in their quest to judge an act as good or evil, reads: Is the act in conformity with God's will (*murād Allāh*)? If the answer is yes, then the act is good, and if no, the act is viewed as bad or evil (Ibn Ḥazm, 1983, vol. 1, p. 8; Juwaynī, 1996, vol. 1, pp. 154, 235; Shirāzī, 2003, p. 127). Muslim religious scholars concluded that the governing framework and the grand rule in this regard is that God primarily wills achieving the good/benefit (*maṣlaḥa*) and averting the bad/harm (*mafsada*); both in this life and in the hereafter (Qarāfī, 1980, vol. 1, p. 120; Shāṭibī, 2003, vol 1, p. 17, vol. 4, p. 346).

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<sup>5</sup> In more than one place in the Quran, the task of "explaining" God's revelation to humans was mentioned as one of the core tasks assigned to the Prophet of Islam, e.g., "And We have sent down to you [O Prophet] the Reminder [i.e., Quran], so that you may explain to people what has been revealed for them so that they may reflect" (16:40).

Muslim scholars use the technical term *mukallaf*, which literally means someone charged with certain duties, to refer to a person with recognized legal capacity. In secular bioethical terms, *mukallaf* comes close to, though not identical with, the term “autonomous person” or someone who possesses autonomy. Autonomy entails the right to make decisions reflecting one’s values, preferences, and sense of self (Veatch & Guidry-Grimes, 2020, pp. 133–134). Essentially, both terms denote the right to decide the proper course of action and the moral responsibility for the decisions taken. In the case of a *mukallaf*, however, the scope of autonomy is voluntarily restricted by one’s belief in God and acceptance of the principle that God knows what is genuinely beneficial or harmful in this life and the hereafter. In this sense, one’s voluntary submission to God’s will and the sincere intention to act accordingly (*imtithāl*) are values in themselves, separate from one’s ability to discern the underlying benefits in obeying God’s specific commandment or one’s eventual success or failure in implementing this divine will (‘Atiyya, 2003, p. 109; Juwaynī, 1996, vol. 1, pp. 159, 442; Shāṭibī, 2003, vol. 2, pp. 171–289, vol. 3, p. 101).

In this context, medical intervention in one’s body necessitates not only the consent of the autonomous patient but also God’s permission in the first instance. The legitimacy of a respective person’s right to accept or reject a specific medical intervention is contingent upon God’s permission to do so. Therefore, inflicting unjustified harm to the body or actively terminating one’s life are unethical practices, even if they were performed on the basis of informed consent that was voluntarily provided by an autonomous person (Bārr, 2005; International Organization for Islamic Medicine, 1981, pp. 30, 53–55; Shāṭibī, 2003, vol. 3, pp. 102–104; Sharaf al-Dīn, 1983, pp. 48–51). Further details on the ramifications of this point and its relevance to the ethical management of IFs will be outlined below, particularly in reference to instances where information disclosure will be judged as obligatory.

## *Normative Ethics*

The above-outlined metaethical framework has been the foundation for centuries-long deliberations within the scholarly community of Muslim scholars on how individuals should align their behavior in various aspects of life with this broad framework. Within the disciplines of Islamic legal theory and jurisprudence, a rigorous and complex system has been developed to demonstrate how relevant references in the primary sources of divine guidance, namely the Quran and Sunna, can be employed to address people’s questions.

One of the key terms in this regard is the concept of *ijtihād* (independent religious reasoning), an Arabic term that literally denotes exerting one’s utmost effort or unsparingly utilizing one’s power and ability. As a technical juristic term, *ijtihād* involves the exertion of one’s utmost effort (*istifrāgh al-wus‘*) by a qualified specialist to discern the will of God in a particular situation and determine how the discovered will should be implemented. In the quest to understand how God wants humans to behave in specific circumstances, the practitioner of *ijtihād*, known as a *mujtahid*,

begins by consulting the two scriptural sources, namely the Quran and Sunna, considered the primary repositories of information about God's will. Additionally, Muslim scholars have developed a wide range of secondary sources, the scope and validity of which in the reasoning process have been the subject of discussions and disagreements throughout history. The utilization of secondary sources in the *ijtihād* process becomes essential when the scriptural sources do not provide direct or conclusive answers about how to understand or implement God's will regarding novel questions (Juwaynī, 1996, pp. 311–422; Qaraḍāwī, 1996; Weiss, 1978).

Through the recurrent and systematic practice of *ijtihād* over centuries, which has scrutinized a large number of cases and issues, several grand rules or maxims have emerged. These maxims serve as principles to which Muslim jurists across different schools appeal when facing new cases or unprecedented questions (Kamali, 2006; Musa, 2014; Zakariyah, 2015, pp. 24–79). As many bioethical questions are novel, an increasing number of modern works have explored the relevance of these maxims to medical practice in general or to specific bioethical issues (Abū Ghudda, 1984; Al-Nomay & Alfayyad, 2015; Dusarī, 2016; Elgariani, 2012; Ghaly, 2015, pp. 28–29, 32–33; Sharīfa, 2018; Sharaf al-Dīn, 1982).

Islamic institutions with an interest in the field of bioethics have played a crucial role in developing significant ethical codes and accessible reference works for interested healthcare professionals. Notable examples include the Islamic Code of Medical Ethics (*Al-Dustūr al-Islāmī li al-mihan al-ṭibbiyya*), issued in 1981, and the International Islamic Code for Medical and Health Ethics (*Al-Mūthāq al-Islāmī al-‘ālamī li al-akhlāqīyyāt al-ṭibbiyya wa al-ṣiḥḥiyya*), released in 2004. The two documents are available in both Arabic and English (International Organization for Islamic Medicine, 1981a, 1981b; Gendy & Awadi, 2005; Jundī & ‘Awaḍī, 2005). Besides presenting more than 100 articles, articulated in a semi-legal language, delineating Islamic perspectives on a wide range of issues (Jundī & ‘Awaḍī, 2005, pp. 55–127), the 2004 Code extensively engages with the International Ethical Guidelines for Biomedical Research Involving Human Subjects, as issued by the Council for International Organizations of Medical Sciences (Jundī & ‘Awaḍī, 2005, pp. 135–289).

In addition to delineating the principles of morally right action, Islamic normative ethics extensively examines the character of the actor or agent, particularly the physician or healthcare practitioner. Both early and modern works authored by physicians and religious scholars delve into the question of which character traits or virtues contribute to making a physician good or virtuous. These works often intertwine the requisites for both professional excellence and virtuous character, emphasizing that both aspects are essential for the development of a “good physician.” Some of these works fall within the genre of *adab al-ṭabīb* (etiquettes of the physician) (Abū Ghudda, 1981; Bār & Sibā‘ī, 2009; Levey, 1967; Ruhāwī, 1992). Additionally, works from other genres such as *ḥisba* have also contributed to these discussions (Abū Ghudda, 1981, pp. 161–162; Qurashī, 1976, pp. 247–259; Subkī, 1986, p. 103).

## Practical Level: Fivefold Classification of Human Acts

Casualty represents the most practical level in moral discourse, involving the ethical evaluation and normative judgment of concrete scenarios and specific actions. To systematize this level, both secular and religious moral discourses have sought to develop schemes or scales for classifying human acts based on their ethical value. These frameworks aim to determine the degree of goodness or badness associated with specific acts. In an effort to maintain a bridge between secular and Islamic bioethical discourses, this section begins with concise notes about the secular deliberations on this issue.

In moral philosophy, the standard threefold scheme for the classification of actions posits that actions fall into one of three main categories, namely (a) obligatory, (b) prohibited and (c) permissible or morally neutral. Actions which are deemed morally required belong to the first category, those which are morally condemned fall into the second category and the actions which do not fit into either of the first two categories are considered neutral and shall make part of the third category. In his article "Saints and Heroes" published in 1958, J. O. Urmson (d. 2012) made a pioneering argument in modern non-religious moral philosophy<sup>6</sup> for the inclusion of a fourth category, namely (d) supererogatory. This fourth category would encompass heroic or saintly self-sacrifices which go beyond the bounds of duty like the doctor who volunteers to help in a foreign, plague-ridden city. Despite Urmson's critique, some moral philosophers continued defending the veracity of the traditional tripartite classification scheme of actions. However, the new fourfold categorization of moral acts (obligatory, prohibited, supererogatory and permissible) proved to be more appealing to the extent that some moral philosophers even described it as approaching the status of "near dogma" (Guevara, 1999, pp. 593–624; Hedberg, 2014, pp. 3623–3624) finding its way into standard works on bioethics (Beauchamp & Childress, 2013, p. 45). Innovative classification, however, coexists with the traditional tripartite scheme, which has not been entirely abandoned or deemed obsolete. The traditional tripartite classification continues to be employed in certain bioethical discussions, including those pertaining to the ethical management of incidental findings (IFs) (Presidential Commission for the Study of Bioethical Issues, 2013, pp. 84–85).

As far as the Islamic tradition is concerned, discussions spanning centuries have explored how human acts can be systematically classified in terms of their underlying ethical value to gauge their degree of goodness or badness. The most mature version, which consisted of five categories, began to take its full shape around the eleventh century (Baghdādī, 1977, pp. 337–338; Baṣrī, vol. 19831, pp. 4–5, 334–341). Since then, this fivefold classification has been consensually adopted and has remained

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<sup>6</sup> It is to be noted that some ethical traditions, including the Roman Catholic, did not embrace the traditional tripartite classification of actions (Hedberg, 2014, p. 3623). Although the Roman Catholic tradition adopted the concept of supererogation, it was strongly attacked by Lutherans and Calvinists.

mainstream, undergoing no major changes up to the present day (Faruki, 1966; Zankī, 2003).

The differences between the abovementioned secular threefold or fourfold scheme (viz, obligatory, prohibited, permissible, and supererogatory) and the fivefold classification in the Islamic tradition extend beyond just the number of categories or their names. They encompass other substantial aspects, including the very foundation of the classification and the essence of the respective categories.

This fivefold classification is referred to in Arabic by the term of *al-ahkām al-khamsa*, which literally means “the five rulings”, and is usually translated into English as “five values”, “five categories” or “five principles” (Faruki, 1966; Firmage et al., 1990, p. 204, Kamali, 2003, p. 413). Given the nuanced perspectives presented in authoritative sources and the specific focus of this study, the fivefold classification of human acts is to be understood and approached through the following parameters.

The foundation of this classification rests on specific theological premises, as outlined in the previous section. Central to these premises is the conviction that the authority to determine what is good and bad fundamentally resides in the Creator of humans, the universe and all creatures therein—namely, God. Within this theological framework, the fivefold classification serves as a practical instrument to help those who believe in God and are convinced that His perfect divine attributes make Him the supreme Lawgiver and Arbitrator, capable of instructing humans on how to conduct themselves in a morally responsible manner. Consequently, both the individual posing the question about behavior in a specific scenario, known as the questioner (*mustaftī*), and the religious scholar acting as the religious advisor (*muftī*), who classifies the questioner’s action into one of the five categories, share a common objective: aligning one’s behavior with God’s will. In essence, the goal is to manifest sincere obedience to God and submission to His will (*imithāl*), as opposed to catering to personal desires and preferences (*hawā*) (Baṣrī, 1983, vol. 2, pp. 211, 242; Faruki, 1966, p. 43; Juwaynī, 1996, vol. 1, pp. 160–171).

Within the context of the human-God relationship, adherence to this value system is primarily overseen by one’s conscience. If one’s behavior betrays any of the requirements ensuing from this system, the main cost here will be one’s moral failure in front of God. Therefore, both the transgression itself and the endeavor to rectify it initially fall within the private sphere of one’s relationship with God, both in the present life and, more significantly, in the Hereafter, where individuals will be held accountable before God (Faruki, 1966, p. 77, p. 91; Shafī’ī, 1940, p. 353;). This domain of individual morality constitutes the central focus of this study.

Moreover, actions that extend beyond the individual and impact others, with societal repercussions, can be subject to regulation by legislative and enforcement bodies. These entities aim to safeguard the rights of individuals and maintain public order in society. For instance, in the context of (non-) disclosure of incidental findings (IFs), hospitals or health ministries can operationalize the, legally speaking, non-binding value system into institutional policies or enforceable laws. While the legal dimension is not the primary focus of this study, the analyses provided can serve as a resource for institutions seeking to develop regulatory frameworks that align with this value system.

The concluding observation here aims to problematize the assumption held by some bioethicists that religious deliberations would necessarily yield positions “based on faith not argument.” This perception has sometimes led to the view that religious normativity stands apart from, or is even in opposition to, philosophical discourse (Blumenthal-Barby et al., 2022, p. 17; Savulescu, 2015, p. 32). The definitions provided below for each of the five categories have been meticulously drafted to highlight the moral dimensions inherent in the overall scheme and emphasize the necessity of supporting the resultant judgments with moral reasoning. This aligns with the mainstream approach adopted by both classical Muslim scholars and their contemporary counterparts. They consistently reiterate the need for prudence and cautiousness before claiming that a specific position represents the ruling of God (*ḥukm Allāh*). Especially when it comes to the novel issues that fall within the scope of *ijtihād*, of which the management of IFs is a perfect example, human acts undergo evaluation to judge their ethical or unethical character (Baṣrī, 1983, vol. 1, pp. 8–9; Zankī, 2003, p. 336). To minimize the scope of error and or fallible subjectivity, scholars’ judgments are to be premised on consistent and robust religio-ethical reasoning. On the other hand, Muslim scholars have always been reluctant to hastily claim someone’s entitlement to divine reward or punishment, recognizing that such judgment primarily rests with God and that humans should not attempt to arrogate to themselves such authority (Abū Yūsuf, 1938, pp. 72–73; Faruki, 1966, pp. 68–79).

Against the backdrop of these parameters, the five categories are defined as follows:

- (a) Prohibited: An act deemed blameworthy when committed by someone who is recognized religiously as an accountable agent (*mukallaf*), as per the guidance of the Lawgiver, namely God.
- (b) Obligatory: An act whose commission by a *mukallaf* is praiseworthy, and its omission is considered blameworthy, as per the guidance of the Lawgiver.
- (c) Reprehensible: An act discouraged by the Lawgiver without being explicitly prohibited, making its commission not blameworthy.
- (d) Recommended: An act considered praiseworthy but not mandated by the Lawgiver; thus, its omission is not blameworthy.
- (e) Permissible: An act where commission or omission doesn’t entitle the *mukallaf* to either praise (*madh/thanā*) or blame (*dham/lawm*). This is because the Lawgiver’s directives either don’t support its classification into any of the four aforementioned categories or do indicate that the act is morally neutral (Baṣrī, vol. 19831, pp. 334–341; Ibn al-‘Arabī, 1999, pp. 21–24; Ibn Qudāma, 2002, vol. 1, pp. 97–151; Sarakhsī, n.d., vol. 1, pp. 110–128; Shīrāzī, 2003, pp. 6–7, 12–25; Zankī, 2003, pp. 336–338).

## Applied Case: Incidental Findings (IFs)

This study will utilize the fivefold categorization of human acts to classify the (non-) disclosure of specific Incidental Findings (IFs). Grounded in the above-outlined frames of metaethics and normative ethics, this fivefold categorization is considered the most fitting tool for an ethical management of IFs, enabling the classification of human acts on the basis of their moral worth. Rooted in the Islamic tradition, this multi-layered ethical analysis also aligns with aspects of secular moral discourses. We posit that constructing Sharia-based perspectives on complex issues, such as the ethical management of IFs, should always involve employing such a comprehensive approach.

This approach gains additional relevance considering the dynamic nature of genomics. The decreasing cost of sequencing, coupled with enhanced bioinformatics capabilities, has made genomic sequencing commonplace in both research and clinical settings. Genomic research routinely produces vast datasets, elevating the probability of encountering IFs unrelated to primary research goals. Moreover, exome and genome sequencing are swiftly being integrated into clinical practices for diverse medical applications, including molecular characterization of rare diseases, personalized treatment, pharmacogenomics, preconception/prenatal screening, and population screening for disease risk. In each of these scenarios, the likelihood of recognizing and reporting IFs with medical significance to the ordering physician and the patient is escalating (Green et al., 2013; Noohi & Ross, 2022). Given these advancements, the ethical management of IFs has become substantially more intricate, rendering a one-size-fits-all approach impractical.

The two categories, namely (a) obligatory and (b) prohibited, will be presented first. Both categories offer distinct and categorical judgments, facilitating straightforward decision-making without significant complexity or nuances. That is why many of the cases that fall within these categories can be incorporated into broad policies and guidelines for research and healthcare institutions. Examples, which will be discussed in detail below, comprise scenarios where the disclosure of life-saving IFs is considered obligatory, while revealing nonpaternity IFs to the presumed father is prohibited.

The other two categories, (c) recommended and (d) reprehensible, share affinities with the obligatory and prohibited categories, respectively. Acts not strictly deemed obligatory may shift to the less stringent category of recommended actions, and similarly, the relationship between reprehensible and forbidden acts follows a similar pattern. However, cases falling under the recommended and reprehensible categories often resist categorical judgments, subject to contextual and variable factors. As a result, these cases are better assessed on a case-by-case basis, ideally through referral to ethics committees. This approach captures the morally relevant nuances, as opposed to integrating them into generalized institutional policies.

The category of “permissible” typically encompasses IFs whose disclosure doesn’t align with any of the acts falling under the other four categories. Consequently, there won’t be a dedicated section for IFs in this category, given their nature of not fitting into the more defined ethical classifications.

It is important to note that the examples provided under each category are not meant to create an exhaustive list of what should or should not be disclosed. Instead, they serve as illustrative instances or representative examples, and many similar cases could already fit into these categories or become eligible for inclusion in the near or distant future. Moreover, it is crucial to acknowledge that classifying specific examples into these categories is dependent on the information available at the time of writing this study in Summer 2023. Updates to the currently available information can result in a shift in the categorization of particular findings.

Thus, it is crucial to realize that this dynamic categorization, particularly in judging the (non-) disclosure of specific findings, is closely linked to the continuous and rapid advancements in genetics and genomics, and cognate fields. Some researchers distinguish between individuals’ genetic “information,” which remains relatively static, and the “results” of genetic tests, the interpretation of which may change in response to advances in these fields (Roberts & Foulkes, 2020). Consequently, the American College of Medical Genetics and Genomics (ACMG) consistently updates their recommendations on which IFs should be disclosed, with the latest revisions released in 2022. These updates aim to accommodate the evolving medical value of certain genetic variants due to new discoveries in these fields (Kalia et al., 2017; Miller et al., 2021a, 2021b, 2022). An illustrative example showcasing the fluidity of the ACMG list is the TTR (transthyretin) gene. It was initially excluded, but was later included based on new data on population prevalence and FDA-approved treatments, indicating links with treatable causes of heart failure (Miller et al., 2022, 1408).

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## Chapter 3

# Ethical Judgment of What (Not) to Be Disclosed



**Abstract** Chapter three provides an in-depth ethical analysis of what types of incidental findings (IFs) from genomic research or clinical testing should or should not be disclosed to individuals. It begins by providing a lucid definition of IFs and delineating the scope under consideration. The chapter then examines two categories where disclosure is judged as obligatory: firstly, informing potential recipients about the likelihood of IFs arising, and secondly, disclosing life-saving IFs associated with actionable genetic conditions. A key focus is the controversial issue of misattributed paternity IFs, which reveal that the assumed father is not the biological father. Two contrasting perspectives are presented: one prohibiting disclosure to the assumed father based on Islamic jurisprudential principles and societal ethical concerns, while another minority viewpoint asserts the obligation to disclose, with supporting arguments outlined, and accompanied with critical commentary. Subsequently, the chapter goes on to analyze IFs recommended (praiseworthy but not obligatory) for disclosure, employing the theoretical framing of the Islamic ethical concepts around seeking/providing medical care, with the American College of Medical Genetics (ACMG) list serving as an applied example. Additionally, a category of IFs judged as reprehensible (blameworthy but not prohibited) to disclose is examined through the lens of distant lineage and demonstrated through the applied case of genetic ancestry findings.

To arrive at a normative judgment on which Incidental Findings (IFs) should or should not be disclosed, it is imperative to establish a precise definition of “IFs” first. This necessity, particularly within the intricate context of genetics and genomics, aligns with a widely accepted legal maxim among Muslim jurists, asserting that “ruling regarding a matter is contingent first upon the perception thereof” (*al-ḥukm ‘ala al-shay’ far’ ‘an taṣawwurih*) (Ghaly 2020, 82). So, the commitment to developing accurate definitions for technical terms and delineating their scope is deeply rooted in a centuries-old tradition in Islamic scholarship (Mitwallī 2018). Specifically, in the context of religious rulings derived from scriptural sources, authoritative works in the discipline of legal theory (*uṣūl al-fiqh*) consistently devote a distinct chapter to

this issue under the title “*al-dalālāt* (indications or implications)” (‘Abd al-Ḥamīd, 2012).

When it comes to IFs as a technical term, the U.S. Presidential Commission for the Study of Bioethical Issues (hereafter, Bioethics Commission) rightly acknowledged the challenge of arriving at a precise definition for this concept. This challenge arises from the fact that different groups have adopted varying definitions of IFs (Presidential Commission for the Study of Bioethical Issues, 2013, pp. 25–29).

## **Incidental Findings (IFs) as a Technical Term**

In this study, the concept of Incidental Findings (IFs), sometimes named secondary findings, and its scope will be defined on the basis of specific parameters. These parameters have been carefully selected and refined to establish a robust foundation for systematic and coherent ethical analysis.

- The findings pertain to the analysis of one’s genetic makeup, whether it involves the entire genome, exome, or specific genes. Therefore, findings resulting from the use of medical images to examine specific organs, such as computed tomography (CT) or magnetic resonance imaging (MRI), may not necessarily fall within the scope of this study. However, some of these results may be relevant to the ethical analyses presented herein.
- The findings fall outside the scope of the original research objective or the clinical test being conducted. Moreover, these findings are not actively sought or intended by the involved researchers or clinicians, and the same holds true for the respective research participants or patients.
- The findings pertain to either a research setting or clinical context. Whenever the differences between these two contexts morally matter, a distinction between the two will be highlighted. The commercial or Direct-to-Consumer (DTC) context falls outside the scope of this study because IFs in this particular context entail significant elements of financial and commercial ethics that go beyond the focus of this study.
- The findings are not necessarily exclusive to the narrow scope of health-related aspects but are broad enough to include those that relate to one’s overall well-being. Although researchers and clinicians in the fields of genetics and genomics primarily focus on healthcare, the IFs they come across can have serious and morally relevant implications that influence one’s overall well-being in the ethical rather than medical sense.

### **(A) Obligatory**

Using two concrete examples, this section will elaborate on when and how the disclosure of IFs can be judged as obligatory.

## ***A-1 Likelihood of IFs***

The first example pertains to the minimum ethical obligation towards potential recipients of IFs, encompassing patients and research participants. The main thesis is that individuals should be adequately informed in advance that IFs may arise. This thesis is rooted in the information briefly outlined earlier, particularly in the “Metaethics” section, and will be expounded upon in this section to underscore the points with relevance to this thesis.

One of the fundamental tenets of Islamic creed is the belief that man, including the body and all capacities and faculties therein, is exclusively created by God. The Quran is replete with numerous verses, which are too many to be enlisted here, conveying this message in various ways. Some verses emphasize the worship of God as the Creator of the human species and other creatures (e.g., 2:21;<sup>1</sup> 45:04<sup>2</sup>). Other verses highlight man’s inherent weakness and powerlessness, emphasizing that it is only God who bestows faculties such as hearing, eyesight, and organs like eyes, tongue, and lips (e.g., 30:54;<sup>3</sup> 23:78;<sup>4</sup> 09:8–9;<sup>5</sup> 67:2<sup>6</sup>). Another group of verses underscores God’s marvelous work in fashioning man in a perfect shape and form (e.g., 95:04;<sup>7</sup> 23:12–14;<sup>8</sup> 15:28–29<sup>9</sup>).

Aligned with these theological premises, Muslim jurists formulated several normative principles that apply to a broad spectrum of rulings. The most pertinent of these principles and legal maxims to the topic of IFs include the following:

- The human body has sanctity (*ḥurma*) and inviolability (*ma ‘ṣūmiyya*)
- God is the sole Owner of the human body.
- Individuals are not owners of their bodies but rather trustees of God.

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<sup>1</sup> “People, worship your Lord, who created you and those before you, so that you may be mindful [of Him].”

<sup>2</sup> “In the creation of you, in the creatures God scattered on earth, there are signs for people of sure faith.”

<sup>3</sup> “It is Allah Who creates you in a state of weakness, then gives you strength, then weakness after strength, together with old age.”

<sup>4</sup> “It is God who endowed you with hearing, sight, and heart.”

<sup>5</sup> “Have We not given him [men] two eyes. And a tongue, and two lips.”

<sup>6</sup> “Indeed, We [alone] created man from a drop of mixed fluids, to test them, so We made them hearing and seeing.”

<sup>7</sup> “Indeed, We created humans in the best form.”

<sup>8</sup> “And indeed, We created man from an extract of clay. Then We placed them as a drop of fluid in a safe place. An then then We made that drop into a clinging form, and We made that form into a lump of flesh, and We made that lump into bones, and We clothed those bones with flesh, and later We made them into another creation—glory be to God, the best of creators.”

<sup>9</sup> “And recall when yours Lord said to the angels, ‘I am creating a human our of dried clay, of fermented mud. When I have fashioned him and breathed from My spirit into him, all down to him, fall down to him, prostrating.’”

- No one is allowed to dispose other people's rights or properties without their permission.<sup>10</sup>

The essence of these principles and maxims is to show that taking actions related to the human body must take into account two fundamental rights or claims. The first pertains to God, in the capacity of the Creator of human body, and the second claim relates to the individual, serving as the body's trustee (Abū Ghudda, 1982, p. 789; Jundī and 'Awaḍī, 2005, p. 262; Sharaf al-Dīn, 1983, pp. 47–48, 1987, p. 128; Taftazānī, n.d., vol. 2, p. 309; Taṅṭāwī, 1995, p. 312).

Conducting research or performing genome testing for the purpose of generating generalizable knowledge that can benefit numerous individuals or populations is, at the very least, considered a permissible act from an Islamic perspective. The categorization of this act may also shift into other categories such as recommended or mandatory, contingent on specific circumstances. The same principle applies to testing someone's genome for diagnostic or therapeutic purposes. Consequently, the research or testing leading to IFs is rooted in an action for which God, the Lawgiver, has granted permission (*idhn al-Shāri*).<sup>11</sup> Following divine authorization, it becomes imperative to seek permission from the autonomous person designated by God as the trustee of their body, encompassing the genome within. Acquiring an individual's consent, as elucidated by Muslim scholars, necessitates a clear and adequate explanation of the situation at hand, ensuring that the person in question is sufficiently well-informed (*'alā bayyina*) to make an autonomous decision (Jundī and 'Awaḍī, 2005, p. 262; Sharaf al-Dīn, 1983, p. 51, 1987, pp. 50–51).

Accessing one's genome often opens the door to a wealth of information, much of which may extend beyond the intended scope of the originally planned research or clinical test. This implies that the likelihood of encountering IFs is almost inevitable. In order to obtain a permission premised on sufficient clarity and would thus qualify as *informed* consent, the consenting process should involve making the respective person aware of the likelihood of IFs. Beyond the juristic aspects related to respecting people's autonomy, disclosing the probability of IFs from the outset holds various benefits for all involved stakeholders. As far as the perspective of the patient or research participant is concerned, having this information empowers these individuals to develop better plans and prepare well for potential ethical questions or dilemmas that may arise. In the context of medical treatment, Muslim scholars emphasized the Lawgiver's permission not only to eliminate existing harm but also to take precautions against future or anticipated harms, whether caused by human

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<sup>10</sup> For the list of consulted sources regarding these principles, see Ibn Qudāma (1968, vol. 4, p. 374), Kāsānī (1986, vol. 7, p. 177), Zarqā (1989, pp. 461–464), Sharaf al-Dīn (1987, p. 76), 'Arjāwī (1991, pp. 153–167), Taṅṭāwī (1995, pp. 306–308), Jundī and 'Awaḍī (2005, p. 159, 191).

<sup>11</sup> The period between 1993 and 2013 witnessed extensive discussions among Muslim religious and biomedical scientists about the religious ruling on conducting genomic research and genomic medicine. Contributors to these discussions adopted positive attitudes towards the field of genomics in general, to the extent that it was sometimes viewed as a "collective obligation". For an analytical overview of these discussions, see Ghaly (2018, 2018a).

or non-human factors (Shāṭibi, 2003, vol. 2, p. 261). Preemptively disclosing information about the likelihood of IFs also contributes to improving the professional image of genomic researchers and clinicians as individuals bound by fiduciary duty, particularly in upholding the value of veracity (Jundī & ‘Awaḍī, 2005, p. 61; Ruhāwī, 1992, p. 287).

## ***A-2 Life-Saving Information***

In accordance with the teachings of the Quran, as articulated in verses such as 2:173,<sup>12</sup> Muslim scholars unanimously agree that preserving human life is a fundamental value that can transform into a stringent religious obligation, the neglect of which would be considered a sin. This obligation arises under specific conditions, particularly when an individual faces a life-threatening situation and can be effectively saved without jeopardizing the life of the rescuer. This perspective aligns with the overarching objective of Sharia, namely, the preservation of life (*ḥifz al-nafs*), which is expounded upon in various disciplines within the Islamic tradition.

While this obligation is indiscriminately applicable to all members of society capable of saving someone’s life, scholars assert that it becomes more compelling for those possessing specialized knowledge and professional capacity enabling them to provide efficient lifesaving support. It is important to note that if providing such support would ultimately endanger the life of the one providing assistance, it may no longer be deemed a religious obligation. This is due to the principle that protecting one’s own life is also an obligation, with some scholars contending that it holds even greater weight than the duty to save the lives of others (Ibn Qudāma, 1968, vol. 9, pp. 421–422; Qurṭubī, 1964, vol. 2, p. 226; Sharaf al-Dīn, 1987, p. 103; Wizārat al-Awqāf wa al-Shu’ūn al-Islāmiyya, 1984–2005, vol. 5, pp. 195–96).

In consideration of the preceding discussion on preserving human life, we contend that it is incumbent to disclose the IFs that meet the following two criteria:

- The IFs slated for disclosure are scientifically validated, clinically significant, and actionable. In essence, their revelation typically precipitates life-saving interventions that are accessible and available.
- The disclosure of these IFs will not jeopardize the life of the involved researcher or clinician.

As for the first criterion, certain IFs relate to a life-threatening condition that can be averted through preventive measures. According to the study of the U.S. Presidential Commission, the genetic predisposition to malignant hyperthermia (MH) is an example of such potential lifesaving IFs. MH is a treatable condition associated

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<sup>12</sup> “He has only forbidden you carrion, blood, and the flesh of swine, and what was dedicated to other than Allah. But if someone is compelled by necessity—neither driven by desire nor exceeding immediate need—they will not be sinful. Surely Allah is Ever-Forgiving, Ever-Merciful.”

with severe and life-threatening reactions to certain kinds of anesthesia (Presidential Commission for the Study of Bioethical Issues, 2013, p. 139, 87). Regarding the second criterion, it appears unlikely that disclosing lifesaving IFs would put the researcher's or clinician's life at risk. However, should such a scenario arise, then the disclosure of the IFs would not be judged as obligatory. Meeting both criteria establishes the obligation to disclose the respective IFs, whose omission would constitute moral negligence and entail a religious sin. The same line of reasoning also extends to IFs associated with communicable and contagious diseases, which pose a public health risk that endangers not only the life of infected individuals but also many others in society. Given their potential to prevent public harm, the ethical obligation to disclose such IFs becomes even more stringent.

In alignment with the outlined examples where the disclosure of IFs is deemed obligatory, we contend that relevant institutions, such as national genome projects, biobanks, research centers, and hospitals, should formulate their own catalog of obligatory actions concerning IFs. This catalog ought to be properly discussed with potential recipients of IFs during the informed consent process. Refusal of some items of listed obligatory disclosures may serve as an exclusion criterion from participation in the research study. In the clinical context, the Institutional Review Board (IRB) or equivalent consultative bodies should be involved in determining the most appropriate course of action for patients who refuse such obligatory disclosures, tailoring decisions to the unique circumstances of each case.

## **(B) Prohibited: Misattributed Paternity**

While conducting family genetic studies, researchers may incidentally come across results showing that one or both of the rearing parents are not the genetic/biological parents. For example, if a child is affected by a recessive disorder and the mother but not the father is a carrier, this would imply that the mother's husband is not the genetic father. If neither of the parents is a carrier, this would suggest the possibility of undisclosed adoption, embryo donation, mix-up of children during an in vitro fertilization (IVF) process or at fertility clinics, etc. Similar IFs may arise during genetic analysis conducted as part of clinical care or reproductive planning for couples or families. Thus, such IFs may be found in both research and non-research settings. Besides misattributed paternity,<sup>13</sup> IFs can also reveal misattributed ethnic or cultural identity in ancestry studies or negate the genetic basis of tribal affiliation (Wolf et al., 2008, p. 222).

In secular bioethical discourse, misattributed paternity has been among the earliest types of IFs to be examined (Wolf et al., 2008, p. 220). After about three decades of deliberations, the (non-) disclosure of misattributed paternity remains a controversial

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<sup>13</sup> Besides misattributed paternity, scholarly literature also used other terms almost synonymously, including non-parent-expected (NPE) finding, nonpaternal and nonpaternity. See Shepard et al. (2022, p. 2).

issue, lacking a unanimous consensus among individual bioethicists or bioethical institutions. In terms of disclosing such IFs to the assumed father, contributors to these debates can be broadly divided into two groups. One group, seemingly representing the majority position, opposes the disclosure of these IFs. They argue that such disclosure would breach the mother's right to privacy and protection from harm, and it could harm family harmony and disrupt its unity. The advocates of this position assert people's right not to know, as these findings eventually remain incidental, with no fundamental obligation to inform people about. To minimize ethical predicaments in this regard, some suggest a targeted approach in both genetic/genomic research and clinical tests to reduce the likelihood of encountering such sensitive IFs as much as possible. This targeted approach is recommended by various international institutions including the European Society of Human Genetics and the UK-based Public Health Genomics (PHG) Foundation (Presidential Commission for the Study of Bioethical Issues, 2013, p. 140). In contrast, the other group advocates for the disclosure of these IFs, arguing that disclosure is essential for the autonomy of the child and presumed father. They also contend that physicians have a general duty to disclose such information, asserting that non-disclosure would undermine trust in medical professionals, because it might be perceived as paternalistic when doctors make value judgments about what is best for a family (Hercher, 2023, p. 2; Lowe et al., 2017, pp. 234–235).

This section will specifically address the particular case of IFs related to misattributed paternity, where the assumed father is not the biological father. Under the title "Prohibited Disclosure", we will argue that the disclosure of nonpaternity IFs to the assumed father should be classified within the above-explained category of prohibited acts. Although Islamic discourse on this specific issue is still in its infancy, this position seems to be gaining an increasing support (Ghaly et al., 2016a, pp. 35–43; Hājj, 2017, pp. 160–165; Yāsīn, 2019, p. 114). On the other hand, an opposing perspective advocating for the obligatory disclosure of these IFs has recently emerged, as outlined in a recently published book (Şāliḥ, 2020, pp. 253–282). This perspective and its reasoning will be presented under the heading "Obligatory Disclosure" by the end of the section.

### ***B-1 Prohibited Disclosure***

For a systematic presentation of the arguments supporting this position, they will be divided into two main categories. The first category of arguments relates to the disciplines of Islamic jurisprudence (*fiqh*) and Islamic legal theory (*uṣūl al-fiqh*). The second category comprises the arguments stemming from the fields of medical and social ethics.

### B-1.1 Juristic Arguments

As for the first category of arguments, comprehending the prohibited disclosure of this specific type of IFs to the assumed father requires an initial exploration of a central concept in the Islamic tradition—*nasab*, often translated as lineage or filiation. This concept has been recurrently addressed in the Quran and Sunna and extensively analyzed in the disciplines of *fiqh* and *uṣūl al-fiqh*. Within the *uṣūl* works, lineage (*nasab*) is discussed within the higher objective of Sharia related to safeguarding offspring (*nasl*). In *fiqh* works, determining one's lineage, including paternity and further lines of kinship, is crucial for implementing a wide range of juristic rulings. The scope of these rulings extends beyond the limited range of family affairs, intersecting with other domains, including financial and penal aspects (Group of Scholars, 1983–2006, vol. 1, p. 126, vol. 40, pp. 254–255; Quradāghī & Muḥammadī, 2008, pp. 342–343; 'Uwayd, 2020, pp. 161–172). Because of this religious dimension of *nasab*, ethical deliberations on the possible disclosure of nonpaternity-related IFs cannot be restricted to balancing the civil rights of the mother, the assumed father and the child. These deliberations should also examine the religious obligations emanating from the *nasab* relationship towards the Lawgiver, i.e., God (Ibn al-Qayyim, 2006, vol. 2, p. 602).

With this understanding of the multidimensional concept of *nasab*, it would be easier to comprehend that biological or genetic relatedness is not the exclusive determinant of fatherhood or man-child *nasab* in Islamic jurisprudence. Many early and contemporary Muslim jurists held that biological relatedness may not even be the most important factor, certainly not the *prima facie* basis for establishing the prospective child's fatherhood and the ensuing kinship networks, together with associated religious obligations and rights. Muslim jurists agree that the couple who plan to have children should first establish a marital relationship or wedlock (*firāsh*)<sup>14</sup> so that the resulting children shall automatically possess a religiously recognized lineage (*nasab shar'ī*), upon which related juristic rulings can be premised (Ghaly et al., 2016a, p. 42, 2020, pp. 21–22.; Group of Scholars, 1983–2006, vol. 32, pp. 80–82; Yāsīn, 2019, pp. 108–110). This marriage-based framework not only aligns with religious norms but is also a fundamental aspect of the lived reality for many Muslims and the codified laws observed in numerous Muslim-majority countries. The existence of a recognized marital relationship is often a prerequisite for the legal entitlement of children to various rights including inheriting property from their parents (Fayḍī, 2013; Laklamī, 2021; Sachedina, 2009, p. 103, 107; Welchman, 2007, pp. 142–150).

Once this marriage-based fatherhood is properly established and duly recognized by the husband of the child's mother, it cannot be easily challenged or negated even if the woman committed adultery. This widely accepted position among Muslim jurists

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<sup>14</sup> *Firāsh* literally means 'anything spread for one to sit or lie upon' and particularly a bed upon which one sleeps. In this sense, the husband, wife, or the sleeping bed they share; each of these can be called *firāsh* (Fayyūmī, 1976, vol. 2, p. 468). In historical discussions, the scope of this term would also cover the slavery-based relationship. Bearing in mind the irrelevance of slavery in the modern context of reproductive technologies and genomics, *firāsh* will exclusively be used in this study to mean wedlock.



is premised on a famous tradition attributed to the Prophet of Islam, which reads “The child belongs to wedlock (*firāsh*) and the stone is for the adulterer”. Muslim scholars have interpreted the tradition to imply that the husband of an adulterous woman will retain the exclusive right to the child’s paternity. In contrast, the adulterous man will not be entitled to any rights in this regard and is metaphorically given ‘stone’ (meaning nothing). According to an alternative interpretation of the same tradition, the adulterous shall be ‘stoned to death’; the prescribed punishment for adultery, if he was married. For these jurists, the fact that the woman committed adultery does not conclusively prove that she was impregnated by the adulterous man, even if apparent physical resemblance (*shabah*) was observed between the child and the adulterous man (Ghaly et al., 2020, p. 22; Group of Scholars, 1983–2006, vol. 40, p. 238; Yāsīn, 2019, pp. 108–11).

Another important argument supporting this position is that early Muslim jurists were already aware of the biological contribution of both the husband and wife in shaping the physical makeup of their child. The terminology used in Prophetic traditions was *al-mā’ān*, which literally means two waters or two fluids.<sup>15</sup> In modern commentaries on these Prophetic traditions and related bioethical discussions, the “two waters” are often interpreted as the male sperm and female egg (Ghaly et al., 2020, p. 22; Lashīn, 2002, vol. 2, p. 308; Madhkūr et al., 1985, p. 59, 109, 150; Şāliḥ, 2020, p. 281). Despite this, the mainstream position among early Muslim jurists is that man’s biological contribution alone, without wedlock (*firāsh*), is insufficient to establish him as the religiously recognized father of a child born to a woman married to another person (Ibn al-‘Arabī, 2003, vol. 3, p. 447; Juhanī, 2010, pp. 13–14). This view persisted even with the advent of modern DNA fingerprinting, which provides nearly conclusive evidence of biological paternity. Thus, the mainstream position among Muslim jurists remained steadfast; marriage-based *nasab* should be the norm for establishing father-child kinship. Once this religiously recognized fatherhood is established, DNA fingerprinting cannot be used to question it, even at the request of the husband. If the husband contends that the born child is the result of his wife’s adulterous relationship, he should resort to the judiciary procedure of mutual oaths of condemnation (*li’ān*), as outlined in the Quran (46:6–9)<sup>16</sup> and Sunna and further detailed in juristic manuals. While not disputing the scientific reliability of the DNA fingerprinting, the majority of Muslim jurists stressed that this new technology cannot completely replace *li’ān* and should not be employed to contest an already established marriage-based *nasab* (Ka’bī, 2006, pp. 376–514; Quradāghī & Muḥammadī, 2008, pp. 367–369).

<sup>15</sup> In his famous canonical collection of Prophetic traditions, Imam Muslim b. al-Ḥajjāj (d. 261/875) dedicated a section to this topic under the title “*Bāb ṣifāt maniyy al-rajul wa al-mar’ā wa anna al-walad makhluq min mā’ihimā* (Chapter on the nature of the man’s and woman’s fluid (semen) and that the child is created from their two waters)”. See Muslim (2003, vol. 1, p. 250).

<sup>16</sup> “And those who accuse their own wives [of adultery] but have no witness except themselves, the accuser must testify, swearing four times by Allah that he is telling the truth. And the fifth (oath) that Allah’s curse indeed be upon him if he is of the liars. For her to be spared the punishment, she must swear four times by Allah that he is telling a lie. And the fifth (oath) that the wrath of Allah shall be upon her in case he is telling the truth.”

Building upon the aforementioned rationale, the advocates of this position stressed the critical distinction between biological or genetic paternity on the one hand and the religiously recognized father-child relationship or *nasab*, on the other hand. The *prima facie* basis for the latter is marital relationship and not genetic relatedness.<sup>17</sup> Although both types typically align in the prevailing reality of Muslim couples, jurists explain that there may be cases where the woman's husband will not be the biological father. In such cases, the religiously recognized father will be the woman's husband, not the biological father. Therefore, disclosing the nonpaternity IFs will only cause harm and ultimately will not change the religiously recognized *nasab* between the respective child and the woman's husband (Yāsīn, 2019, pp. 111–112). Additionally, the context of IFs related to nonpaternity has to do with families who have what jurists call “established lineage (*nasab mustaqirra*)”, where children are born within wedlock (*firāsh*). As demonstrated earlier, challenging an established lineage in such cases is extremely difficult, with only the husband having the right to initiate the judiciary procedure of *li'ān* under strict conditions.

### B-1.1 Ethical Arguments

In addition to the aforementioned juristic arguments, proponents of the “Prohibited Disclosure” position underscored ethical concerns related to societal, medical, and professional ethics, although these aspects were often not given due attention.

Concerning medical ethics, the primary consideration revolves around the moral values that should govern the physician–patient relationship or that between the researcher and research participant. In contrast to a judge, who is professionally obligated to settle paternity disputes when a case reaches the court, such a role lies outside the purview of the clinician or researcher who encounters a nonpaternity IF. On the contrary, the physician is morally bound, by profession, to uphold the privacy of patients and the confidentiality of their information (Ghaly et al., 2016a, p. 43; Ḥājj, 2017, p. 1601; Yāsīn, 2019, p. 112).

This rationale aligns with centuries-old Islamic deliberations on medical confidentiality. Such discussions trace back to early works in the genre of *adab al-ṭabīb* (etiquettes of the physician), where the ability to keep secrets was introduced as one of the characteristics of the virtuous physician (Rāzī, 1977, p. 27; Ruhāwī, 1992, p. 287). Similar insights also figure in the modified and monotheism-friendly

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<sup>17</sup> Early and contemporary Muslim jurists used different terms to name each of these two types and highlight the discrepancies between them. For instance, the Mālikī jurist Ibn al-ʿArabī (d. 1148) differentiated between “mere creation (*khalq muṭlaq*)” to indicate biological relatedness and “confirmed lineage (*nasab muḥaqqaq*)” to signify the religiously recognized paternity (Ibn al-ʿArabī, 2003, vol. 3, p. 447). However, the late Jordian jurist Muḥammad Naʿīm Yāsīn (d. 2023) used the term biological father (*al-abb al-bayuwliji*) for the former and Sharia-recognized or legitimate father (*al-abb al-Sharī*) for the latter (Yāsīn, 2019, p. 109, note 4). It is worth mentioning that the distinction between genetic and non-genetic paternity is acknowledged by some voices in secular bioethical discourses who differentiate between genetic fatherhood and moral fatherhood (e.g., Draper & Ives, 2009).

versions of the Hippocratic oath, which has been integrated into the medical profession throughout the history of Islamic civilization. The Arabic version of the physician oath included phrases such as, “As for whatever I witness during the treatment of patients or hear about outside the time of their treatment, regarding matters that should not be spoken of openly, I refrain from disclosing them. I believe that such matters should not be spoken of at all” (Ibn Abī Uṣayby‘a, n.d., p. 45). The principle that healthcare providers are committed to respecting the privacy of their patients was also reiterated in modern Islamic codes of medical and health ethics, as seen in the bioethical discussions facilitated by transnational authoritative institutions like the Islamic Organization for Medical Sciences (IOMS) (Jundī & ‘Awaḍī, 2005, pp. 366–368; Madhkūr et al., 1995, pp. 21–202, 753–755) and the International Islamic Fiqh Academy (IIFA, 2020, pp. 250–252). Both early and modern discussions endorse a broad scope of medical confidentiality, encompassing all information healthcare providers learn about their patients in their professional capacity, including details about patients’ sexual relations. Any deviation from this moral obligation should only be made by way of exception, subject to a rigorous assessment of anticipated benefits and potential harms. Importantly, it was emphasized that the list of permitted exceptions should be clearly defined in the regulatory frameworks or codes governing the practice of medical professions, along with guidelines on how such information should be disclosed and to whom. Unjustified breaches of this moral obligation were classified as both religious disobedience, subject to accountability before God, and professional violations that would eventually erode public trust in the profession. Broadly speaking, similar positions regarding the principle of medical confidentiality are reflected in the codified laws of different Muslim-majority countries (IIFA, 2020, pp. 250–252; ‘Inabī, 2017; Ḥājj, 2017, pp. 155–157; Madhkūr et al., 1995, pp. 753–755; Muṣliḥ, 2021; Quradāghī & Muḥammadī, 2008, pp. 113–118).

In terms of societal values and social norms, proponents of this position highlighted various concerns. They argued that allowing the disclosure of nonpaternity IFs to the assumed father could destabilize the marital bond (*rābiṭat al-zawjiyya*) between the child’s mother and her husband, potentially leading to serious harm, and even the disintegration or complete destruction of an established family. Taking into account the prevailing cultural norms in diverse Muslim societies, revealing nonpaternity not only brings disgrace to the woman, even potentially jeopardizing her life, but also carries the risk of stigmatizing all her children. This could negatively impact their chances of marriage and establishing their own families in the future (Ḥājj, 2017, p. 164; Yāsīn, 2019, pp. 108–109).

Regarding the psychological impact on children, only a few studies have explored this aspect among groups of European ancestral descent. Despite some positive aspects reported by some, such as relief, comfort, and self-assuredness, available results overwhelmingly show negative influences on individuals’ overall well-being and identity formation. These negative effects include feelings of sadness, grief, loss, betrayal, anger, and existential concerns (Shepard et al., 2022). Currently, there is a lack of empirical data to make well-informed estimations about the possible impact of sharing the news of nonpaternity IFs with children in Muslim communities. However, beyond the question of genetic or non-genetic paternity, it is evident

that knowing that one's assumed parent is not one's actual parent would adversely influence the child's overall well-being.

Another moral concern is that the nonpaternity IFs almost inevitably leads to moral condemnation for the child's mother because she was impregnated by someone other than her husband; an act which is both moral violation towards her husband and religious sin towards God. In response, it should be clear that both early and contemporary Muslim jurists did not see necessary relation between woman's pregnancy, even if unmarried, and her having an adulterous relation. Muslim jurists envisaged different scenarios that would make such a woman innocent, such as rape, sleep sex or sexsomnia, erroneous sexual relationship (*waq' al-shubha*), where one would mistakenly think that he/she is having intimacy with one's spouse, etc. (Group of Scholars, 1983–2006, vol. 24, pp. 25–32). It is very unlikely that the nonpaternity IFs would be sufficient to be sure that none of these innocent scenarios would apply to the woman in question and that she has engaged in an adulterous relation. Even if the worst-case scenario of an adulterous relation was the case, the ethical value of *satr* (literally “covering”), which means the concealment of people's moral failures and sins would be in place.

Numerous Prophetic traditions recorded in canonical collections recommend that Muslims conceal not only their own faults and sins but also their brethren's. Through this behavior, one becomes entitled to fitting rewards from God, like concealing one's own transgressions on the Resurrection Day. As commentaries on these Prophetic traditions, Islamic literature on religious etiquettes (*ādāb Shar'īyya*), Sufism and other disciplines provided insights on this value, explaining how to respect the privacy of individuals without sacrificing the value of collaboration to build a morally committed society. The main idea with relevance to the current discussion is that the value of *satr* should prevail as long as the person in question does not insist on challenging dominant social norms in public, and their moral transgression have not reached the judiciary authorities (Bayhaqī, 2003, vol. 9, 12, p. 39, pp. 154–171; Bukhārī, 1989, p. 266; Ghazālī, n.d., vol. 2, pp. 177–179, 199–201; Ibn al-Jarrāh, 1984, pp. 768–775; Ibn Ḥajar, 1959, vol. 5, pp. 97–98; Ibn Muflīh, n.d., vol. 1, pp. 234–235; Kharā'itī, 1986, pp. 97–103; Nawawī, 1972, vol. 16, p. 135; Qushayrī, 2013, p. 10). Some scholars held that the value of *satr* would particularly apply to the case of adultery (Nasā'ī, 2001, vol. 6, p. 461; Qarāfī, n.d., vol. 3, p. 203). In the same vein, some Shāfi'ī and Ḥanafī jurists confirmed the position of al-Ghazālī (d. 1111), arguing that if an individual is questioned by a ruler about a grave sin (e.g., adultery or drinking alcohol) committed in secret by themselves or someone else, it will not be morally wrong in this context to deny that this sin was committed (Dimiyāfī, 1997, vol. 3, p. 288; Ghazālī n.d., vol. 3, p. 138; Haytamī, 1987; vol. 2, p. 326; Ibn 'Ābidīn, 1992, vol. 6, p. 427).

In light of the above-outlined reasoning, revealing nonpaternity IFs to the assumed father is incompatible with the broad religio-ethical framework governing lineage or filiation (*nasab*) in Islamic jurisprudence and legal theory. Moreover, such disclosure would constitute a violation of religio-ethical and professional principles related to medical confidentiality. This disclosure lacks a foundation in a meticulous harm-benefit analysis that considers not only the assumed father but also the broader

network of stakeholders involved, encompassing the child, the mother, and the family institution. Additionally, by disclosing IFs related to individuals' moral lapses, one would transgress significant Islamic values, such as *satr*, which entails respecting people's private lives, sometimes extending to concealing their moral transgressions and sins. In light of these considerations, we argue that both genetic/genomic research and clinical tests should adopt a targeted approach to minimize, if not avoid, encountering this type of sensitive IFs. Doing so would mitigate potentially stressful situations for researchers and clinicians.

## ***B-2 Obligatory Disclosure***

In contrast to the previously stated "Prohibited Disclosure" position, this standpoint asserts that the disclosure of nonpaternity Incidental Findings (IFs) to the assumed father is obligatory (*wājib*). This perspective, explored in-depth in a recently published book by Dr. Ayman Ṣāliḥ, delves into broader discussions on the interplay of DNA paternity and lineage (*nasab*). His perspectives on these broader issues align with an increasing number of Muslim jurists who defend the religio-moral significance of genetics in matters related to paternity. Dr. Ṣāliḥ, a specialist in comparative *fiqh* and legal theory (*uṣūl*) affiliated with the College of Sharia and Islamic Studies at Qatar University, stands alone among Muslim religious scholars in defending this position, as of the writing of this study in the summer of 2023. This uniqueness is underscored by the subtitle of his book, 'New Juristic Insights (*Nazarāt Fiqhiyya Jadīda*)' (Ṣāliḥ, 2020). Given the singularity of his perspective on the disclosure of nonpaternity IFs, it is imperative to include it in this study. The book, published in Arabic, a language not accessible to many bioethicists worldwide, presents a position advocated by a specialist in Islamic jurisprudence and legal theory. Due to Ṣāliḥ's well-constructed argumentation, aligned with a growing trend among contemporary Muslim jurists that places increasing emphasis on DNA paternity, it is likely to elicit diverse responses from other jurists and bioethicists in the future. The main arguments advanced by Ṣāliḥ to defend this position will be presented below under the heading "Main Arguments". Thereafter, some brief comments and observations on his perspective will be outlined under the heading "Critical Remarks".

### **B-2.1 Main Arguments**

Before delving into the detailed arguments provided by Ṣāliḥ, a preliminary note is warranted on the foundational ideas upon which he has constructed the entire framework of his reasoning. Throughout the book, he emphasizes the revolutionary nature of DNA fingerprinting, not only as a modern technology unknown to early Muslim jurists but, more importantly, as a tool that jurists can employ to reconsider a substantial number of juristic rulings related to the concept of lineage (*nasab*). From the outset of the book, Ṣāliḥ contends that the discovery of DNA fingerprinting is one

of God's greatest gifts to humanity and should be regarded as a "revolution," not only in scientific domains but also in the fields of jurisprudence and law. If used properly, Şālih argues, DNA fingerprinting can significantly contribute to achieving one of the most crucial benefits for humans—safeguarding the lines of their lineage with an unprecedented degree of certainty that reaches almost 100%. In Şālih's perspective, this makes DNA fingerprinting a stronger proof for paternity and blood kinship than any other tool known to Islam and previous religions, including wedlock (*firāsh*) (Şālih, 2020, pp. 5–6).

Within this conceptualization of DNA fingerprinting, the distinction upheld by the proponents of the "Prohibited Disclosure" position between religiously recognized lineage (*nasab sharī*) and biological relatedness (*nasab bayuwlūjī*) appears hardly relevant. According to this conceptualization, such a distinction would only hold merit in the era preceding the discovery of DNA fingerprinting, which now should stand as the *prima facie* basis for religiously recognized lineage as well. Furthermore, Şālih asserts that biological relatedness, for which early jurists employed terms like *ba'diyya* or *juz'iyya* (literally part-ness or portion-ness), has consistently been the genuine basis for religiously recognized lineage (*nasab*). Early jurists would only resort to alternative tools and proofs when conclusive means, such as DNA fingerprinting, were unavailable for examining this biological relatedness (Şālih, 2020, pp. 28–63).

Against the above-sketched backdrop, Şālih put forth four main arguments to defend his "Obligatory Disclosure" position. Within each argument, he provided very detailed reasoning, including possible critiques to his argument and his response to these critiques. Below, we will provide a condensed overview of these four arguments.

The first argument, which stands as the most detailed one, is premised on the moral principle of "forbidding wrong (*al-nahy 'an al-munkar*)", which has been widely discussed by Muslim scholars throughout Islamic history, as part of their commentaries on relevant scriptural references. In simple terms, this principle dictates that one should restrain people from doing wrong, evil or immoral acts (*munkar*) through available means and under specific conditions and etiquettes (Cook, 2001, 2003). Building upon the above-explained foundational idea that biological/genetic relatedness is the genuine lineage (*nasab*) recognized by Islam, Şālih speaks about the evil of having a child misattributed to the woman's husband although he is not the biological father. As this information is exclusively accessible to the researchers or the clinicians who came to know about the nonpaternity IF, no one else but them will be under religious obligation to take the responsibility of "denouncing the evil (*inkār al-munkar*)" and "speaking the truth (*al-bawḥ bi al-ḥaqq*)" (Şālih, 2020, pp. 257–258). By disclosing the nonpaternity IFs, the respective researchers or clinicians will also aid in encountering other forms of *munkar*, e.g., fooling the woman's husband and preventing the adulterous woman from continuing the crime of falsely attributing a child to her husband and unlawfully benefiting, along with her child, from seizing her husband's property, inheritance, and more (Şālih, 2020, pp. 259, 273).

The other three arguments are premised on scriptural references, especially Prophetic traditions, whose overall purport stresses the obligation of providing information that would help others avoid serious harm or gain benefit. In the second

argument, Ṣāliḥ focused on the thesis that bearing testimony (*adā' al-shahāda*), in the capacity of a witness, even if unsolicited, is obligatory. To defend this thesis, he quoted the commentaries of Muslim religious scholars on some Prophetic traditions pertinent to the concept of (unsolicited) testimony. Based on this premise, Ṣāliḥ reached the conclusion that the clinician is under obligation to disclose the nonpaternity IFs. The minimum obligation, according to Ṣāliḥ, is to disclose this information to the “one whose gene/genome has been screened, i.e., the examinee (*al-mafhūṣ*)”, presumably the assumed father, and to show willingness to testify before the judge, if required. However, informing judiciary authorities directly about the nonpaternity IFs cannot be strictly judged as obligation because there is disagreement among Muslims jurists on this issue (Ṣāliḥ, 2020, pp. 278–279).

The third argument follows the same lines of reasoning but through the lens of providing advice (*naṣiḥa*) that would help others gain benefits or avoid harms. In the case of nonpaternity IFs, Ṣāliḥ explained that informing the assumed father would help him safeguard his religion, property, and honor. According to Ṣāliḥ, “no one would like to be fooled by adopting a child whom he thinks is his own, spending on him, and leaving him an inheritance, while he is not actually his own child, but rather the child of another man who is his enemy, who trespasses on his sanctity and honor”, in reference to the supposed wife’s adulterous relation (Ṣāliḥ, 2020, pp. 280–281).

The fourth argument revolves around a historical incident that took place during the lifetime of the Prophet of Islam, where a wet nurse claimed that she breastfed an already married couple. If proved true, the wet nurse’s unsolicited testimony would mean that the married couple were related to each other through milk kinship; a type of kinship that bars marriage in Islam. Although the husband insisted that the wet nurse must be lying, it was reported that the Prophet of Islam instructed the husband to leave his wife. Ṣāliḥ drew an analogy between the wet nurse’s unsolicited testimony and the clinician’s disclosure of the nonpaternity IF. In both cases, revealing such previously unknown information is religiously justified although it may eventually result in the disintegration of an established family. This is because, Ṣāliḥ explained, honoring the Lawgiver’s rulings should take precedence over the interest of maintaining family stability (Ṣāliḥ, 2020, pp. 281–282).

## B-2.2 Critical Remarks

Throughout his book, Ṣāliḥ showed profound knowledge of the authoritative sources in the disciplines of *fiqh* and *uṣūl*. He also provided critical analyses and significant insights on how the modern technology of DNA fingerprinting can be integrated into related sets of juristic rulings. By valuing the semi-conclusive evidence of this technology to confirm or negate biological/genetic paternity, Ṣāliḥ rightfully criticized the rigidity (*jumūd*) of the contemporaneous jurists who insisted on ignoring this technology, while accepting much less scientifically proven tools, such as classical physiognomics (*qiyāfa*), simply because the latter was documented in the works of early jurists (Ṣāliḥ, 2020, pp. 9–11, 167, 291). As for his position on the nonpaternity IFs, especially when it comes to his thesis that disclosing these IFs to the assumed

father is a religious obligation, three broad remarks will be outlined to engage with the problematic aspects of Ṣāliḥ's thesis.

The first remark has to do with the concept of geneticization; a term whose coinage dates back to the 1990s and since then has been used by different researchers to express concerns about the essentializing effects of genetics and its technologies on different aspects of life, including fundamental concepts in our life like paternity and genealogy (Arribas-Ayllon, 2016; Marks, 2002; Nash, 2004). Ṣāliḥ's overall framing of DNA paternity, as explained above, reflects a strong inclination towards the geneticization of lineage (*nasab*). The fascination with the novelty of DNA paternity, its semi-conclusive evidence, and its potential to resolve many classical controversies in *fiqh*, led Ṣāliḥ and likeminded contemporary jurists to lean towards reducing *nasab* to the biological contribution of man's sperm and woman's egg (Ṣāliḥ, 2020, pp. 18–21, 28–63, 246). Besides the concerns raised by secular ethicists about the geneticization of complex and central concepts in shaping people's moral worlds like kinship and family (Copeland, 2020; Marks, 2002), we briefly highlight two possible critiques from within the Islamic tradition.

One critique is related to the consensually recognized non-genetic form of kinship, namely milk-kinship. By breastfeeding a child who is two-years or younger, under specific conditions, the breastfeeding woman becomes the nursling's surrogate mother, and her husband becomes the surrogate father. This type of *nasab* also prohibits marriage among "milk-relatives" in the same way that genetic/blood relationships do not permit marriage between such relatives (Giladi, 1999, pp. 68–114). Strikingly enough, Ṣāliḥ sees the concept of milk kinship as supportive evidence for his perspective, rather than a challenge to it. According to him, an analogy can be drawn between genetic kinship and milk kinship because early Muslim jurists held that both types are premised on the abovementioned concept of *ba'diyya*, literally part-ness or portion-ness. In the case of milk kinship, the wet nurse's milk provides nutrition for the nursling and in the case of genetic kinship, the woman provides the egg (Ṣāliḥ, 2020, p. 47). However, this comparison is open to another, possibly more reasonable, reading holding that the classical term of *ba'diyya* cannot be reduced to the modern concept of genetic kinship. According to early jurists, a woman's contribution to the makeup of a child, whether by providing an egg that carries genetic components or breastfeeding milk that does not, is acknowledged as a "*ba'd* (part)" that serves as the foundation for a religiously-recognized kinship. This perspective, which does not differentiate between the genetic and non-genetic component (*ba'd*), contradicts the geneticization thesis.

Another critique for the geneticization of *nasab* lies in the overwhelmingly "innocent" approach to genetics, considering it a neutral tool that would help contemporary Muslim jurists resolve all the complex dilemmas that their predecessors could not. However, genetics does not only *provide* information about how humans are biogenetically related to each other, but it can also *re-shape* or even *manipulate* the genetic components that create kinship. So, while it may resolve previous dilemmas, genetics also introduces new ones in which establishing paternity will no longer be straightforward, even within the geneticized approach. For instance, the



female genetic contribution that entitles a woman to motherhood, as per the geneticized approach, can be fragmented through technologies like mitochondrial transfer, involving genetic material from more than one woman. Possible (future) applications of advanced technologies, like human genome editing, may be able to do the same with male genetic contribution. Some advancements may also make human reproduction possible without the direct contribution of female egg and male sperm (Craven et al., 2018; Serour, 2022).

In his book, Ṣāliḥ did not pay attention to such complications and challenges and how they would affect his perspective on paternity. In a section entitled “Modern Reproductive Means (*wasāil al-injāb al-mustajadda*)”, he only discussed in vitro fertilization (IVF), surrogacy and cloning. Regarding cloning, he found it challenging for his perspective of the geneticized *nasab*, saying that he is still unsure about how to determine the paternity of the cloned child. One option he considered was that the man who provided the DNA can be considered the child’s father, with no genetic mother because no woman provided an egg. The surrogate mother would then be considered a foster- or milk-mother. Alternatively, he suggested considering the DNA donor as the cloned child’s twin brother, because they both originated from the gametes of the genetic parents of the DNA donor. While admitting uncertainty in choosing between these options, he speculated that perhaps divine intervention would prevent successful human cloning, sparing men from the need to resolve this dilemma (Ṣāliḥ, 2020, p. 248).

In all cases, with such a geneticized approach the thick and multi-layered religio-ethical concept of *nasab*, intricately tied to the institution of marriage and related notions like wedlock (*firāsh*), would hardly play any role in the juristic reasoning about paternity. At the very least, one can safely say that this way of geneticizing *nasab* and disconnecting it from marriage does not align with the prevailing position adopted by the majority of individual Muslim jurists and transnational Islamic institutions, which discuss bioethical issues by engaging both religious scholars and biomedical scientists (IIFA, 2020, pp. 661–662; Jundī and ‘Awaḍī, 2005, pp. 461–465; Ka‘bī, 2006, pp. 369–381; Quradāghī & Muḥammadī, 2008, pp. 337–369; Ṣāliḥ, 2020, pp. 17–18). Therefore, building upon this geneticized framing of paternity to argue that it is a religious obligation to disclose nonpaternity IFs is, at best, problematic and does not align with the prevailing perspective of how the majority of Muslim jurists conceptualize the relationship between genetics and lineage.

An additional critical remark can be framed within the context of “*fiqh*-abstracted-from-ethics” approach, which permeates Ṣāliḥ’s book and dominates his reasoning for the “Obligatory Disclosure” position. He adopted a predominantly legalistic approach, with a clear focus on the technical aspects of construing a juristic ruling (*ḥukm fiqhī*). In Ṣāliḥ’s reasoning, the ruling on its own should guide one’s behavior even if its consequences may give rise to certain ethical concerns. For instance, in asserting that the disclosure of nonpaternity IFs to the assumed father is a religious obligation, Ṣāliḥ posits that the primary benefit is to prevent mixing lineage (*khalt al-nasab*) so that children will not be misattributed to mistakenly assumed fathers. Consequently, he contends that the moral risks associated with destabilizing family, violating the woman’s privacy and causing her disgrace do not outweigh the religious

obligation of disclosing the nonpaternity IFs to the assumed father. Regarding the aforementioned value of *satr* or the concealment of people's moral failures and sins, Şāliḥ holds that honoring this value does not apply to the case under discussion. Remaining silent about a woman's moral transgression of adultery, he explained, would result in neglecting the rights of her husband, e.g., knowing that he was betrayed and that an unrelated child has been falsely attributed to him (Şāliḥ, 2020, p. 264, p. 265).

Such an excessively legalistic approach, which does not afford due consideration to significant values like *satr*, does not accurately reflect the tolerant and nuanced positions adopted by many early Muslim jurists. The perspective expressed by the prominent Mālikī jurist al-Qarāfī (d. 1285), frequently cited by Şāliḥ, will serve as an illustrative example in this respect. Al-Qarāfī discussed the maximum duration of pregnancy, during which the child would be attributed to the woman's husband, assuming that she was impregnated by him. Classical medical knowledge available to jurists suggested that, in exceptional cases, pregnancy could extend for years. In response, Muslim jurists, including al-Qarāfī, accepted the possibility of an extended pregnancy, up to two years or even more according to some opinions.<sup>18</sup> The question arises: Why would jurists accept the idea of such an extended pregnancy although its likelihood is much lower than that of a woman's adultery? In response, al-Qarāfī provided a profound ethical explanation. He explained that preference was given to the low probability of the rare case (i.e., extended pregnancy within marriage) than to the high probability of the common case (pregnancy resulting from a woman's adulterous relationship) because of ethical considerations. These considerations include God's kindness (*lutf*) towards His servants, concealment (*satr*) of their defects, and the establishment of barriers preventing adultery from being legally proven. Unlike other offences, al-Qarāfī concluded, we have been commanded to exert the utmost effort in concealing the identity of the adulterous persons, not to bear unsolicited testimony related to adultery, and to decline bearing such testimony if we are solicited to (Qarāfī, n.d., vol. 3, p. 203).

Al-Qarāfī's aforementioned reasoning is pertinent to the nonpaternity IFs because a woman's adultery in this context also remains a matter of likelihood. The conclusive evidence of DNA paternity only relates to determining the genetic relatedness between the child and the woman's husband. On multiple occasions, Şāliḥ himself conceded this fact and introduced possible scenarios, where a woman could be impregnated by someone other than her husband without engaging in adulterous relation, such as cases of rape or sexual intercourse while intoxicated or unconscious (Şāliḥ, 2020, p. 171, 261, 266, 279). However, Şāliḥ's argumentation for the

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<sup>18</sup> It should be noted that the notion of extended (multi-year) pregnancy has been universally rejected by contemporary medical experts, emphasizing that such prolonged pregnancies, even if they were to occur, would not result in a viable child. From the early twentieth century onward, discussions between Muslim jurists and biomedical scientists have explored how these developments can be incorporated into Islamic jurisprudence. The prevailing consensus among individual jurists and translational institutions is that the maximum conceivable duration of pregnancy should be forty-seven weeks or three hundred and thirty days, allowing for rare and abnormal cases. For further details, refer to Ghaly (2015, pp. 289–296).

“Obligatory-Disclosure” position is replete with references to a woman’s adulterous relations that result in a child genetically unrelated to her husband (Şālih, 2020, pp. 257–282). In some instances, he also alluded to the argument that the woman should have been aware that her husband is not the biological father of her child and, thus, she has deliberately hidden this fact from her husband (Şālih, 2020, p. 272).

The third critical remark builds upon the second, which showed the marginal attention paid to related ethical aspects in Şālih’s reasoning. In fact, this remark relates more to researchers interested in Islamic bioethics than to Şālih’s specific work. Many works authored by specialists in *fiqh* and *uṣūl* tend to approach bioethical questions through the exclusive lens of their own specialization. This approach should be named “medical jurisprudence (*al-fiqh al-ṭibbī*)” to differentiate it from the bioethical discourse, which should have a strong interdisciplinary character. Thus, bioethics researchers should be aware that consulting these works, although indispensable for Islamic bioethical reasoning, cannot be the sole type of sources and that other relevant disciplines should also be involved. An increasing number of publications have already been examining the broader question of how *fiqh* and bioethics should relate to each other, arguing that the *fiqhī* approach alone is insufficient to address the complexity of many bioethical issues (Ghaly, 2022, p. 13; Khaṭīb, 2019; Sachedina, 2008a, pp. 25–31, 2009, pp. 3–23; Sartell & Padela, 2015, p. 756).

However, as discussed in the previous section on the “Prohibited Disclosure” position, this stance poses significant challenges from a medical ethics perspective. It conflicts with the professional obligation to adhere to the principle of confidentiality. According to this principle, healthcare professionals are ethically bound to respect their patients’ privacy, unless exceptional circumstances dictate otherwise. Within this medical ethical framework, the circumstances where patients’ confidential information can be disclosed are much more restricted compared to Şālih’s approach. As elucidated earlier, the former framework is endorsed by both Islamic codes of medical ethics and codified laws in many Muslim-majority countries.

Upon examining the list of references in Şālih’s book, the predominance of the *fiqhī* approach is evident. Even when examining issues with direct relevance to the field of ethics, like the value of *ṣatr*, he continued consulting juristic sources exclusively. Works that addressed these issues through the lens of ethical or religious etiquettes (*ādāb Shar‘iyya*) were not consulted (Kharā‘iṭī, 1986, pp. 97–103; Ibn Muflīḥ, n.d., vol. 1, pp. 234–235). Additionally, what is missing in Şālih’s reasoning is engagement with the field of healthcare and medical professional ethics. In his first argument explained above, related to “denouncing wrong”, Şālih stressed that the medical specialist who discovered the non-paternity IFs is as religiously responsible (*mukallaf*) as other stakeholders, including the woman and her husband. Therefore, the specialist, upon learning of something wrong or evil (*munkar*), such as misattributed paternity or adultery, is under a religious obligation to denounce it and to speak the truth. In other words, the clinician’s primary religious commitment mandates adopting a proactive stance by denouncing patient’s evils unless there are exceptional circumstances to judge otherwise. However, as explained in the previous section on the “Prohibited Disclosure” position, this stance poses significant challenges from the medical ethics perspective. It clashes with the professional

obligation to adhere to the principle of confidentiality. According to this principle, the ethical commitment of healthcare professionals will be conversed, compared to Ṣāliḥ's approach. Within this medical ethical framework, healthcare professionals are under obligation to respect their patients' privacy unless exceptional circumstances dictate otherwise. Therefore, the list of cases where patients' confidential information can be revealed will be much shorter than within Ṣāliḥ's framework. As explained in the previous section, the former framework is endorsed by both Islamic codes of medical ethics and codified laws in many Muslim-majority countries.

Ṣāliḥ acknowledges that existing codified laws generally prohibit the disclosure of nonpaternity IF. While he holds that such laws are incompatible with Sharia, he suggests that the clinician would be exempted from the religious obligation to disclose nonpaternity IF, if these laws would impose disciplinary measures such as heavy fines, imprisonment, or dismissal from work. Another acceptable exception for Ṣāliḥ is when the clinician fears that disclosing these IFs would lead to the woman being killed or severely harmed by her husband or her own family, with no one to protect her. If this was the case, he explained, disclosing these IFs would be prohibited because the evil of unlawful murder outweighs that of misattributed paternity (Ṣāliḥ, 2020, p. 260). An M.A. thesis supervised by Ṣāliḥ and defended at Qatar University in 2017, confirmed these concerns about woman's safety, speaking about conservative societies that still harshly deal with such sensitive issues, although the severity of this reaction may have decreased by time (Ḥājjī, 2017, p. 164). With these two barriers in place, namely existing laws that do not permit the disclosure of nonpaternity IFs and the potential risks to the woman's life or safety if they are disclosed, Ṣāliḥ's "Obligatory Disclosure" position, in his own perspective, remains unapplicable for the time being. If these two barriers were ever lifted, several unanswered questions would still need consideration to enhance the consistency and coherence of this position. For instance, would the disclosure of the nonpaternity IFs entitle the assumed father to claim reimbursement for the financial and emotional cost of raising an unrelated child, as well as for the psychological harm resulting from paternity fraud, etc.?<sup>19</sup> Besides the nonpaternity IFs, which other evils or wrong acts (*munkarāt*) would healthcare professionals be under obligation to disclose, to whom, and under what conditions?

### (C) Recommended

The key features of the IFs whose disclosure would fall within the category of "recommended" acts can be outlined at the hand of the following thesis: Unless it was agreed otherwise, it is recommended to share information with adult and religiously accountable (*mukallaf*) individuals whose genes/genomes were sequenced about the IFs that help them prevent or treat diseases or improve one's overall health. The main lines of reasoning in defense of this thesis and related cases will be detailed under

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<sup>19</sup> This question was examined in secular bioethical discourse (e.g., Draper, 2007; Efut & Chiagoziem, 2021), but I am unaware of studies that addressed it from an Islamic perspective.

two sub-headings, namely “Theoretical framing: Seeking medical treatment (*tadāwī*) and providing medical care (*taṭbīb*)” and “Applied Example: ACMG List”.

### ***C-1 Theoretical Framing: Seeking Medical Treatment (tadāwī) and Providing Medical Care (taṭbīb)***

Beyond the above-explained lifesaving situations, the dominant majority of both early and contemporary jurists opine that seeking medical treatment (*tadāwī*) is in principle permissible (Group of Scholars, 1983–2006, vol. 11, pp. 115–124; Ibn Muflīḥ, n.d., vol. 2, p. 349; IIFA, 2020, pp. 210–213; Quradāghī & Muḥammadī, 2008, pp. 187–202). Additionally, many early and contemporary Muslim jurists hold that the act of medical treatment (*tadāwī*) will be recommended when the expected medical benefit would fall within the scope of “overwhelming probability (*ghalabat al-zann*)” (Ḥārithī, 2009, pp. 334–336; Ghazālī, n.d., vol. 4, p. 265, 283; Nawawī, 1972, vol. 14, p. 191). This concept represents a middle ground between the category of doubt (*shakk*) and that of certainty (*yaqīn*) (Abū Ya‘lā, 1990, vol. 1, p. 135; Fā‘ūrī, 2019, pp. 217–218; IIFA, 2022, p. 211; Jaṣṣās, 1994, vol. 1, 2, p. 214, 320; Sam‘ānī, 1999, vol. 1, p. 23). The juristic ruling pertains here to the patient, enabling them to make autonomous decisions about their body and health conditions, as elucidated in the previous section on “Obligatory”.

Another crucial concept, which is particularly relevant to the act of disclosing IFs, is the provision of medical care (*taṭbīb*). Unfortunately, various authors have not consistently captured the morally relevant nuances between the two terms of *tadāwī* and *taṭbīb*, often using them interchangeably, or employing the latter term to mean learning the profession of medicine itself. In this context, many argued that learning the medical profession is a collective obligation (*farḍ kifāya*) (e.g., Quradāghī & Muḥammadī, 2008, pp. 103–104). For those who interpret the term *taṭbīb* as the routine practice of medicine, it is deemed fundamentally permissible. However, it is elevated to the rank of recommended acts, if the practicing physician intends to emulate the Prophetic role model by being beneficial to other Muslims, as instructed in the Prophetic tradition “Whoever among you is in a position to benefit his brother, he should do so.” *Taṭbīb* becomes obligatory, scholars explain, when the practicing physician is the sole individual capable of assisting the patient, such as in certain emergency cases, or when committed by the force of a contractual obligation (Group of Scholars, 1983–2006, pp. 12–135).

Disclosing the IFs that would fall within the scope of the above-sketched thesis, with the aim of enabling individuals to take good care of their health, is a beneficial act whose nobility is particularly valued because the prospective beneficiary did not ask for and did not know about them. Whether the receiver of these IFs eventually decides to use them or not, disclosing the IFs remains a praiseworthy act in itself. As disclosing the IFs does not automatically involve an intervention in the patient’s body, the absence of consent beforehand should not impede classifying this act as

recommended. The possible harm that the patient may feel distressed or concerned about one's health condition is overruled by the expected benefit. As articulated in the thesis above, shared information should be "actionable", in the sense that the patient will be able to use this information to improve his/her health. That is why the disclosure of these IFs should be part of a broader package of actions, including not only the availability of clinical follow-up but also religio-culturally sensitive genetic counseling services. On the other hand, the basic ruling of judging the disclosure of these IFs as "recommended" would move to the category of "reprehensible" or even "prohibited" if specific contextual factors change. For instance, if the respective individual expressly asserts their "right not to know" during informed consent process, expressing their unwillingness to receive this type of IFs. Conversely, if the research or healthcare institution or the authorized national governmental body mandate the disclosure of IFs related to specific diseases, affiliated healthcare professionals should abide by these professional regulations.

### ***C-2 Applied Example: ACMG List***

The chosen applied example of the IFs whose disclosure fits within this category is the widely accepted "minimum gene list" developed by the American College of Medical Genetics (ACMG), below the ACMG list or minimum list. Initial efforts to develop this list date back to 2011 when the ACMG established a "Working Group on Incidental Findings in Clinical Exome and Genome Sequencing (below, Working Group)" and assigned its members the task of making recommendations on the responsible management of IFs when patients undergo exome or genome sequencing (Green et al., 2013, pp. 565–566). Since then, ACMG has been updating, revising and refining this list, with the help of "Secondary Findings Maintenance Working Group (SFWG)" that the ACMG created in 2014. The current ACMG practice involves annual updates to the gene list, published every January, and a general policy statement every 3–4 years (Kalia et al., 2017; Miller et al., 2021, 2021a, 2022). We argue that disclosing the IFs included in the ACMG list falls in principle within the category of recommended acts. The rationale of this position is premised on two main aspects.

The first aspect has to do with the meticulous way through which the ACMG list is compiled, the follow-up processes of verification and revision, and the serious health risk that can be prevented or significantly reduced. The members of the Working Group were appointed and approved by the ACMG Board. Different drafts of their proposed principles and plans underwent extensive reviews and revisions at multiple stages, involving different experts. This included evaluation during the ACMG Annual Meeting, feedback from ACMG members, review by the ACMG Board, a subsequent review by fifteen external reviewers, and then final approval by the ACMG Board. Additionally, members of the aforementioned SFWG have diverse and interdisciplinary specializations, including biochemical, molecular, and/

or cytogenetics clinical laboratory directors, clinical geneticists of differing specialties, genetic counselors, cardiologists, medical geneticists, pharmacogenomics experts, patient advocates, bioinformaticians, bioethicists, and specialists in genetic disorders in diverse populations (Miller et al., 2021, p. 1382, 2022, pp. 1407–1408). Throughout these different processes, the minimum list is developed and further refined on the basis of consistent criteria, including the severity of the health threat and likelihood of it materializing, the efficacy of available interventions and their acceptability based on risks and benefits, and the overall knowledge base about the gene or condition. Regarding the health risk that can be prevented or reduced, most of the conditions on the ACMG list are associated with serious diseases, especially heart disease and cancer, which are among the leading causes of mortality (Miller et al., 2021; Wilfond et al., 2022, p. 87).

The other aspect relates to the potential medical benefit associated with the use of the ACMG list. Available data and analyses presented in the ACMG publications, along with findings from external academic research, demonstrate that the medical benefit expected from disclosing the IFs related to the minimum list remains within the realm of probability and likelihood. It is true that the ACMG is continuously refining its processes for developing and revising and updating the minimum list, especially responding to critical remarks pertaining to scientific and ethical aspects (e.g., Allyse & Michie, 2013; Burke et al., 2013; Hofmann, 2016; Holtzman, 2013; Korf, 2013; Townsend et al., 2013;). However, it is acknowledged that the list does not yield fixed results or conclusive findings, to the extent that genes can be, and some have already been, removed or added over time, depending on updated information and feedback from the scientific community. In this regard, it is also stressed that reporting IFs related to the ACMG list should be transparent about existing limitations so that the disclosure of IFs will not be misrepresented or misinterpreted as an exhaustive evaluation of all variations within the genes on this list (Green et al., 2013, p. 572).

Another challenge in developing and verifying the ACMG list is the potential bias in research, with some genes or variants being predominantly studied in European-dominant cohorts, thus lacking evidence from diverse patient populations. This raises concerns about the generalizability of findings to other ethnicities. Recent updates in the minimum list show that the SFWG has been paying attention to this challenge. The addition of the aforementioned TTR gene in the ACMG list of v. 3.1, although it was rejected in v. 3.0, is a good example in this regard. The most pathogenic variant in TTR worldwide has a particularly high frequency in individuals with West African ancestry and is a common cause of heart failure in persons of African descent. Through this shift, the SFWG wanted to avoid penalizing “genes associated with conditions that disproportionately affect 1 or more minoritized group if they are rare or have lower penetrance in the US population as a whole” (Miller et al. 2022, 1408). Geneticists working in the Muslim world, actively engaged in these discussions (e.g., Abouelhoda et al., 2016),<sup>20</sup> have confirmed the relevance of ACMG

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<sup>20</sup> I hereby would like to submit special thanks to the medical geneticist Fowzan Alkuraya (Chairman, Translational Genomics, Center for Genomic Medicine, King Faisal Specialist Hospital

list and the likelihood of its medical benefit across all populations, including Muslim communities with non-European descent. The same position is also shared by the authors of different publications that have examined available whole genome and exome datasets from the Gulf region to identify medically actionable variants in the ACMG list (e.g. Elfatih et al., 2021, 2021a; Jain et al., 2018).

By aligning these two aspects of the ACMG list with the theoretical discussions on the two concepts of *tadāwī* and *taṭbīb*, we conclude that the medical benefit accruing from disclosing the IFs of the minimum list fits within the scope of the above-mentioned “overwhelming probability (*ghalabat al-zann*)”. Thus, the disclosure of these IFs falls, in principle, within the category of “recommended” acts. As explained in the previous section, this basic ruling would change if morally significant characteristics of these IFs or the context of their disclosure differed.

As per the ACMG guidelines, the minimum list applies to the clinical setting (Green et al., 2013, p. 569; Miller et al., 2021a, p. 1393). This limitation in scope is in alignment with the scope of *tadāwī* and *taṭbīb*, as outlined in the previous section. Some of the differences between the clinical and research contexts do morally matter, such as the lack of patient-physician relationship between the researcher and participant and the lack of resources (financial, appropriate counseling skills, and time) for appropriate clinical follow-up in the research setting. Considering such differences, we argue, it will be unjustified to hold that it is equally recommended to disclose the IFs of the ACMG list in the research context.

As per our thesis above, what is recommended is the *disclosure* of these IFs. Besides that, the ACMG also recommends *actively searching* for them (Green et al., 2013, p. 567). We argue that the two acts (viz., disclosing the IFs and actively searching for them) cannot be judged as equally recommended. Active searching for a continuously increasing list of genes—currently 73 in total, as per the ACMG minimum list v. 3 (Miller et al., 2021, p. 1382)—would place extra, and sometimes even disproportional, burden on laboratories working in many Muslim countries to the extent that it may eventually divert them from their mandatory and primary tasks.

In addition to the straightforward option of responding to these different characteristics and contextual changes by classifying related acts within different categories, we can also draw upon the perspective held by various early and contemporary jurists, holding that the broad category of “recommended” can be further divided into sub-categories (Ghandal, 2020, pp. 193–195; Ibn al-Najjār, 1997, vol. 1, pp. 404–405; Ibn Daqīq al-‘Īd, 2009, vol. 3, p. 38; Khamrī, 2015, pp. 211–221; Māzarī, n. d., p. 241; Raysūnī, 2022, pp. 123–127 I; ‘Umayrī, 2005, pp. 137–141). Thus, disclosing these IFs in a research context can be judged as “less recommended”, or classified in a lower sub-category, than the act of disclosing them in a clinical context that would be deemed as “more recommended”. The same distinction would also apply to the difference between disclosing and actively searching for these IFs.

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and Research Center) and the geneticist and molecular biologist Said Ismail (Director, Qatar Genome Programme).



## (D) Reprehensible

The main characteristics of the IFs whose disclosure fall under the category of “reprehensible” acts can be outlined at the hand of the following statement: Unless it was regulated otherwise by the force of binding laws or professional regulations, it would be reprehensible to disclose IFs related to misattributed distant lineage, especially tribal filiation, to an adult and religiously accountable individual (*mukallaf*), whose genes/genomes were sequenced.

To articulate a reasoned argument for this thesis and its corresponding instances, details will be presented in two distinct sections, namely “Theoretical Framing: Distant Lineage” and “Applied Example: Genetic Ancestry.”

### *D-1 Theoretical Framing: Distant Lineage*

In addition to the above-outlined significance of establishing paternity or “immediate lineage”, determining one’s distant lineage (*nasab ba ‘īd*), which stretches numerous generations back, also holds religio-cultural significance. Before the advent of Islam, Arabs regulated different aspects of their life, especially in the socio-political domain, based on the lines of tribe-based lineage. This lineage would largely determine not only one’s individual status but would also influence broader kinship and socio-political structures within society. Which tribe one belongs to and how tribes are related to each other were all essential factors in the determination of individual and collective realities, and ultimately organizing, periodizing and eventually shaping Arab history through an extensive family-tree framework. Within such framing of distant *nasab*, the degree of one’s nobility and aristocracy (*hasab*) was strongly tied to one’s genealogy, as individual status was contingent upon the noble deeds and exploits of ancestors (Khalidi, 1994, p. 5; Marlow, 2012; Ghazālī, 2021).

With the advent of Islam, the pre-Islamic significance of *nasab* and tribal pride got neither completely dismissed nor uncritically embraced. A distinction needs to be made between the cultural aspects of distant *nasab* and the empirical reality of Muslims on one hand, and related religious norms, on the other. These two dimensions sometimes ran parallel to each other, yet at other times, they diverged. The socio-cultural significance of *nasab* continued to play out in different aspects of life during the early history of Islam, notably during the Umayyad period (661–750). For instance, the state-administered payment of stipends (*‘aṭā’*), the allocation of residential quarters and lands, and other administrative exigencies made the identification of individuals through genealogical registers necessary. These developments, in combination with other factors, led to heightened interest in genealogy, and different works were compiled to write down, systematize and preserve the repertoire of Arab genealogies (Duri, 2014, p. 50; Khalidi, 1994, p. 5, pp. 49–61).

The role played by tribal filiation or tribe-based *nasab* evolved across different historical periods. So, Arab tribal aristocracy lost much of its socio-political prestige

and military influence during the early Abbasid period (750–861), due to different factors such as the expansion of the Islamic empire far beyond the Arabic peninsula, and the conversion of non-Arabs who assumed high-rank positions and made seminal contribution to Islamic scholarship. After various ups and downs, tribe-based *nasab* in the context of modern nation-state lost much of its socio-cultural significance in some Muslim-majority countries (Bakhsh, 2022). However, it has acquired new forms of significance in other countries, especially in the Gulf region. Besides its role in the formation of collective identity in these countries, tribal filiation determines one's socio-political status, marriageability, and eligibility to political positions. Additionally, it entitles individuals and groups to numerous benefits offered by these oil-rich economies (Al-Farsi, 2013; Al-Sharekh & Freer, 2022; Möller, 2022; Samin, 2015; Tok et al., 2016).

Concerning religious normativity, an excessive pursuit of *nasab* and exaggerated tribal pride can be classified as antithetical to the purport of different references in the Islamic scriptures, where it was emphatically stated that religious piety is the source of one's nobility and dignity in this life and salvation in the hereafter. In the context of this life, a Quranic verse clearly gives preference to religious piety, "O mankind! Surely, We created you from a male and a female, and made you into races and tribes so that you may know one another. In God's eyes, surely the most noble of you is the most pious among you. Allah is truly All-Knowing, All-Aware." (49:13). Regarding the hereafter, another Quranic verse underscores the dissolution of kinship ties on the Day of Resurrection, asserting "Then, when the Trumpet is blown, no ties of kinship (*ansāb*) between them exist on that Day, nor do they ask about one another" (23:10). This illustrates that all kinship ties and concerns related to them will vanish on the Day of Resurrection. Similar sentiments have been reiterated in different Prophetic traditions. Just as a representative example, the Prophet of Islam was asked "Who is the most noble among humans?" The Prophet replied by saying, "The most noble among them is the most pious" (Ibn Hajar, 1959, vol. 6, pp. 414–415).

Within such religiously informed framing, Islamic scholarship developed new forms of religion-based collective identities and "genealogies", as reflected in some historical genres. For instance, biographical works, known by the term of *ṭabaqāt* or *siyar*, introduced religious nobility as embodied in the exploits of the Prophet of Islam and His Companions, in addition to prominent Muslim religious scholars and pious figures. These figures were bonded to each other through non-biological means, e.g., religious scholarship, school of thought, etc. (e.g., Aṣḥabānī, 1974; Dhahabī, 2006; Ibn Sa'd, 1990; Shirāzī, 1970).

While Islamic normativity places religion-based collective identities above tribe-based genealogy, it does not render distant lineage culturally or religiously irrelevant. Available fatwas issued by contemporary jurists demonstrate notable interest among Muslim individuals and groups in questions about tribal filiation and distant lineage. The underlying reasons behind this seemingly growing interest are diverse. At times, it involves the social prestige associated with one's filiation to a certain tribe, especially those whose genealogy stretches back to the family of the Prophet of Islam, known by the honorific title of *Āl al-Bayt* or *al-Ashraf*. Such questions also touch upon the issue of marriageability and whether distant lineage would impact

one's competence (*kafā'a*) and eligibility to marry someone from a more prestigious tribe (Ibn Bāz et al., 1994, vol. 3, pp. 162–166; Islamweb, 2009). This issue can sometimes be intensely sensitive and controversial to the extent that involved parties would seek judiciary verdicts (Samin 2012). In other instances, questioners express concerns about the misuse of tribal filiation for political gains or feeling shameful to be associated with what one judges as a notorious tribe (Dār al-Iftā', 2012, 2019).

These different aspects underscore the enduring significance of distant lineage up to the modern time. Thus, contemporary Muslim jurists built upon the discussions of previous scholars on how distant lineage and tribal filiation should be regulated from an Islamic perspective. They reaffirmed the agreements of early Muslim jurists that it is categorically forbidden to fake or falsify one's distant lineage or tribal filiation. According to some jurists, both distant and immediate lineage do equally matter in this respect. The often-quoted Prophetic tradition to support this position reads "A person who, knowingly, claims to be filiated with someone other than one's real father commits an act of disbelief. And whoever claims filiation to a group (*qawm*) with whom he has no lineage, let him take his abode in Hell" (Ibn Ḥajar, 1959, vol. 6, p. 540).

Additionally, distant lineage or tribal filiation would be established and religiously recognized through one of the following means:

- Widespread knowledge (*istifāda*): When someone's distant filiation to a specific tribe or extended family is "widely known", it should be a sufficient ground to recognize that lineage. Muslim jurists, however, disagreed on the required minimum threshold through which *istifāda* can be established. Some held that the testimony of two upright witnesses should suffice, whereas others insisted on a more substantial number. The latter group stressed the confirmation should come from a significant group of people, ensuring that their collective affirmation reflects common knowledge within their community (Ibn Qudāma, 1968, vol. 10, p. 141; Shaddī, 2023, pp. 425–426).
- Acknowledgement (*iqrār*): When the chiefs of a certain tribe acknowledge the claim of filiation made by the leaders of another tribe, then lineage is to be established as long as this acknowledgement is not disputed by others and it does not contradict empirical reality, thus avoiding scenarios as a claim of lineage between an Arab and non-Arab tribe (Buhūṭī, n.d., vol. 6, p. 461; Shaddī, 2023, p. 427; Zuḥaylī, n.d., vol. 8, pp. 6122–6127).
- Clientage (*walā'*) and alliance (*ḥilf*): The two institutions of clientage or mutual loyalty (*walā'*) and alliance (*ḥilf*) were prevalent forms of relationships in Islamic history, which connected different groups and tribes and created thereby a particular type of kinship. Established through a contractual bond of mutual rights and obligations, these institutions fostered not only social solidarity but also created unique type of non-biological or non-genetic filiation. Consequently, individuals involved in these relationships became subject to some lineage-based juristic rulings. Clientage was linked to the practice of slavery, which is considered antithetical to the Islamic value system by the overwhelming majority of contemporary Muslim scholars. However, both early clientage and tribal alliance-based

connections are still recognized by contemporary Muslim jurists, as long as they do not negate, replace or overrule biological kinship (Islam QA, 2019; Shaddī, 2023, pp. 436–437).

- Documented proof (*bayyina*): Contemporary Muslim jurists and fatwa institutions held that documents, such as historical sources or family trees, when endorsed by trustworthy genealogists or judiciary authorities, can serve as a valid basis for establishing one's distant lineage (Shaddī, 2023, p. 426).

With the advent of advanced genetic and genomic technologies (e.g., genealogical DNA tests), questions were raised about the religious permissibility of utilizing these technologies to establish or negate distant lineage. In response, many fatwas held that these technologies should not be used for these purposes. The main argument used to defend this position is that these techniques do not furnish conclusive evidence about one's distant lineage. It is noteworthy that this argument has influenced some of the advocates of geneticized paternity, including the abovementioned Dr. Ayman Ṣāliḥ, who acknowledged the lack of definitiveness in the results produced by genealogical DNA tests (Ṣāliḥ, 2020, p. 135). If the International Islamic Fiqh Academy (IIFA) held that DNA paternity test whose results are (semi-)conclusive cannot be used for examining paternity, so goes the reasoning, then other technologies with much less reliable results should not be employed in cases related to distant lineage. Beyond these scientific considerations, blocking the means to potential misuse of these technologies concerning distant lineage and preferring the slippery slope logic (*sadd al-dharā'i'*) has also to do with broad socio-political concerns, e.g., the risk of generating discord and social unrest, casting doubts on long-established relationships and kinships that shape societal fabric, and eventually contributing to societal disintegration (Islamweb, 2009; Shaddī, 2023, p. 442). In addition to these non-binding religio-ethical perspectives, some countries such as Saudi Arabia have adopted stringent measures integrated into the binding legal and judiciary systems for those who want to employ any of the above genetic or non-genetic technologies to make changes in an existing distant lineage. According to these procedures, claims regarding tribal filiation shall not be entertained in the judiciary system without prior royal approval (Shaddī, 2023, pp. 442–446, 451–453).

## ***D-2 Applied Example: Genetic Ancestry***

Genetics and genomics have ushered in remarkable advances and technological tools, such as genetic ancestry tests (GAT), genealogical DNA tests, facilitating the identification of one's distant lineage and genealogical relationships. The increasing availability and affordability of these tools, coupled with skyrocketing public interest, have fueled the rapid expansion of genetic ancestry, also known as genetic genealogy. In simple terms, GAT and analogous tests typically scrutinize specific regions of an individual's DNA to identify genetic markers shared with other individuals, groups,

specific ethnicities or populations (Bolnick et al., 2007; Jorde & Bamshad, 2020; Mauro et al., 2022).

Genetic ancestry and related tests can in principle be used for a wide range of purposes, blurring the lines between what is sometimes labelled as “recreational”, “forensic” and “clinical” genetics, while introducing and revisiting concepts like “biological” or “genetic citizenship”. So, these tests can be used to satisfy one’s curiosity by uncovering their ancestral roots and connecting with long-lost relatives. However, databases developed for this “recreational” purpose are also leveraged by the emerging forensic genetic genealogy (FGG) to identify suspects or victims in criminal cases, now a burgeoning aspect of the field (Glynn, 2022; Kling et al., 2021). On the other hand, these databases can be used by immigration authorities for the exclusion or restriction of citizenship rights and families’ entitlement to the right of reunification (Heinemann & Lemke, 2014; Helén, 2014). Research institutes and pharmaceutical companies can tap into similar databases to develop profit-oriented research projects with the goal of producing new drugs (Garner & Kim, 2019, p. 1221; Philippidis, 2018).

Most of the secular bioethical deliberations predominantly focus on the domain of direct-to-consumer (DTC) testing, where involved parties actively seek ancestry-related information, thereby leaving minimal room for the incidence of IFs. These deliberations reflect heated controversies surrounding the use of population descriptors (e.g., race, ethnicity, ancestry, etc.) within the broader realms of science and medicine, with a specific focus on genetics. Researchers disagree on whether genetic ancestry information would deliver any health-related benefits and, if so, whether these potential benefits would outweigh the expected harms and risks. Some researchers argue that genetic ancestry can contribute to insights into health outcomes, contending that omitting awareness of race and ethnicity from health-care practices may exacerbate racial and ethnic disparities. Conversely, other voices express a wide range of concerns and warn against a recurrence of dark episodes in the history of genetics, stemming from malicious employment of racial categories. One of these concerns relates to genetic reductionism and essentialism, where racial disparities, despite the sometimes hazily defined racial categories, may be erroneously attributed to genetics rather than socially determined factors. Researchers from outside the field of genetics argue that these genetic tests remain poor proxy measures of race since they lack representation of the social, cultural, relational, and experiential norms that shape one’s identity. The probabilistic and inconclusive nature of many genetic ancestry estimates is another major concern. So, researchers often question the validity of different techniques, including the above-mentioned GATs, because they are heavily reliant on reference populations in the customer databases of respective companies or institutions. Other concerns have to do with the fear of violating one’s privacy, unauthorized access to, and commercial exploitation of, collected data and potential misuse by law enforcement agencies (Johfre et al., 2021; Jones & Roberts, 2020; Mauro et al., 2022).

The above-mentioned concern regarding the probabilistic and uncertain nature of the genetic ancestry estimates particularly applies to Arab and broader Middle Eastern populations. In this region, data serving as reliable references are either

underrepresented or entirely lacking (Al-Ali et al., 2018; Fakhro et al., 2016; Mbarek & Ismail, 2022; Mbarek et al., 2022; Saad et al., 2022; Thareja, 2021; Zhou et al., 2022). To capture the genetic diversity of populations living in the Gulf region, published studies have adopted various ancestry-based classifications and clustering models, which varied from one country to another, and would sometimes differ even within the same country (Alsmadi et al., 2013, 2014; Elliott et al., 2022; John et al., 2015; Mineta et al., 2021; Thareja et al., 2015).

For instance, some studies divided ethnic Qataris into three sub-populations, namely those with a mixture of Bedouin/Arab ancestry, Persian/South Asian ancestry and African ancestry (Fakhro et al., 2016; Hunter-Zinck et al., 2010; Rodriguez-Flores et al., 2014). Other studies identified six major ancestries in this population, namely General Arabs, Peninsular Arabs, Arabs of Western Eurasia and Persia, South Asian Arabs, African Arabs, and Admixed Arabs (Mbarek et al., 2022, p. 504; Razali et al., 2021). These studies show that the adopted clustering models and classifications are mainly developed for health-related and scientific research purposes to determine the varying levels of susceptibility to health risks (e.g., mendelian disorders, cancer, obesity, or asthma) and thereby trying to improve precision medicine in general (John et al., 2015; Rodriguez-Flores et al., 2014; Saad et al., 2022). Additionally, the race-based classification in these studies is neither clear-cut nor fixed. Reference to tribes in the Arabian Peninsula was usually cautiously formulated and tribal identity anonymized (e.g., Alsmadi et al., 2014; Hunter-Zinck et al., 2010; Mineta et al., 2021) to avoid ethical violations related to privacy and confidentiality and the potential of genetic stigmatization. By time, more and more data will likely be generated in the future, revealing possible links between one's tribal filiation and susceptibility to genetic disorders. This would result from different factors, e.g., the increasing volume of genetic and genomic research conducted in the Gulf region and the wide-scale practice of premarital genetic screening that most Gulf countries have made it mandatory by law (Ghaly et al., 2022, pp. 6–10, 17–22).

With the increasing volume of such sensitive genetic data, the likelihood of encountering ethically challenging situations and possible ethical violations would also increase. In June 2014, a study was published in *PLOS* examining a subgroup of Kuwaiti people with inferred Saudi Arabian tribe ancestry. In July 2014, a revised version of this study was re-published, accompanied by a note from the journal stating that this was “due to the publishing of an incorrect version of Fig. 3 and the release of confidential information,” without specifying the retracted confidential details (PLOS ONE Staff, 2014). In a paper submitted to a meeting held by the aforementioned International Islamic Fiqh Academy (IIFA), the Syrian and Saudi-based cardiologist Ḥassān Shamsī Pāshā also mentioned that some genetic research conducted in certain Arab countries and published in scientific medical journals did not adhere to the principle of respecting “tribal privacy”, when they discussed genetic information about specific tribes. Pāshā, without specifying the studies, noted that some of these studies contributed to stigmatizing certain tribes by disclosing the name of the tribe and place of residence in the context of genetic predisposition to specific diseases (Pāshā, 2017, p. 214, 257). These developments and the associated ethical challenges would likely increase the incidence of IFs related to distant lineage

and tribal filiation in the Gulf region. Thus, genetic researchers and clinicians must be cognizant of the pertinent ethical considerations.

By aligning genetic ancestry research with the religio-ethical framing of distant lineage (*nasab ba'īd*) and tribal affiliation in particular, we draw the following conclusions about the thesis outlined at the beginning of this section. Disclosure of IFs about distant lineage or tribal filiation to an adult and religiously accountable individual (*mukallaf*) whose genome was sequenced is, in principle, reprehensible, and thus should be discouraged. Although usually less significant than one's immediate lineage or paternity, distant lineage can sometimes have a serious impact on one's life in different societies in the Arab world, and may influence certain religious rulings. In this context, it does not fit neatly within the category of "recreational" genetics/genomics, as often portrayed in the Western literature on genetic ancestry. Therefore, the disclosure of allegedly misattributed tribal filiation could cause various harms to the concerned person. Besides potential psychological harm, it can also influence one's entitlement to certain social and political privileges.

Despite the often probabilistic and inconclusive nature of genetic ancestry estimates and resulting health-related information, tribal filiation in Arabic culture and Islamic normativity is not exclusively biological or genetic. As stated previously, it can be based on historical practices of patronage and alliances between tribes. The disclosure of these IFs, we argue in this study, would fall within the category of reprehensible acts, considering these morally significant aspects. However, we do not agree with the opinion holding that the disclosure of these IFs should be categorized as strictly prohibited, as is the case with nonpaternity IFs (Yāsīn, 2019, pp. 113–114). Religiously, morally, and often also culturally, immediate lineage (i.e., paternity) is not identical to distant lineage. Additionally, disclosing the IFs only to the respective person who can autonomously make decisions regarding them is not the same as disclosing them to someone else, potentially jeopardizing the reputation and, in some cases, even the life of the persons involved.

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## Afterword

Genetics and genomics have progressively become integral components of global scientific research and clinical applications. The sequencing of human genomes, along with genetic/genomic screenings and tests, is steadily shifting from the domain of innovative experiments to that of standard and routine practices in research and healthcare institutions worldwide. A crucial lesson drawn from the thriving field of genomics is that human bodies are inherently diverse. Thus, the move towards personalized and precision medicine necessitates proper understanding of every difference, no matter how minute, especially at the genotype level, because they would clinically matter.

The scientific domain of genomics has achieved global reach, and we contend that genomic ethics should follow suit. The global appeal of genomics stems from recognizing the diversity in genetic composition among individuals and communities and thereby emphasizing the need for tailored medical approaches. Similarly, we argue that genomic ethics must possess a global appeal by recognizing the diversity in people's moral thinking and value systems. It should facilitate informed dialogues among different ethical perspectives.

The Human Genome Project (HGP), launched in 1990 alongside its ethical arm, the Ethical, Legal, and Social Implications (ELSI) program, demonstrated the need to examine the profound questions and challenges sparked by the field of genomics. Nevertheless, the predominant secular bioethical discourse in Western academia has often overlooked religious perspectives, including Islamic ethical deliberations, which started during the 1990s. The apparent allure of genomics in the Muslim world, as a scientific enterprise, does not imply uncritical appropriation of secular bioethical perspectives. Within the context of incidental findings (IFs), this study has explored the construction of a comprehensive Islamic discourse on genomic ethics which is rooted in the religious tradition, while remaining open to dialogue with other religious and secular discourses. To achieve this, we first tried to explain how Islamic ethical reasoning is premised on scriptural evidence-based system interwoven with rational thinking, embodying a consistent logic accessible to specialists in other moral traditions. Additionally, we employed a classification scheme of human acts,



which is rooted in the Islamic tradition, yet its overall idea is also known in secular moral philosophy.

The theoretical-cum-practical framework, outlined in this study, serves as the foundation for understanding the ethical judgment of what should or should not be disclosed when encountering IFs. The likelihood of IFs and life-saving information fall under the category of obligatory disclosure. Prohibited disclosure pertains to instances of the so-called misattributed paternity, acknowledging that there is a disagreeing viewpoint suggesting that such IFs must be disclosed. Recommended disclosure pertains to IFs that help in seeking medical treatment and providing care, with the “minimum gene list” developed by the American College of Medical Genetics (ACMG) serving as a fitting applied example. Reprehensible disclosure addressed distant lineage and genetic ancestry, urging for cautious approach.

These judgments of what IFs should (not) be disclosed may eventually be similar to, or different from, secular or other religious perspectives. Possible agreements at the level of theoretical frameworks delivers no guarantee for similar agreements at the practical level or vice versa, and thus continuous discussions at both levels remain indispensable. This study has aimed to bridge the gap in scholarship between secular bioethics and Islamic bioethics, laying the groundwork for further research and dialogue. By opening new avenues for engagement, both secular bioethics and Islamic bioethics can benefit from a mutually enriching exchange of ideas and perspectives. By perpetuating these discussions and exchange of ideas, we may not succeed in achieving unanimity on all fronts, but we will surely build solid ground for mutual informed understanding—the initial step toward a genuinely global bioethical discourse.

## Appendix A

# Ethical Judgments on Incidental Findings (IFs): A Systematic Overview

IFs	Judgment	Main arguments
The likelihood of incidental findings (IFs)	Obligatory	<ul style="list-style-type: none"> <li>• Upholding the dignity of humans, as individuals entrusted by God with authority over their bodies</li> <li>• The consent process for patients or research participants hinges on furnishing “sufficient information” and ensuring clarity, guaranteeing that consent is well-informed</li> <li>• Neglecting to apprise the potential recipient of the IFs stands in violation of the essential principles of informed consent, compromising the ethical foundation of the entire process</li> </ul>
Life-saving IFs • Example: Genetic predisposition to malignant hyperthermia (MH)	Obligatory	<ul style="list-style-type: none"> <li>• Upholding one of the higher objectives of Sharia, namely the preservation of life (<i>hifz al-nafs</i>), is a fundamental principle. Thus, this duty reflects a profound commitment to the sanctity of human life</li> <li>• The act of saving someone’s life is not merely commendable but a religious and moral obligation, particularly for those possessing the expertise to rescue someone in peril without endangering their own life. This underscores the importance of leveraging one’s skills to prevent harm and promote the well-being of others</li> </ul>

(continued)

(continued)

IFs	Judgment	Main arguments
<p>Disclosing misattributed paternity, by informing the father that his legally recognized child is genetically unrelated to him</p>	(A) Prohibited	<ul style="list-style-type: none"> <li>• Religiously recognized paternity extends beyond the narrow scope of genetic/ biological relatedness</li> <li>• The primary condition for establishing fatherhood is the marital bond or wedlock (<i>firāsh</i>) between the child’s biological parents</li> <li>• Islam recognizes non-genetic forms of kinship, such as milk kinship, which is premised on breastfeeding</li> <li>• Revealing paternity IFs inflicts various religious, moral, psychological, social, and financial harms on the mother, child, family, and society at large</li> <li>• These harms include breaching privacy and confidentiality, stigmatizing women and children, violating the social value of <i>star</i>, which involves concealing private moral shortcomings, thereby destabilizing established families, and fostering social unrest</li> </ul>
	(B) Obligatory	<ul style="list-style-type: none"> <li>• In Islam, genuine paternity traditionally hinged on biological/genetic ties but was historically established through the marital bond or wedlock (<i>firāsh</i>) due to a lack of reliable genetic tools in the pre-modern era</li> <li>• With the advent of DNA fingerprinting, the distinction between religiously recognized lineage and biological relatedness has become irrelevant</li> <li>• Misattributing a child by a woman to her husband, knowing he is not the biological father, is deemed an evil (<i>munkar</i>) deserving denouncement</li> <li>• Informing the assumed father of nonpaternity IFs helps him safeguard his religion, property, and honor, and protects him from being fooled by adopting a child whom he thinks is his own</li> <li>• Offering unsolicited testimony or advice (<i>naṣīḥa</i>) to help others avoid harm or gain benefit is a religious and moral obligation</li> </ul>

(continued)

(continued)

IFs	Judgment	Main arguments
Leveraging the minimum gene list developed by the American College of Medical Genetics (ACMG) to disclose information contributing to disease prevention, treatment, or overall health improvement	Recommended	<ul style="list-style-type: none"> <li>• Pursuing medical treatment (<i>tadāwī</i>) with efficacy reaching the level of “overwhelming probability” (<i>ghalabat al-zann</i>) is recommended</li> <li>• The ACMG list, compiled with rigorous verification and revision, effectively prevents health risks. However, it remains dynamic, allowing gene addition or removal based on updated information and scientific community feedback, addressing concerns of potential bias in research, particularly in European-dominant cohorts</li> <li>• This categorizes the medical benefit accruing from disclosing the ACMG minimum gene list as falling within the realm of “overwhelming probability.”</li> </ul>
Details about misattributed distant lineage, such as tribal filiation	Reprehensible	<ul style="list-style-type: none"> <li>• In Islam, distant lineage (<i>nasab ba'īd</i>), such as tribal affiliation, holds less significance than immediate lineage, namely paternity</li> <li>• In certain Muslim-majority societies, distant lineage shapes collective identities and can determine one’s socio-political status, marriageability, political eligibility, and access to benefits provided by oil-rich governments</li> <li>• Distant lineage is not exclusively premised on biological or genetic factors, allowing various means for its establishment</li> <li>• Modern tools like Genealogical DNA tests, applied to distant lineage, usually lack conclusive evidence, and could raise socio-political concerns such as social unrest and societal disintegration</li> <li>• Some researchers consider recognizing race and ethnicity in healthcare essential for understanding how genetic ancestry influences health outcomes and addressing disparities</li> </ul>

## Appendix B

# Islamic Ethics and Genomics: Drafting National Policy

This appendix presents the author's draft of a national policy document addressing the intersection of Islamic ethics and genomics. Commissioned by the Research Governance Department at the Qatar Ministry of Public Health (MoPH), this document is included in the study to underscore the importance of religious perspectives for the general public. It highlights how governmental authorities engage experts in religious ethics to formulate national policies that align with the moral values upheld by the public. It is crucial to note that this draft is currently under revision by the MoPH. The version to be subsequently published by the MoPH should be considered as representing the Ministry's official position, rather than this draft, which only reflects the author's personal perspective.

## Background

Biomedical advancements do not operate in a vacuum and they are always affected by, or are affecting, the surrounding cultural and moral landscape. Qatar is one of the leading countries in genomics in the Gulf region and throughout the Arab and Muslim world, with keen interest in collaboration with regional and international leading institutions. The MoPH contends that joining the genomic revolution is not only a scientific challenge but also a moral one. Thus, cutting-edge scientific research should be espoused with rigorous research that explores arising moral questions and challenges, with the aim of eventually producing religio-culturally sensitive regulations and codified laws.

Against this background, the Ministry of Public Health (MoPH), represented here by the Health Research Governance Department (HRGD), felt the need to develop a national policy document (below *Policy Document*) on genomics. It shall take into consideration both the Islamic moral tradition, which makes an integral part of the socio-cultural fabric of a country like Qatar, and related international deliberations.

To achieve this target, the HRGD commissioned the Doha-based Research Center for Islamic Legislation & Ethics (CILE) at Hamad Bin Khalifa University (HBKU),

represented here by the Research Unity of Islamic Bioethics under the supervision of Dr. Mohammed Ghaly, HBKU professor of Islam and Biomedical Ethics, to draft this *Policy Document*.

## Scope and Purpose

This document provides an analytical overview of how the religio-ethical deliberations within the Islamic tradition relate to the policymaking and regulatory aspects of conducting research in the field of genomics and its (possible) clinical applications. Besides its focus on Islamic ethical perspectives, this *Policy Document* will pay attention to, and whenever relevant will engage with, the broad international bioethical discourse and relevant national laws and regulations.

This document makes part of the MoPH commitment to facilitate genomic research and possible clinical applications, protect human subjects, and promote public trust in this promising field and awareness of its ethical questions and policy-making implications. One of the earlier examples in this regard is the interdisciplinary study published by the World Innovative Summit for Health (WISH) on the ethical management of IFs, which is listed below, in the section “References”.

This document is intended for guiding, facilitating and improving the work of a wide range of stakeholders, including research institutions, investigators, healthcare professionals, Institutional Review Boards (IRBs) members, institutional research ethics boards and healthcare policymakers.

## Related Documents

Whenever relevant and applicable, this *Policy Document* should be further interpreted and implemented in the light of previous documents produced by the MoPH, including the following:

- Guidance for the Design, Ethical Review, and Conduct of Genomic Research in Qatar.
- Guidance for the Use of Stored Data and Biological Specimens in Human Research.
- Guidelines for Gene Transfer Research in Humans.
- Guidelines for Research Involving Human Stem Cells.
- Policies, Regulations and Guidelines for Research Involving Human Subjects.

## References

This *Policy Document* is also premised on earlier research conducted on examining the interplay of genomics and Islamic ethics, especially those that focused on the

interdisciplinary deliberations, known as “collective *ijtihad*”, of both Muslim religious scholars and biomedical scientists. Many of these deliberations were facilitated by three prominent institutions, namely the Islamic Organization for Medical Sciences (IOMS) in Kuwait, the Islamic Fiqh Academy (IFA) in Mecca, and the International Islamic Fiqh Academy (IIFA) in Jeddah, Saudi Arabia. A wide range of publications were consulted, especially the following:

- El-Gendy, A. R. (Ed.). (2005). *The International Islamic Code for Medical and Health Ethics*. Islamic Organization for Medical Sciences.
- Ghaly, M. (Ed.). (2018). *Islamic ethics and the genome question*. Brill.
- Ghaly, M., Sadoun, E., Alkuraya, F., Fakhro, K., Ismail, S., & Ben-Omran, T. (2016). *Genomics in the Gulf region and Islamic ethics: Ethical management of incidental findings*. Worl Innovative Summit for Health (WISH).
- Rahim, H. F. A., Ismail, S. I., Hassan, A., Fadl, T., Khaled, S. M., Shockley, B., Nasrallah, C., Qutteina, Y., Elmaghraby, E., Yasin, H., Darwish, D., Fakhro, K. A., Badji, R., Al-Muftah, W., Afifi, N., & Althani, A. (2020). Willingness to participate in genome testing: a survey of public attitudes from Qatar. *Journal of human genetics*, 65(12), 1067–1073.

## Abbreviations

GINA	Genetic Information Nondiscrimination Act
HRGD	Health Research Governance Department
IFA	Islamic Fiqh Academy
IFs	Incidental Findings
IIFA	International Islamic Fiqh Academy
IOMS	Islamic Organization for Medical Sciences
IRB	Institutional Review Board
MoPH	Ministry of Public Health
QBB	Qatar Biobank
QGP	Qatar Genome Program
SESRI	Economic Survey Research Institute

## Religio-Ethical Framing

Shortly after the launch of the widely-celebrated Human Genome Project (HGP), especially during three decades between 1993 and 2013, both Muslim religious scholars and biomedical scientists engaged in intensive discussions on how genomics should be approached, and how expected benefits and harms should be evaluated, from an Islamic perspective. These questions were deliberated in more than fifteen interdisciplinary symposia and conferences. Throughout all these discussions,

frequent references were made to available updated scientific knowledge and to the international bioethical discourse on genomics.

### ***Collective Duty***

In a general sense, genomics has been portrayed in a positive light, representing a significant milestone in humanity's millennia-old quest for understanding ourselves, the universe we inhabit, and the God who created everything. Throughout history, humans could employ their God-gifted intellectual capacities to contemplate the universe. And unearth its various secrets, one after the other, to the extent that they could achieve such breakthroughs and revolutions as those facilitated by genomics. Such endeavors have been commended in more than one place in the Quran, e.g., "Say, 'Travel throughout the earth and see how He has originated the creation'. Then God will bring the next life into being. Surely, God has power over everything" (29:20) and "We will show them Our signs in the universe and within themselves until it becomes clear to them that this Quran is the truth" (41:53).

With this positive theological framing and the (potential/promised) benefits of the new field of genomics, there was a broad agreement that conducting genomic research is to be seen as something noble and compatible with Islamic moral normativity. Additionally, the mainstream position went further to argue that sequencing human genomes with the aim of identifying genetic diseases and people's susceptibility to these diseases should be seen as a collective duty (*fard kifāya*). Thus, Muslim countries should collaboratively work on putting it into practice.

Within the broad context of genetic engineering, it is also stressed that the potential of related technologies should not be misused to achieve unethical, evil or aggressive purposes. Moreover, breaking down the genetic barriers between different species with the intention of creating aliens composed of mixed-up genomes and similar hazardous explorations are all judged as unethical practices.

### ***Benefit-Harm Assessment***

Despite its promising and dominantly positive character, it is also recognized that genomics can entail serious risks and harms. Consequently, all possible means should be developed and employed to minimize or mitigate them. The balancing of possible benefits against expected harms proved to be a complex process. When it comes to the harms and risks related to the scientific aspects and their impact on the human body, Muslim religious scholars conceded that information provided by biomedical scientists is crucial in this regard. However, both concepts, viz., harms and benefits, should be seen through a broader lens than the narrow scope of physical or health-related aspects. They should encompass one's overall social and religious wellbeing. In order to safeguard their compatibility with the holistic Islamic value-system (Sharia) and



religious rulings, Muslim religious scholars stressed the significance of developing meticulous Sharia-based determinants or criteria (*Dawābiṭ Shar‘iyya*) through which one can judge the (un)ethical character of a wide range of practices within the field of genomics. Many of these determinants will be outlined in the detailed sections below.

Additionally, discussions on genomics and related fields like genetic engineering are usually inclined to make a morally significant distinction between “fundamental or basic research”, which is mainly theoretical in nature and usually intended to develop new theories or modify existing ones, and “applied research”, which is more practice-oriented and is intended to solve practical problems, develop technologies or cure diseases. Because Islam is understood as a religion that promotes knowledge and science, conducting fundamental or basic genomic research is in principle a good deed in itself and thus should be permitted, or even encouraged, as long as there is no compelling reason to judge it differently. However, translating the results of this fundamental research and adopting them in a clinical setting or other applied fields should always be preceded by a rigorous benefit-risk assessment, where the abovementioned Sharia-based determinants should be considered.

## Informed Consent

Any attempt to circumvent a proper informed consent process under the pretext of religious reservations in the name of Islam is doomed to failure. It is true that “informed consent”, as a technical term, is relatively new but the purport of this concept is well-rooted in the Islamic tradition, as demonstrated by modern interdisciplinary bioethical discussions. The influential *International Islamic Code for Medical and Health Ethics*, issued in 2004, illuminated a number of governing ethical principles. The first principle, “respect for persons”, was introduced as a firmly established fundament in Sharia, as dictated by the Quranic verse “And We have truly honored the Children of Adam” (17:70). This broad principle was translated by early Muslim scholars to mean man’s authority over his/her body and that no intervention in one’s body can be tolerated without his/her prior permission. This mainstream position was expressed in a number of Islamic legal maxims, including “Sharia is meant to safeguard the rights of humans”, “the right of a human-being cannot be disposed of or relinquished without his permission”, and “man’s rights cannot be nullified without his consent”.

By applying this principle within the context of biomedical research and clinical applications, this *Code* stressed that legally competent persons, with decisional capacities, are entitled to freely make the decisions that they deem suitable without any form of coercion, fraud or exploitation. Those whose legal capacity is incomplete, or missing, are in need of further protection to safeguard their best interests by assigning a legally authorized guardian to serve these interests. Having a

legal guardian does not negate the moral duty to attend to the opinions and preferences of individuals with diminished legal capacity, each to the extent of his/her comprehension skills and the nature of the planned research or medical intervention.

### ***Women's Consent***

The governing principle here is that obtaining informed consent from legally competent research participants and/or patients is an ethical requirement for both men and women. In alignment with international guidelines, the abovementioned *International Islamic Code for Medical and Health Ethics* argued that differentiating between men and women in this context will be unethical from an Islamic perspective, because of the discriminatory nature of such differentiation.

Due to its significance, we quote the following passage from the *Code*:

The participation of a woman in research is, the same as in the case of a man, contingent upon her voluntary and informed consent, which she gives after receiving all adequate information and proper understanding of what she is consenting to, and after she is provided of all specific data including those related to potential risks and consequences that she needs to know beforehand. Therefore, the research investigator must obtain the personal and voluntary consent of an adult female to participate in research. It is religiously speaking unacceptable for the permission of a husband or anyone else to replace that of an adult woman. Otherwise, that would be an affront to her human rights, because both men and women enjoy full legal competence. That is why individual's independence, being male or female, should be honored, and he/she should be empowered to take his/her personal choice and make the decision he/she deems suitable when it comes to participating in research. This should be done without any form of coercion, undue influence, deception, or exploitation, and after the person concerned receives the necessary information and comprehends it fully.

This *Policy Document* stresses the moral obligation of obtaining the consent of adult women in their capacity as research participants or patients, independent of anyone else including the husband or the father. Out of respect for marital ties and the family institution, it is recommended that the woman would consult with her husband, father or other family members that she trusts. This recommendation also goes for the husband or other male family members when they are about to take such decisions. The biographical records of the Prophet of Islam and his Companions show several examples of consultation with male and female members of one's family and Muslim community at large before taking important decisions in various contexts.

Only few exceptional cases would require obtaining the additional consent of one's spouse. For instance, if the expected risks of a planned genomic research or clinical intervention would have an impact on one's fertility or the spouses' sexual relationship, then the consent of both spouses will be necessary. This is because of the nature of the religio-moral obligations that the spouses are committed to as part of their consensual marital relationship. Additionally, when the list of expected risks would affect the health condition of an embryo/fetus, then the pregnant woman's consent should be supplemented with her husband's consent. As explained by the

abovementioned *Code*, this is because caring for the embryo/fetus is a joint obligation that both husband and wife, in their capacity as prospective parents, should abide by.

### ***Genomics and Consent***

Like other biomedical practices, the general principle is that whenever the data or bodily samples of humans are to be used for genomic research, or for clinical applications, informed consent should be obtained beforehand. The process of obtaining informed consent should be premised on providing the research participant or patient with sufficient and meaningful information regarding what he/she needs to know about the research or the medical intervention at hand. The process should further comply with applicable national laws, professional standards of practice and regulations endorsed by the MoPH, especially the above-enlisted documents in the section “Related Documents”.

Additionally, the particular context of genomics sometimes raises its own distinctive questions about how the informed consent process should be managed. For instance, it is possible that donated biospecimens for one research study may be needed for re-use in another study. In such cases, what type of consent will be required for re-using these specimens in other research studies, usually known as “secondary uses”, or secondary search”? In an earlier MoPH document, entitled “Guidance for the Design, Ethical Review, and Conduct of Genomic Research in Qatar”, a distinction was made between three types of consent:

- (1) Donated specimens and data, collected as part of clinical research, can be used for a specific type of research (e.g., diabetes), and the consent clearly states that that the donated material will not be used for any other forms of research.
- (2) Donated specimens and data, collected as part of clinical research, can be used without limitation for future research.
- (3) Donated specimens and data, collected as part of clinical research, can be used for a specific type of research (e.g., diabetes), but the consent does not explicitly state that the donated material will, or will not, be used for other forms of research.

The MoPH document commented further by stating that a proper consent form should either use the consent type no. (1) or (2), by including an explanation about whether the donated material will be shared through unrestricted- or controlled-access repositories. Whenever the language of the consent is vague, an independent review of the original informed consent language will be necessary to determine whether the donated may be shared for secondary research.

In addition to these helpful guidelines, this *Policy Document* further recommends providing precise information, as much as possible, in the consent form about future research plans, including the possibility of secondary research. This is because mutual agreements should be based on clarity and transparency to avoid possible conflicts in the future between the parties committed to the agreement. In the Islamic tradition,

uncertainty (*gharar*) should be avoided as much as possible, and its presence can even result in the invalidity of certain financial contracts. It is to be noted, however, that the consent form here does not fall into the category of financial contracts (*mu'awadāt*) but is rather considered a form of voluntary donations (*tabarru'āt*). In Islamic jurisprudence, the absence of uncertain elements (*gharar*) is strictly required in the former category but not in the latter. This is because the act of donation is premised on altruistic motivations and thus its charitable nature would minimize the likelihood of conflict between the donor and the receiver. This principle is couched in the Islamic legal maxim which states “Uncertainty, which is not tolerated in financial contracts, can be tolerated in donations”.

Against this background, consenting research participants or patients for possible re-use of their donated biospecimens or data can be broadly divided into three ranks (see Table B.1), as follows:

The *first* rank represents the morally superior option, because of the absence of uncertainty. This rank will include the consent forms, which provide a specific list of possible research studies, for which the donated material can be used. Whenever any of the enlisted research studies begins, there will be no need for re-consenting the research participants or patients. Also, consent forms that clearly indicate that the donated material will not be used for any other forms of research in the future are ethically sound. Both types of forms are morally superior because the involved parties have a clear idea of the terms of their agreement.

The *second* rank is the morally inferior option, which is in principle “inferior” because of the presence of a certain level of uncertainty but can still be tolerated.

**Table B.1** Ranks of consent for secondary research

Rank	Type(s) of consent	Action
Superior	Donated specimens and data will be used for a specific list of research studies in the future	Re-use of the donated specimens and data for the enlisted research studies is possible, with no need for re-consenting
	Donated specimens and data will not be used for any other forms of research in the future	Any re-use of the donated specimens and data will require re-consenting
Inferior	Donated specimens and data can be used for future research, without further specifications	<ul style="list-style-type: none"> <li>• Currently, this seems to be the only available option for national institutes like Qatar Biobank</li> <li>• For clinical research, this option can be used only when the morally superior option is not possible. Possible re-use of the donated material is to be judged, on a case-by-case basis, by an IRB or ethics committee</li> </ul>
Controversial	The consent form does not explicitly state whether the donated material will, or will not, be used for other forms of research in the future	This option should be avoided in the first instance and whenever it happens, an IRB or ethics committee should get involved

This will include a “broad consent”, where the consent form will clearly state that the donated material can be used for any future research, without giving a specific list of possible research studies. The absence of a specific list creates a certain level of uncertainty for the research participant or the patient and that is why it is in principle considered “morally inferior”, compared to the first rank. However, in the case of national institutes, like Qatar Biobank (QBB), the broad consent seems to be the only currently available option. Such institutions are mainly tasked with collecting the donated samples and getting them ready for future interested researchers, whose research plans can hardly be precisely predicted beforehand.

For the clinical research context, however, we recommend that this type of consent is used only when the type of consent explained in the first rank cannot be used, for reasons to be judged on a case-by-case basis by the respective Institutional Review Board (IRB) or an independent ethics committee. However, this level of uncertainty does not make the whole process unethical, because of the charitable and altruistic nature of this practice, as outlined above. Furthermore, the donor still has a broad or basic idea about what the donated material may be used for in the future, e.g., something related to genomics and/or genetics, which means that the level of uncertainty is still limited.

Finally, the *third* rank is the morally controversial option, because it entails a higher level of uncertainty than the second rank. This includes the type of consent in which the form does not explicitly state whether the donated material will, or will not, be used for other forms of research in the future. This *Policy Document* recommends that the IRBs or concerned ethics committees should reject this type of consent and ask for modifications to minimize or mitigate uncertainty. Again, we are not inclined to judge this type of consent as outspokenly unethical, because the whole consent process assumes a charitable character. The main problem here is that this type of consent does not show whether the research participants or patients are willing to donate their specimen or data beyond the specific research for which they were consented.

## Privacy and Confidentiality

The famous metaphor of “reading the book of life”, used to express sequencing a human genome, already shows how much knowledge we can get by employing advanced genomic technologies. The enormous scope of knowledge, which goes far beyond information about a specific disease or even one’s overall health condition, raises serious questions about how to balance between advancing scientific knowledge on one hand and protecting people’s privacy and confidentiality of their information on the other hand.

Respect for people’s privacy is a basic value in Islam, which naturally flows from the recognized principle of human dignity and the essentiality of gaining people’s trust. For the particular context of biomedical practices, the abovementioned International Islamic Fiqh Academy (IIFA), in its eighth session held in 1993, set forth

resolution no. 79 (10/8) which stressed the strict prohibition of revealing people's confidential information accessible by researchers or physicians as part of their professions. Any exceptions to this general rule, the resolution added, should be based on strong justifications, explicitly stated in the professional codes or policies adopted by official institutions and finally, they should be properly communicated to the concerned individuals.

The MoPH has repeatedly addressed issues related to privacy and confidentiality and various guidelines were outlined in the documents enlisted above in the section "Related Documents". In this respect, the document "Guidance for the Design, Ethical Review, and Conduct of Genomic Research in Qatar" particularly specified a number of protective measures, which varied between physical, technical and administrative procedures. We believe these measures and procedures provide practical and helpful tools for researchers to safeguard people's privacy. It seems, however, that it is almost impossible to guarantee full and permanent protection for people's genomic data. Ongoing advances in this growing field shows that data sets with reasonable protection and with no traditional identifiers could still be re-identified. Such developments show that measures employed for the protection of people's privacy and their data should undergo regular revisions, scrutiny and, whenever necessary, updates. Additionally, there should be transparency during the consent process about the risk of possible re-identification, whether it was a minimal risk or higher than that.

We hereby add that the strictness of the measures employed to protect people's privacy should be proportional to some key factors whose careful consideration can help researchers, IRBs and policymakers to efficiently balance between respecting privacy and advancing scientific knowledge. Three main factors need to be carefully considered, as follows:

- *Type of information:* Not all pieces of information are equally identifiable. Some information (e.g., full name combined with birth date and/or passport number) can directly result in identifying individuals. With other types of information (e.g., genetic condition combined with person's weight and/or certain habits like smoking), identifying individuals will be more difficult. Identifying people will be much more difficult when the identifiable information is coded or (ir)revocably anonymized. The general governing rule here is that the easier the type of information may lead to identification, the stricter the measures of protecting privacy should be, and vice versa.
- *Nature of the research:* Sometimes the value of advancing scientific knowledge can be properly achieved without the need to access identifiable information, as it is in the case of searching databases to get statistics about the pathogenic character of certain genetic variants. In such cases, there is no justification to make any concessions about protecting people's privacy and thus no access should be given to information about specific individuals. On the other hand, other research projects may necessitate accessing certain identifiable information in addition to the biospecimens, such as the person's age, weight, ethnic background, genetic history of family members, etc. In such cases, well-reasoned justifications should

be provided to show that the value of advancing scientific knowledge will be compromised without having access to such information.

- *Wishes of the research participant:* Contributing to the advancement of scientific knowledge is for some people so valuable to the extent that they would accept giving unrestricted public access to specific identifiable information. As long as access to this identifiable information will not affect other people who are not involved in the consent process (e.g., family members whose identity can be revealed), the need for strict privacy protective measures will be much less urgent. This should not be seen as circumventing or breaching the obligation of respecting people's privacy or overall dignity, because they are the ones who knowingly and voluntarily made this decision, out of moral considerations.

## Data Sharing

In principle, sharing genomic data makes part of the noble value of promoting knowledge and advancing science. The significance of this value has been reiterated in various traditions attributed to the Prophet of Islam and was the subject of distinct works in the Islamic scholarly tradition. In the "Guidance for the Design, Ethical Review, and Conduct of Genomic Research in Qatar", the MoPH adopted the position of encouraging data sharing between institutions and promoting greater access to data in a responsible, equitable, ethical and efficient manner. Besides its contribution to the advancement of knowledge and eventually developing better science by paving the way for translating genomic research into clinical applications, data sharing can also be cost-effective by facilitating regional or international partnerships for funding large-scale and multi-institutional projects.

On the other hand, due attention should be paid to the possible concerns that can be raised by data sharing, which may be scientific, financial or ethical in nature. For scientific aspects, data sharing may urge researchers to rush into quick publications, at the cost of engaging in much more time-consuming processes of rigorous analysis. This is because they want to make sure that they will not lag behind other researchers who have access to the data they work on. Moreover, open data sharing regimes may undermine the scientific capacity in low-income countries, because the research teams with more advanced resources will be in a better position to study the data coming from these countries. As for the financial aspects, prioritizing data sharing may make careers in generating new data less interesting for young researchers. Thus, dedicating more resources for data sharing may eventually come at the cost of funding projects and careers in generating new data or other new scientific ventures. Ethically speaking, the main concern will be about safeguarding the privacy of people whose data is being shared and the confidentiality of their information. That is why, whenever relevant, a distinction should be made between sharing data and sharing physical samples in the agreements between institutions. There are also valid concerns regarding the equitable distribution of burdens and benefits between those who contributed and collected the data and those who utilize the data

to generate various advantages. Fairness in allocating the responsibilities and rewards associated with data donation and collection remains an important consideration.

Against this background, the MoPH requires that data sharing initiatives between institutions should be based on transparent and fair terms of sharing and be in compliance with the regulations, policies, and guidelines approved by the MoPH, including the ones enlisted in the “Related Documents” section above.

## Incidental Findings

The aforementioned metaphor of “reading the book of life” used for sequencing human genomes is indicative of the massively wide scope of information that such technologies can generate. That is why sequencing human genomes in research or clinical contexts is likely to result in findings that go beyond the research plan or the original purpose of the clinical intervention. The technical term used for referring to such “unplanned” results is “Incidental Findings (IFs)”, whose ethical management is not straightforward. Thus, a one-size-fits-all approach does not work, because of their multidimensional and complex character.

A proper ethical management of the IFs starts with anticipation. Potential recipients of these findings, whether in a research or clinical context, should be informed that such findings may arise, whenever it is likely that the planned research or medical intervention will produce them. Without communicating the likelihood of IFs, consent obtained from these people cannot be called “informed”. Unless there are compelling reasons that dictate doing otherwise, the standard practice should honor the research participants’ autonomy by respecting both their right *to know* and their right *not to know* certain IFs. In its symposium held in 1998, which discussed genomics, the abovementioned IOMS stated that “Every person’s right to decide whether he wants to be told the findings or consequences of any genetic test should be respected.”

As for the question about which IFs should (not) be disclosed, we recommend classifying each finding into one of three categories, as per the following typology:

- (1) *Mandatory disclosure*: This category includes the findings whose disclosure will likely lead to actionable lifesaving procedures. This is because saving life in Islam is not an option but a moral obligation and thus all possible means leading to saving people’s lives should be taken. During the process of obtaining informed consent, it should be made clear that such findings will be disclosed to the research participant. This condition can also be included as part of the eligibility criteria for inclusion in the research project. In order to be able to implement this moral obligation, genomic research institutes and biobanks need to have policies and anticipatory planning schemes. For instance, they need to have plans for covering the disclosure-related costs, alternative plans to adjust the possible diversion of some research resources from the primary goals of the research, and to have collaboration schemes with clinical institutes and hospitals,



to which their research participants will be referred to in order to proceed with the life-saving interventions. One of the good examples in this regard is the collaboration between Qatar Biobank and Qatar Genome Program (QGP) as research institutes with the National Center for Cancer Care and Research at Hamad Medical Corporation. The purpose of the collaboration is to facilitate helping the research participants in the QGP, whose sequencing results showed susceptibility to breast cancer.

- (2) *Mandatory non-disclosure*: This category includes the IFs that should not be disclosed because their harm disproportionately outweighs expected benefits, if any. This position is justified by various Islamic legal maxims, which regulate the process of harm-benefit balancing, including “No harm and no counter harm”, “harmful items are in principle prohibited” “harm is to be eliminated”, “averting harms takes precedence over achieving benefits”, etc. The main example in this category is represented by the IFs related to (misattributed) paternity. At the international level, non-disclosure is the standard and mainstream practice for the IFs of misattributed parentage. This position is in alignment with the Islamic moral tradition for various reasons. To start with, paternity in the Islamic tradition is not an exclusively biological/genetic issue but it is mainly premised on the existence of a religiously valid marital contract between the couple, to whom the newborn will automatically be attributed as their son/daughter. Negating the paternity established by the default of marriage requires specific and strict judicial procedures, which have their basis in the Quran and Sunna. These procedures completely fall outside the scope and goals of genomic research. Additionally, misattributed paternity is not just a matter of religious normativity, but it also has considerable socio-cultural implications. Children born out of marital wedlock can lose (much of) their dignity in society and end up suffering serious stigmatization. This was also reflected in the modern legal systems of most Muslim-majority countries, where the institution of marriage is usually viewed as a condition for the children’s entitlement to many rights, including maintenance and inheritance.
- (3) *In-Between Cases*: The IFs which do not fall in either of the abovementioned two categories should be evaluated and judged on a case-by-case basis. The whole process of evaluation should be guided by the principle of serving the best interests of the research participants or patients through maximizing possible benefits and minimizing potential harms. Despite the inconsistencies in its proposed definition and scope, the widely used concept “clinical utility” has been instrumental for managing the process of harm-benefit assessment in the Western bioethical literature. In order to overcome the pitfalls of the narrow health-related understanding of clinical utility, institutions like the American College of Medical Genetics and Genomics (ACMG) and Medical Genome Initiative (MGI) have tried to broaden its scope by including non-clinical aspects such as psychosocial wellbeing and personal utility, e.g., mental preparedness, sense of security, marriage opportunities or marriageability, reproduction plans, career development, retirement, etc.

This *Policy Document* supports the broad understanding of clinical utility but further recommends a higher level of religious awareness. This means that the process of benefit-harm assessment, to decide which IFs will (not) be disclosed, should also consider religious dimensions, including spiritual wellbeing and the impact of one's actions on his/her salvation in the hereafter.

### ***Family Members***

Whenever it is concluded that it is morally acceptable to disclose certain IFs, the follow up question will be whether these findings can also be communicated to the research participants' family members. *The International Ethical Guidelines for Biomedical Research Involving Human Subjects*, issued by the Council for International Organizations of Medical Sciences (CIOMS), took a clear position in this regard by stating:

Investigators should not disclose results of diagnostic genetic tests to relatives of subjects without the subjects' consent. In places where immediate family relatives would usually expect to be informed of such results, the research protocol, as approved or cleared by the ethical review committee, should indicate the precautions in place to prevent such disclosure of results without the subjects' consent; such plans should be clearly explained during the process of obtaining informed consent.

This statement was incorporated in the abovementioned *International Islamic Code for Medical and Health Ethics* which did not elaborate on this position. Yet, the position adopted by the MoPH document "Guidance for the Design, Ethical Review, and Conduct of Genomic Research in Qatar" was not identical. The MoPH encouraged providing IFs not only to the research participants but also, where possible, to the affected known family members with similar genetic mutations. However, the document did not specify what is meant by "where possible".

Against this background, this *Policy Document* recommends that communication with the family members of the research participants should be guided by striking balance between the principle of beneficence, which dictates informing the family members who may be at risk so that they can take their precautions, and the principle of respect for the autonomy of the research participant or patient. This means that whenever it is possible, family members who are at risk should be approached without revealing the identity of the one whose susceptibility to a genetic disease was discovered. Both principles can also be honored when the research participant or patient gives a voluntary consent of informing his/her family members. Balancing between these two principles will be difficult when the participant or patient rejects informing his/her family members and informing them cannot be done without revealing his/her identity. By employing the criteria outlined in the abovementioned typology, we recommend that only the IFs that fall into the first category should be communicated to family members after taking all possible measures to protect the privacy of the research participant or the patient.

### ***Adult-Onset Only Conditions***

The abovementioned recommendations about (not) disclosing incidental finding to family members only apply to adult persons with full legal capacity. As outlined in the section on “Informed Consent”, the research participants or patients whose legal capacity is incomplete or missing are in need of protection by involving a legally authorized guardian, usually one’s parent or close family member. In such cases, the ethically justified and best practice will dictate informing the child’s parents or guardian about the IFs linked to childhood-onset diseases, for which intervention is possible during childhood. Having such information in hand will be necessary to make informed decisions with the aim of protecting the best interest (*maslaha*) of the child, which is part of the duty to care for these vulnerable people.

The ethical dilemma arises when the IFs would relate to adult-onset only conditions, for which preventive, curative or other medical interventions will not be available during childhood, but in adulthood. Out of respect for the child’s future autonomy and saving the family unnecessary concerns without having the ability to take any helpful measures before adulthood, we recommend the option of non-disclosure. After reaching adulthood, the disclosure of IFs will be subject to the criteria outlined in the abovementioned typology. However, this will not be the case when disclosing such IFs during childhood will be of benefit for the child’s family members, especially parents, who will be able to take protective measures against their own genetic risks. In this case, they can be approached and information can be disclosed to them; based on the criteria outlined in the abovementioned typology.

This position is justified by the moral significance of the family institution in general and the high esteem accorded to parents in the Islamic tradition, which is translated in a long list of obligations to take care of them. Additionally, Muslims are required to keep good ties with family members; an obligation which is rooted in the concept of *silat al-rahim* (literally, womb-ties), which means that kinship ties should be maintained and strengthen and should not be severed.

### **Premarital Genetic Testing**

One of the unique practices in some Middle Eastern countries, especially those in the Arab world, is “premarital genetic testing”, which is mandatory by law in more than one country. As per the Qatari family law no. 22 of 2006, article no. 18 which stated that the to-be-married couples have to “submit to the marriage attestator/notary a medical certificate from a competent medical authority specifying that parties are free from genetic diseases and the other diseases specified by the National Health Authority in coordination with the relevant authorities.” The law added that each one of the to-be-married-couple will be notified of the results of the test before signing the marital contract. In case the results of the test showed that the prospective marriage would entail genetic risks, the law held that the concerned authorities are not entitled

to reject the registration of the marital contract as long as the involved parties are still willing to conclude their marriage.

The codification of these laws was accompanied by intensive deliberations among individual Muslim religious scholars in addition to the interdisciplinary discussions facilitated by the aforementioned institutions, namely the IOMS, IFA and IIFA. The mandatory character of these tests and making them a condition for the official authorization of marriage raised various concerns. Some concerns related to the very nature of the marital contract in Islam and whether new conditions can be added to it. Other moral concerns had to do with respecting the contracting parties' autonomy and whether the mandatory character of the test would compromise the due respect for their autonomy. The laws were eventually introduced as a necessary public health measure meant to reduce the number of children born with genetic diseases, sometimes correlated with the spread of consanguineous marriages which can reach up to 50% or higher in some Arab countries. In order to address these moral concerns, the codified laws left the final decision of (not) getting married to the discretion of the to-be-married couples, irrespective of the negative/positive results of the genetic test. In 2013, the IIFA issued a resolution stating that premarital genetic testing can be made mandatory, as a means of achieving a recognized public benefit.

Protecting the genetic privacy of the to-be-married couples and, by extension, their respective families is another significant concern raised by these mandatory premarital genetic tests. In order to address this concern, the current standard practice in Qatar is that the to-be-married couple will be informed if their plans for marriage would entail genetic risks. If the results are positive and the initial advice is not to proceed with marriage, neither the nature of the genetic risk nor the one(s) whose genetic makeup is creating this risk will be communicated to the couple. Only if they do proceed with their marriage plan will the to-be-married couple be referred to available genetic counseling services. Further details about the genetic risks will be communicated to, and discussed with, them there. In this scenario, the problem arises if a member of the to-be-married couple revealed the information about genetic risks to others, because this may affect not only the opinion of the future partner but also other family members. To address such a risk, this *Policy Document* recommends that the to-be-married couple sign a confidentiality agreement in which they pledge not to reveal the genetic information they would come to know as part of these mandatory genetic tests. Because of the nature of their profession, healthcare professionals are already committed, usually by the force of law or national regulations, to the obligation of protecting people's privacy and confidentiality of their information.

### ***Genetic Discrimination and Stigmatization***

One of the serious risks in the field of genomics is that genetic data can be used to discriminate against individuals, families, groups or ethnicities. This can happen within the genomic research context through a data breach by those who have access

to this data. Fear of genetic discrimination is also a common concern among people who undergo genetic testing. An example for this would be the abovementioned premarital genetic testing, where circulating information about people's gene mutations responsible for an inherited disorder that can be passed to one's future offspring can result in discriminatory or stigmatizing practices.

International literature on genetic discrimination focuses on the repercussions related to one's employment or health insurance. People with certain gene mutations can be the subject of discriminatory treatment by their employer or insurance company. This is because they will be labelled as an "at-risk group", despite the absence of any significant phenotypical or symptomatic differences that would affect their eligibility for work or insurance coverage. One of the famous laws introduced to protect people against this particular type of discrimination is the US federal law of Genetic Information Nondiscrimination Act (GINA). In alignment with international standards and with earlier documents issued by the MoPH, this *Policy Document* endorses the position that neither employers nor insurance companies should have access to the results of genomic research or genetic tests. In addition, these institutions should be committed to non-discrimination policies in order to make sure that the research participants and patients will not be treated unfairly as a result of any possible genetic data breach.

As for the particular context of the Arab world, the above-outlined mandatory premarital genetic testing shows that marriage is one of the possible areas of genetic discrimination and stigmatization. The breach of the to-be-married couple's genetic data can have dramatic consequences on the marriageability of not only the two partners but also their extended families. They can be stigmatized and labelled as "genetically unfit" for marriage. On the other hand, marriage is the only available route for Muslim individuals to set up a family, as dictated by both the Islamic value-system and the binding legal systems in most of the Muslim-majority countries, which outlaw extramarital relations. Thus, this *Policy Document* recommends developing a protective legal framework that strictly prohibits the various forms of genetic discrimination which result in unfair treatment, especially those forms which impact people's marriageability. This position is in line with the strong recommendation adopted respectively by the IOMS in 1998 and IIFA in 2013, which stated that "No person should be subject to any form of discrimination which is based on his genetic characteristics and which aims at, or results in, undermining his basic rights and freedoms and his dignity."

## **Public Engagement**

It is now internationally recognized that the success, and even the "legitimacy", of genomic research in the eyes of the public are strongly contingent upon developing scientific enterprises which are more socially robust and culturally sensitive. That is why many national genome projects worldwide developed initiatives and projects intended to improve public awareness of, and engagement with, genomic research.

They are keen to make their scientific ventures attentive to, and fine-tuned with, the dominant socio-cultural and ethical norms and the commonly shared values within each society.

In the abovementioned document “Guidance for the Design, Ethical Review, and Conduct of Genomic Research in Qatar”, the MoPH encouraged the involved institutions to increase public awareness of the purpose and potential benefits of genomic research. Improvements in this regard are seen as an important factor to making the public more comfortable with the ethical, cultural, and scientific issues in genomic research and thus making people more willing to participate in genomic research.

This *Policy Document* endorses this pro-public engagement position and further stresses the need for broadening the scope of related initiatives to breathe an overall pro-science spirit in Muslim societies, which is key to building up mutual trust between the scientific community and the general public. It should be made clear to the general public that supporting scientific ventures is not at the cost of socio-cultural and religious values. On the contrary, the Islamic value-system can be a motivating factor for scientific renaissance in a country like Qatar and in the broader Muslim world.

To actualize the idea that neither genomics nor Islamic ethics should remain “elitist” fields in the Muslim world, short- and long-term plans should involve various stakeholders including the general public, religious scholars, scientists, policymakers, journalists and media personalities, social scientists, public figures and influencers, etc. Besides employing the usual social media campaigns, we provide below some concrete examples of initiatives and plans that take into consideration the religious and socio-cultural setting of a country like Qatar.

- Whenever possible, the design of the genomic research projects should include elements related to public awareness and/or engagement. Research funding institutions can create certain incentives for the projects that achieve success in this regard.
- Research projects in the fields of religious studies and humanities (e.g., Islamic Studies, Ethics, social sciences, etc.) should be encouraged to examine issues related to improving public awareness of, and engagement with genomics.
- The curricula of (high) schools and (graduate) university programs in both biomedical sciences and humanities should include courses, or parts thereof, which contribute to increasing students’ awareness of the ethical issues raised by genomics. Interdisciplinary courses, jointly taught by specialists in more than one field, will be of added value in this regard.
- Occasions of religious preaching, especially on Friday and during the month of Ramadan, represent great opportunities for enlightening the attendees about how the interplay of advanced scientific research in fields like genomics and one’s religiosity. To maximize the benefit of such opportunities, training programs should be designed for the imams and Muslim religious scholars, who preach on these occasions.

- *Majlis*, an Arabic term that literally means a place of sitting, refers to the long-standing tradition, which goes back to the pre-Islamic Arabia, where special gatherings and counselling are held among groups of common interest to discuss, and decide on, political, social or religious issues. This tradition is still widespread, and sometimes quite influential, in Qatar and other countries in the Gulf region. Especially the socio-culturally sensitive issues related to a complex field like genomics can best be examined within the *majlis* context.
- Concerns and questions raised by the public and the possible changes and fluctuations in their attitudes towards genomic research should be the subject of recurrent surveys and empirical studies. The surveys conducted by the Social and Economic Survey Research Institute (SESRI) at Qatar University and the Qatar Genome Program (QGP) at Qatar Foundation and related academic publications are exemplary in this regard.

# Glossary

**Alliance (*ḥilf*)** An institution prevalent in Islamic history that facilitated relationships among various groups and tribes. Similar to the institution of clientage (*walāʾ*), alliance created a sense of mutual loyalty and solidarity. It involved the establishment of formal agreements or pacts, often with specific obligations and benefits for the parties involved. Contemporary Muslim jurists recognize the historical practice of tribal alliances as long as they do not negate or overrule biological kinship.

**Clientage (*walāʾ*)** An institution that existed in Islamic history, fostering relationships between different groups and tribes. It involves a contractual bond of mutual rights and obligations, creating a form of kinship that is non-biological or non-genetic in nature. Clientage established social solidarity and, in some cases, subjected the parties involved to certain juristic rulings pertaining to lineage.

**Collective Duty (*Fard kifāya*)** Unlike individual obligation (*fard ʿayn*), collective duty rests upon the Muslim community (*ummah*) as a whole. When some people perform the duty, the obligation is suspended for all others. But if no one performs the duty, then everyone is held accountable.

**Etiquettes of the physician (*adab al-ṭabīb*)** A set of moral and professional guidelines that govern the behavior and conduct of physicians in the context of Islamic medical ethics. These guidelines encompass the ethical responsibilities and duties expected of a physician in the physician–patient encounter. Throughout Islamic history, different books were written and codes of ethics were drafted to outline relevant guidelines.

**Geneticization** A term that goes back to the 1990s and since then has been employed by different researchers to express concerns about the essentializing effects of genetic knowledge and technologies on different aspects of life. This study showed that some contemporary Muslim jurists generally supported the idea of geneticized paternity or lineage (*nasab*) and thus would be established or negated via technologies like the DNA paternity test.



**Hisba** An Arabic term denoting a centuries-old Islamic institution aimed at promoting public morality by ensuring the adherence to morally approved practices, while preventing unethical behaviors. This institution traditionally encompassed the supervision of various professions, including healthcare practitioners such as physicians, surgeons, opticians, midwives, and others.

**Independent Religio-ethical Reasoning (*Ijtihād*)** It literally means in Arabic the act of exerting one's utmost effort in a particular activity. As a technical term, it means exerting the maximum effort to master and apply the principles and rules of interpreting the scriptural texts and related evidence-systems for the purpose of exploring how the will of God can be discovered and implemented in specific situations.

**Islamic Jurisprudence (*Fiqh*)** The scholarly discipline whose experts are occupied with extracting religious rulings, pertaining to conduct, from their adequate scriptural sources and evidence-systems. Throughout Islamic history, five main schools of Islamic law proved to be dominant, namely the Ḥanafī, Mālikī, Shāfi'ī, and Ḥanbalī schools (within the Sunni tradition) and the Ja'farī school (within the Shī'a tradition).

**Islamic Legal Theory (*Uṣūl al-Fiqh*)** Literally, it means the roots or fundamentals of *fiqh*. Technically, it refers to the scholarly discipline that examines the body of principles and investigative methodologies through which religious rulings are developed from the foundational sources.

**Islamic Theology (*Aqīda* or *kalām*)** The scholarly discipline that examines the set of beliefs, particularly those with relevance to the nature of God and the relationship between God and His creatures, which Muslims embrace. Some criticize contemporary discourse on Islam and biomedical ethics for focusing excessively on the *fiqh*-related aspects at the expense of giving proper consideration to the theological aspects.

**Jurisprudence of Balances (*Fiqh al-Muwāzanāt*)** An Islamic juristic term which was coined by some contemporary Muslim jurists. Their aim was to construct a particular branch of *fiqh* that focuses on studying the possible methods of balancing and weighting between different and competing factors. Within the context of principle-based bioethics, it is sometimes suggested that this branch can be a helpful tool for resolving the problem of conflict between some general principles.

**Legal Maxims (*Qawā'id Fiqhiyya*)** A distinct genre within *fiqh* that constitute general rules that cut across a great number of areas and themes. This genre is usually employed to address a wide range of modern issues including those related to bioethics. Many researchers believe that this genre can help in the construction of a principle-based bioethics rooted in the Islamic tradition.

**Sharia (*Sharī'a*)** An Arabic word which literally means way, road, or path to a source of water. In Islamic thought, this literal meaning was metaphorically employed to mean the way assigned by God for humanity to achieve success in this life and in the Hereafter. However, there are wide differences in the modern discussions about the exact scope of this term.

# References

- 'Abd al-Ḥamīd, D. (2012). Al-Manhaj al-uṣūlī fī bayān athar al-dalāla fī al-ḥukm al-shar'ī. *Majallat al-Ḥuqūq wa al-'Ulūm al-Insāniyya*, 10, 197–217.
- Abū Ghudda. (1981). Fiḥ al-ṭabīb wa adabuh. *Al-Muslim al-Mu'āṣir*, 28, 145–165.
- Abū Ghudda. (1984). Al-Mabādī' al-shar'iyya li al-tatbīb wa al-'ilāj. In *Al-Abḥāth wa a'māl al-mu'tamar al-'ālamī al-thālīth 'an al-ṭibb al-Islāmī* (pp. 780–792). Islamic Organization for Medical Sciences & Kuwait Foundation for the Advancement of Sciences.
- Abū Ya' lā. (1990). *Al-'Udda fī uṣūl al-fiḥ*. No publisher.
- Abouelhoda, M., Faquih, T., El-Kalioby, T., & Alkuraya, F. (2016). Revisiting the morbid genome of Mendelian disorders. *Genome Biology*, 17(235), 1–7.
- 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-Aṣbahānī, A. (1974). *Ḥilyat al-awliyā' wa ṭabaqāt al-aṣfiyā'*. Al-Sa'āda.
- Al-Aṣfahānī, R. (2007). *Al-Dharī'a ilā makārim al-Sharī'a*. Dār al-Salām.
- Al-Bar, M., & Chamsi-Pasha, H. (2015). *Contemporary bioethics: Islamic perspective*. Springer Nature.
- Al-Bayḍāwī. (1991). *Ṭawālī' al-anwār min maṭālī' al-anzār*. Dār al-Jīl and Al-Maktaba al-Azhariyya li al-Turāth.
- Al-Bayhaqī. (2003). *Shu'ab al-īmān*. Maktabat al-Rushd.
- Al-Buhūtī, M. (n.d.). *Kashshāf al-qinā' 'an matn al-iqnā'*. Dār al-Kutub al-'Ilmiyya.
- Al-Bukhārī. (1989). *Al-Adab al-mufrad*. Dār al-Bashā'ir al-Islāmiyya.
- Al-Dhahabī. (2006). *Siyar al-lām al-nubalā'*. Dār al-Ḥadīth.
- Al-Dīmyāṭī, A. (1997). *I'ānat al-ṭālibīn 'alā ḥall al-fāz fath al-mu'in*. Dār al-Fikr li al-Ṭibā'a wa al-Nashr wa al-Twayī'.
- Al-Dusarī, M. (2016). Ma'ākhdh al-khilāf al-mut'alliqa bi al-qawā'id al-fiḥiyya fī ḥukm al-mawt al-dimāghī. *Majallat al-Buḥūth wa al-Dirāsāt al-Shar'iyya*, 5(52), 7–40.
- Al-Farsi, S. (2013). *Democracy and youth in the Middle East: Islam, tribalism and the rentier state in Oman*. Bloomsbury Publishing.
- Al-Fā'ūrī, M. (2019). Namādhij ṭabībīyya 'alā al-'amal bi ghalabat al-zann fī al-fiḥ al-Islāmī. *Al-Majalla al-Urduniyya fī al-Dirāsāt al-Islāmiyya*, 15(2), 215–236.
- Al-Fayḍī, A. (2013). Ḥaqq al-nasab li al-janīn fī al-Sharī'a al-Islāmiyya wa al-qānūn. *Majallat Al-Buḥūth wa al-Dirāsāt al-Islāmiyya*, 32, 111–181.
- Al-Gendy, A., & Awadi, A. (2005). *The International Islamic code for medical and health ethics*. Islamic Organization for Medical Sciences.
- Al-Ghazālī. (1971). *Shifā' al-ghalīl*. Maṭba'at al-Irshād.
- Al-Ghazālī. (1987). *Al-Maqṣad al-asnā' fī sharḥ ma'ānī asmā' Allāh al-ḥusnā*. Al-Jaffān wa al-Jābī.

- Al-Ghazālī, 'A. (2021). Al-intisāb li al-qabīla 'inda al-'Arabī qabl al-Islām: Ahmiyatuh, wa atharuh fi mujtama' Shihb al-Jazīra al-'Arabiyya. *Majallat Kulliyat al-Tarbiya li al-Banāt li al-'Ulūm al-Insāniyya*, 15(28), 153–186.
- Al-Ghazālī. (n.d.). *Iḥyā' 'ulūm al-dīn*. Dār al-Ma'rifa.
- Al-Hājj, J. (2017). *Katm al-asrār al-ṭibbiyya wa ifshā'uhā fi majāl al-'alāqāt al-usariyya*. M.A. Thesis. Qatar University. Retrieved from <https://qspace.qu.edu.qa/handle/10576/5399>. Accessed 17 May 2023.
- Al-Ḥārithī, M. (2009). Ḥukm al-tadāwī: Bayān aqwāl 'ulamā' al-madhāhib al-fiqhiyyah al-arba'a fi uṣūl al-tadāwī wa al-ra'y al-mukhtār. *Majallat Kulliyat Dār al-'Ulūm*, 49, 325–356.
- Al-Haytamī, I. Ḥ. (1987). *Al-Zawājir 'an iqtirāf al-kabā'ir*. Dār al-Fikr.
- Al-Ījī, A. (1997). *Sharḥ al-mawāqif*. Dār al-Kutub al-'Ilmiyya.
- Al-Inābī, R. (2017). Jarīmat ifshā' al-sirr al-mihanī li al-ṭabīb fi al-qānūn al-Maghribī. *Majallat al-Manāra li al-Dirāsāt al-Qānūniyya wa al-Idāriyya*, 17, 369–372.
- Al-Jaṣṣāṣ, A. (1994). *Al-Fuṣūl fi al-uṣūl*. Wizārat al-Awqāf al-Kuwaytiyya.
- Al-Juhanī, F. (2010). *Aḥkām al-awlād al-nātijin 'an al-zinā*. A paper presented during the 20th session of the Islamic Fiqh Academy. Islamic Fiqh Academy.
- Al-Juwaynī. (1996). *Kitāb al-talkhīṣ fi uṣūl al-fiqh*. Dār al-Bashā'ir al-Islāmiyya.
- Al-Ka'bi, K. (2006). *Al-Baṣma al-warāthiyya wa atharuhā 'alā al-aḥkām al-fiqhiyya*. Dār al-Nafā'is.
- Al-Kāsānī, A. (1986). *Badā'i' al-ṣanā'i' fi tartīb al-sharā'i'*. Dār al-Kutub al-'Ilmiyya.
- Al-Khādīmī, N. (2004). Al-Khāriṭa al-jīniyya al-bashariyya (al-jīnūm al-basharī): Al-Aḥkām al-Shar'iyya wa-al-ḍawābiṭ al-akhlāqiyya. *Majallat al-Mishkāt*, 4(2), 59–76.
- Al-Kharā'ifī, A. (1986). *Al-Muntaqā min kitāb makārim al-akhlāq wa ma'ālīhā wa mahmūd tarā'iqihā*. Dār al-Fikr.
- Al-Khaṭīb, M. (2019). Min al-muqāraba al-fiqhiyya ilā al-muqāraba al-akhlāqiyya: Al-Ijtihād al-mu'āṣir wa-al-jīnūm namūdhajan. *Journal of Islamic Ethics*, 3, 90–127.
- Al-Māzarī, M. (n.d.). *Idāh al-maḥṣūl min burhān al-uṣūl*. Dār al-Gharb al-Islāmī.
- Al-Najjār, I. (1997). *Sharḥ al-kawkab al-munīr*. Maktabat al-'Ubaykān.
- Al-Nasā'ī. (2001). *Al-Sunan al-kubrā*. Mu'ssasat al-Risāla.
- Al-Nawawī. (1972). *Al-Manhaj sharḥ Ṣaḥīḥ Muslim ibn al-Ḥajjāj*. Dār Iḥyā' al-Turāth al-'Arabī.
- Al-Nomay, N., & Alfayyad, I. (2015). Review of the legal maxims of Islamic law on palliative sedation: Concerns of the Arabic bioethicists. *Journal of Public Health in Developing Countries*, 1(2), 83–88.
- Al-Qarāfī. (1980). *Anwār al-burūq fi anwā' al-furūq*. 'Ālam al-Kutub.
- Al-Qaraḍāwī, Y. (1996). *Al-Ijtihād fi al-sharī'a al-Islāmiyya*. Dār al-Qalam.
- Al-Qurashī, M. (1976). *Ma'ālim al-qurba fi ṭalab al-hisba*. Al-Hay'a al-Miṣriyya al-'Āmma li al-Kitāb.
- Al-Qurṭubī. (1964). *Al-Jāmi' li aḥkām al-Qur'ān*. Dār al-Kutub al-Miṣriyya.
- Al-Qushayrī. (2013). *Kitāb al-Araba'yīn fi taṣḥīḥ al-mu'āmalā*. Dār al-Faṭḥ.
- Al-Raysūnī, Q. (2022). Al-Tanāwul al-uṣūlī li al-mandūb: Thaghārāt wa nazarāt. *Majallat al-Buḥūth al-'Ilmiyya wa al-Dirāsāt al-Islāmiyya*, 14(1), 115–1140.
- Al-Rāzī, A. (1977). *Akhlāq al-ṭabīb*. Maktabat Dār al-Turāth.
- Al-Ruhāwī, I., (1992). *Adab al-ṭabīb*. Markaz al-Malik Fayṣal li al-Buḥūth wa al-Dirāsāt al-Islāmiyya.
- Al-Sam'ānī. (1999). *Qawā'ī' al-al-adilla fi al-uṣūl*. Dār al-Kutub al-'Ilmiyya.
- Al-Sarakhsī. (n.d.). *Uṣūl al-Sarakhsī*. Dār al-Ma'rifa.
- Al-Shāfi'ī. (1940). *Al-Risāla*. Maktabat al-Ḥalabī.
- Al-Shakaki, A. (2019a). *Bioethical deliberation on genomic testing: Islamic perspectives*. M.A. thesis. Hamad Bin Khalifa University.
- Al-Shakaki, A. (2019b). Islamic bioethical discourse in incidental findings: Research genetic context. *Innovations in Global Health Professions Education*.
- Al-Shāṭibī. (2003). *Al-Muwāfaqāt*. Dār Ibn 'Affān.
- Al-Shirāzī, A. (1970). *Ṭabaqāt al-fuqahā'*. Beirut: Dār al-Rā'id al-'Arabī.

- Al-Shūrāzī, A. (2003). *Al-Luma' fī uṣūl al-fiqh*. Dār al-Kutub al-'Ilmiyya.
- Al-Sharekh, A., & Freer, C. (2022). *Tribalism and political power in the Gulf: State-building and national identity in Kuwait, Qatar and the UAE*. I.B. Tauris.
- Al-Subkī, T., (1986). *Mu'īd al-ni'am wa mubīd al-niqam*. Mu'assasat al-Kutub al-Thaqāfiyya.
- Al-Taftazānī, S. (n.d.). *Sharḥ al-talwīḥ 'ala al-tawḍīḥ*. Maktabat Ṣubayḥ.
- Al-Zankī, Ṣ. (2003). Al-Ḥukm al-shar'ī fī al-baḥṡ al-uṣūlī: Dirāsa taḥlīliyya naqdiyya. *Majallat al-Hikma*, 26, 327–354.
- Al-Zarqā, A. (1989). *Sharḥ al-qawā'id al-fiqhiyya*. Dār al-Qalam.
- Al-Zuhaylī, W. (n.d.). *Al-Fiqh al-Islāmī wa adīllatuh*. Dār al-Fikr.
- Allyse, M., & Michie, M. (2013). Not-so-incident findings: The ACMG recommendations on the reporting of incidental findings in clinical whole genome and whole exome sequencing. *Trends in Biotechnology*, 31(8), 439–441.
- Alsmadi, O., Thareja, G., Alkayal, F., Rajagopalan, R., John, S., Hebbar, P., Behbehani, K., & Thanaraj, T. (2013). Genetic substructure of Kuwaiti population reveals migration history. *PLOS ONE*, 8(9), e74913.
- Alsmadi, O., John, S., Thareja, G., Hebbar, P., Antony, D., Behbehani, K., & Thanaraj, T. (2014). Genome at juncture of early human migration: A Systematic analysis of two whole genomes and thirteen exomes from Kuwaiti population subgroup of inferred Saudi Arabian tribe ancestry. *PLoS ONE*, 9(6), e99069.
- Arjāwī, M. (1991). *Aḥkām naql al-dam fī al-qānūn al-madanī wa al-fiqh al-Islāmī*. Dār al-Manār.
- Arribas-Ayllon, M. (2016). After geneticization. *Social Science & Medicine*, 159, 132–139.
- Atiyya, J. (2003). *Naḥwa taf'īl maqāṣid al-Sharī'a*. Al-Ma'had al-'Ālamī li al-Fikr al-Islāmī & Dār al-Fikr.
- Baghdādī, A. (1977). *Al-Farq bayna al-firaq*. Dār al-Āfāq al-Jadīda.
- Bakhsh, A. (2022). Nihāyat al-qabīla bi shamāl al-Maghrib: Mauqāraba sūsiyūlūjiyya. *Bāḥithūn: Al-Majalla al-Maghribiyya li al-'Ulūm al-Ītimā'iyya wa al-Insāniyya*, 18, 13–25.
- Bār, M. (2005). Al-Idhn bi al-'amal al-ṡibbī (idhn al-marīḍ wa idhn al-Shārī'). *Majallat al-Majma' al-Fiqhī al-Islāmī*, 8(10), 255–278.
- Bār, M., & Al-Sibā'ī, Z. (2009). *Al-Ṭabīb: Adabuh wa-fiqhuh*. Dār al-Qalam.
- Baṣrī, A. (1983). *Al-Mu'tamad fī uṣūl al-fiqh*. Dār al-Kutub al-'Ilmiyya.
- Bāz, U. I., & Jibrīn. (1994). *Fatāwā Islāmīyya*. Dār al-Waṭan li al-Nashr.
- Beauchamp, T., & Childress, J. (2013). *Principles of biomedical ethics*. Oxford University Press.
- Blumenthal-Barby, J., Aas, S., Brudney, D., Flanigan, J., Lia, M., London, A., Summer, W., & Savulescu, J. (2022). The Place of philosophy in bioethics today. *The American Journal of Bioethics*, 22(12), 10–21.
- Boddington, P. (2012). *Ethical challenges in genomics research: A Guide to understanding ethics in context*. Springer.
- Bolnick, D., Fullwiley, D., Duster, T., Cooper, R., Fujimura, J., Kahn, J., Kaufman, J., Morning, A., Nelson, A., Ossorio, P., Reardon, J., Reverby, S.M., & TallBear, K. (2007). Genetics. The Science and business of genetic ancestry testing. *Science*, 318(5849), 399–400.
- Burke, W., Antommara, A. M., Bennett, R., Botkin, J., Clayton, E., Henderson, G., Holm, I. A., Jarvik, G. P., Khoury, M. J., Knoppers, B. M., Press, N. A., Ross, L. F., Rothstein, M. A., Saal, H., Uhlmann, W. R., Wilfond, B., Wolf, S. M., & Zimmern, R. (2013). Recommendations for returning genomic incidental findings? We need to talk!. *Genetics in Medicine*, 15(11), 854–859.
- Christenhusz, G., Devriendt, K., & Dierickx, K. (2013). To tell or not to tell? A systematic review of ethical reflections on incidental findings arising in genetics contexts. *European Journal of Human Genetics*, 21(3), 248–255.
- Cole-Turner, R. (1992). Religion and the human genome. *Journal of Religion and Health*, 31(2), 161–173.
- Collins, F. (2003). Genomics: The Coming revolution in medicine. *Global Agenda: Magazine of the World Economics Forum Annual Meeting*, 152–154.
- Collins, F. (2011). *The Language of life: DNA and the revolution in personalized medicine*. Harper.

- Cook, M. (2001). *Commanding right and forbidding wrong in Islamic thought*. Cambridge University Press.
- Cook, M. (2003). *Forbidding wrong in Islam: An introduction*. Cambridge University Press.
- Craven, L., Murphy, J., Turnbull, D. M., Taylor, R. W., Gorman, G. S., & McFarland, R. (2018). Scientific and ethical issues in mitochondrial donation. *The New Bioethics*, 24(1), 57–73.
- Dār al-Iftā'. (2012). *Hukm tarshīh nuwwāb binā'an 'alā intima'ihim li qabīla mu'ayyina aw jiha*. Online Fatwa published by the Libyan Fatwa House (Dār al-Iftā'). Retrieved from <https://rb.gy/2ylo>. Accessed 12 April 2023.
- Dār al-Iftā'. (2019). *Al-Insilākh min al-qabīla*. Online Fatwa published by the Libyan Fatwa House (Dār al-Iftā'). Retrieved from <https://rb.gy/po1h2>. Accessed 12 April 2023.
- Dolan, D., Lee, J., & Cho, M. (2022). Three decades of ethical, legal, and social implications research: Looking back to chart a path forward. *Cell Genomics*, 2(7), 1–125.
- Draper, H. (2007). Paternity fraud and compensation for misattributed paternity. *Journal of Medical Ethics*, 33(8), 475–480.
- Draper, H., & Ives, J. (2009). Paternity testing: A Poor test of fatherhood. *Journal of Social Welfare and Family Law*, 31(4), 407–418.
- Duivenbode, R., & Padela, A. (2019). Contextualizing the role of religion in the global bioethics discourse: A Response to the new publication policy of Developing World Bioethics. *Developing World Bioethics*, 1–3.
- Duri, A. (2014). *The rise of historical writing among the Arabs*. Princeton University Press.
- Efut, M., & Chiagoziem, A. (2021). Paternity fraud: Examining its causes, tort of Deceit and victims compensation. *Global Scientific Journal*, 9(12), 738–747.
- Elfatih, A., Mifsud, B., Syed, N., Badii, R., Mbarek, H., Abbaszadeh, F., Qatar Genome Program Research Consortium, & Estivill, X. (2021a). Actionable genomic variants in 6045 participants from the Qatar Genome Program. *Human Mutation*, 42 (12), 1584–1601.
- Elfatih, A., Mohammed, I., Abdelrahman, D., & Mifsud, B. (2021b). Frequency and management of medically actionable incidental findings from genome and exome sequencing data: A Systematic review. *Physiological Genomics*, 53(9), 373–384.
- Elgariani, F. (2012). *Al-Qawā'id al-fiqhiyya (Islamic legal maxims): Concept, functions, history, classifications and application to contemporary medical issues*. PhD Dissertation. University of Exeter.
- Elliott, K., Haber, M., Daggag, H., Busby, G., Sarwar, R., Kennet, D., Petraglia, M., Petherbridge, L. J., Yavari, P., Heard-Bey, F. U., Shobi, B., Ghulam, T., Haj, D., Tikriti, A., Mohammad, A., Antony, S., Alyileili, M., Alaydaros, S., Lau, E., ... & Barakat, M. (2022). Fine-scale genetic structure in the United Arab Emirates reflects endogamous and Consanguineous culture, population history, and geography. *Molecular Biology and Evolution*, 39(3), msac039.
- Emmerich, N. (2019). The multiplicity of bioethical expertise in the context of secular liberal democracies. *Society*, 56, 481–488.
- Evans, J. H. (2020). The social context of religion in the jurisdictions of bioethics. *The American Journal of Bioethics*, 20(12), 1–4.
- Ewuoso, C. (2016). A systematic review of the management of incidental findings in genomic research. *BEOnline: Journal of the West African Bioethics Training Program*, 3(1), 1–21.
- Fakhro, K., Staudt, M.R., Ramstetter, M.D., Robay, A. Malek, J.A., Badii, R., Al-Marri, A. A., Khalil, C. A., Al-Shakaki, A., Chidiac, O., Stadler, D., Zirie, M., Jayyousi, A., Salit, J., Mezey, J. G., Crystal, R. G., & Rodriguez-Flores, J.L. (2016). The Qatar genome: A Population-specific tool for precision medicine in the Middle East. *Human Genome Variation*, 3(1), 1–7.
- Faruki, K. (1966). Al-aḥkām al-khamsah: The Five values. *Islamic Studies*, 5(1), 43–98.
- Fayyūmī, A. (1976). *Al-Miṣbāḥ al-munīr fī gharīb al-sharḥ al-kabīr*. Al-Maktaba al-'Ilmiyya.
- Firmage, E., Weiss, B., & Welsh, J. (Eds.). (1990). *Religion and law: Biblical-Judaic and Islamic perspectives*. Eisenbrauns.
- Garner, S., & Kim, J. (2019). The privacy risks of direct-to-consumer genetic testing: A Case study of 23andMe and Ancestry. *Washington University Law Review*, 96, 1219–1265.

- Ghaly, M. (2010). Human cloning through the eyes of Muslim scholars: The New phenomenon of the Islamic international religious/scientific institutions. *Zygon*, 45(1), 7–35.
- Ghaly, M. (2012). The beginning of human life: Islamic bioethical perspectives. *Zygon*, 47(1), 175–213.
- Ghaly, M. (2015). Biomedical scientists as co-muftis: Their contribution to contemporary Islamic bioethics. *Die Welt Des Islams*, 55(3–4), 286–311.
- Ghaly, M. (Ed.). (2016). *Islamic perspectives on the principles of biomedical ethics*. London: Imperial College Press & World Scientific.
- Ghaly, M. (2018a). Islamic ethics and genomics: Mapping the collective deliberations of Muslim religious scholars and biomedical scientists. In *Islamic ethics and the genome question* (pp. 47–79). Brill.
- Ghaly, M. (2018b). Sharia scholars and modern biomedical advancements: What role for religious ethics in the genomic era?. In *Islamic ethics and the genome question* (pp. 17–46). Brill.
- Ghaly, M. (Ed.). (2018c). *Islamic ethics and the genome question*. Brill.
- Ghaly, M. (2019). The convention on the rights of persons with disabilities and the Islamic tradition: The Question of legal capacity in focus. *Journal of Disability & Religion*, 23(3), 251–278.
- Ghaly, M. (2020). Al-Jīn wa manzūmat al-ṭibb al-ḥadīth fī al-mudawwana al-fiqhiyya al-mu'āshira. *Majallat al-Sharī'a wa al-Dirāsāt al-Islāmiyya* Special Issue, 79–132.
- Ghaly, M. (2021). Muslim jurists revisiting “paternity” & “maternity” in the age of ART. In J. Tham, A.G. Gomez, & J. Lunstroth (Eds.), *Multicultural and interreligious perspectives on the ethics of human reproduction* (pp. 191–199). Springer.
- Ghaly, M. (2022). End-of-life care, dying and death in Islamic ethics: A primer. In *End-of-life care, dying and death in the Islamic moral tradition* (pp. 13–49). Brill.
- Ghaly, M. (Ed.), Sadoun, E., Alkuraya, F., Fakhro, K., Zawati, M., Ismail, S., & Ben-Omran, T. (2016). *Genomics in the Gulf region and Islamic ethics*. World Innovation Summit for Health (WISH).
- Ghaly, M., El Akoum, M., Abd El Hadi, A., & Yousuf, A. (2020). *Islamic ethics and infertility treatment*. World Innovation Summit for Health.
- Ghaly, M., El Akoum, M., Alkuraya, F., Al-Shafai, M., Al-Abdulla, S., Fakhro, K., & Ben Omran, T. (2022). *Islamic ethics and the healthcare of children in the genetics era*. World Innovation Summit for Health.
- Ghandal, A. (2020). Al-Mandūb fī al-dars al-uṣūlī. *Majallat Al-Jāmi'a Al-Wataniyya*, 14, 185–220.
- Giladi, A. (1999). *Infants, parents and wet nurses: Medieval Islamic views on breastfeeding and their social implications*. Brill.
- Glynn, C. (2022). Bridging disciplines to form a new one: The Emergence of forensic genetic genealogy. *Genes*, 13(1381), 1–16.
- Green, R., Berg, J.S., Grody, W., Kalia, S., Korf, B., Martin, C., McGuire, A. L., Nussbaum, R. L., O'Daniel, J. M., Ormond, K. E., Rehm, H. L., Watson, M. S., Williams, M. S., Biesecker, L. (2013). ACMG recommendations for reporting of incidental findings in clinical exome and genome sequencing. *Genetics in Medicine*, 15(7), 565–574.
- Green, E., Watson, J., & Collins, F. (2015). Human genome project: Twenty-five years of big biology. *Nature*, 526, 29–31.
- Group of Scholars. (1983–2006). *Al-Mawsū'a al-fiqhiyya*. Wizārat al-Awqāf wa al-Shu'ūn al-Islāmiyya.
- Guevara, D. (1999). The impossibility of supererogation in Kant's moral theory. *Philosophy and Phenomenological Research*, 59(3), 593–624.
- Guinn, D. (Ed.). (2006). *Handbook of bioethics and religion*. Oxford University Press.
- Hedberg, T. (2014). Epistemic supererogation and its implications. *Synthese*, 191, 3621–3637.
- Heinemann, T., & Lemke, T. (2014). Biological citizenship reconsidered: The Use of DNA analysis by immigration authorities in Germany. *Science, Technology, & Human Values*, 39(4), 488–510.
- Helén, I. (2014). Biological citizenship across the borders: Politics of DNA profiling for family reunification. *Distinktion: Scandinavian Journal of Social Theory*, 15(3), 343–360.

- Henderson, G., Juengst, E., King, N., Kuczynski, K., & Michie, M. (2012). What research ethics should learn from genomics and society research: Lessons from the ELSI Congress of 2011. *The Journal of Law, Medicine & Ethics*, 40(4), 1008–1024.
- Hercher, L. (2023). To be or not to be (honest): The Persistent problem of misattributed paternity. *Journal of Genetic Counseling*, 1–4. <https://doi.org/10.1002/jgc4.1681>.
- Hochschild, J. (2021). *Genomic politics: How the revolution in genomic science is shaping American society*. Oxford University Press.
- Hofmann, B. (2016). Incidental findings of uncertain significance: To know or not to know—that is not the question. *BMC Medical Ethics*, 17, 1–9.
- Holtzman, N. (2013). ACMG recommendations on incidental findings are flawed scientifically and ethically. *Genetics in Medicine*, 15(9), 750–751.
- Hunter-Zinck, H., Musharoff, S., Salit, J., Al-Ali, K., Chouchane, L., Gohar, A., Matthews, R., Butler, M. W., Fuller, J., Hackett, N. R., Crystal, R. G., & Clark, A. (2010). Population genetic structure of the people of Qatar. *The American Journal of Human Genetics*, 87(1), 17–25.
- Ibn ‘Ābidīn. (1992). *Radd al-muhtār ‘alā al-durr al-mukhtār*. Dār al-Fikr.
- Ibn Abī Uṣayby‘a. (n.d.). ‘*Uyūn al-anbā’ fī ṭabaqāt al-atibbā’*. Dār Maktabat al-Ḥayāh.
- Ibn al-Arabī. (1999). *Al-Maḥṣūl fī uṣūl al-fiqh*. Dār al-Bayāriq.
- Ibn al-Arabī. (2003). *Aḥkām al-Qur‘ān*. Dār al-Kutub al-‘Ilmiyya.
- Ibn al-Jarrāh. (1984). *Al-Zuhd li wakī’*. Maktabat al-Dār.
- Ibn al-Qayyim (2006). *Al-Ṭurūq al-ḥukmiyya fī al-siyāsa al-Shar‘iyya*. Dār ‘Ālam al-Fawā’id.
- Ibn Daḥīq al-‘Īd. (2009). *Sharḥ al-ilmām bi aḥādīth al-aḥkām*. Dār al-Nawādir.
- Ibn Ḥajar. (1959). *Fath al-bārī sharḥ ṣaḥīḥ al-Bukhārī*. Dār al-Ma‘rifā.
- Ibn Ḥazm. (1983). *Al-Iḥkām fī uṣūl al-aḥkām*. Dār al-Āfāq al-Jadīda.
- Ibn Qudāma. (2002). *Rawdat al-nāzīr wa jannat al-munāzīr*. Mu‘assasat al-Rayyān li al-Ṭibā‘a wal-Nashr wal-Tawzī‘.
- Ibn Qudāma. (1968). *Al-Mughnī*. Cairo: Maktabat al-Qāhira.
- Ibn Sa‘d. (1990). *Al-Ṭabaqāt al-kubrā*. Dār al-Kutub al-‘Ilmiyya.
- Inhorn, M. C. (2006). Making Muslim babies: IVF and gamete donation in Sunni versus Shi‘a Islam. *Culture, Medicine and Psychiatry*, 30, 427–450.
- International Organization for Islamic Medicine. (1981a). *Al-Dustūr al-Islāmī li al-mihan al-ṭibbiyya*. International Organization for Islamic Medicine.
- International Organization for Islamic Medicine. (1981b). *Islamic code of medical ethics*. International Organization for Islamic Medicine.
- International Islamic Fiqh Academy (IIFA) (2020). *Qarārāt wa tawṣiyyāt* (4th ed.). International Islamic Fiqh Academy.
- Islam, Q. A. (2019). *Hukm intisāb al-insān ilā qabīla bi al-ḥilf ma‘a ‘adam al-intifā’ min qabīlatih al-aṣliyya*. Online Fatwa published by the website Islam QA. Retrieved from <https://rb.gy/ckcc7>. Accessed 12 April 2023.
- Islamweb. (2009). *Lā yu‘tamad ‘alā taḥlīl al-ḥamid al-nawawī fī nafy al-ansāb al-thābita*. Online Fatwa published via Qatari website Islamweb. Retrieved from <https://www.islamweb.org/ar/fatwa/125471>. Accessed 10 April 2023.
- Jackson, L., Goldsmith, L., O’Connor, A., & Skirton, H. (2012). Incidental findings in genetic research and clinical diagnostic tests: A Systematic review. *American Journal of Medical Genetics, Part A*, 158(12), 3159–3167.
- Jain, A., Gandhi, S., Koshy, R., & Scaria, V. (2018). Incidental and clinically actionable genetic variants in 1005 whole exomes and genomes from Qatar. *Molecular Genetics and Genomics*, 293, 919–929.
- Johfre, S., Saperstein, A., & Hollenbach, J. (2021). Measuring race and ancestry in the age of genetic testing. *Demography*, 58(3), 785–810.
- John, S., Thareja, G., Hebbar, P., Behbehani, K., Thanaraj, T., & Alsmadi, O. (2015). Kuwaiti population subgroup of nomadic Bedouin ancestry—whole genome sequence and analysis. *Genomics Data*, 3, 116–127.

- Jones, T., & Roberts, J. L. (2020). Genetic race? DNA ancestry tests, racial identity, and the law. *Columbia Law Review*, 120(7), 1929–2016.
- Jorde, L., & Bamshad, M. (2020). Genetic ancestry testing: What is it and why is it important? *JAMA*, 323(11), 1089–1090.
- Juengst, E. (1991). The Human genome project and bioethics. *Kennedy Institute of Ethics Journal*, 1(1), 71–74.
- Jundī, A., & 'Awaḏī, 'A. (2005). *Al-Mīthāq al-Islāmī al-'ālami li al-akhlāqiyyāt al-ṭibbiyya wa al-ṣiḥhiyya*. Islamic Organization for Medical Sciences.
- Kalia, S., Adelman, K., Bale, S., Chung, W., Eng, C., Evans, J., Herman, G. E., Hufnagel, S. B., Klein, T. E., Korf, B. R., McKelvey, K. D., Ormond, K. E., Richards, C. S., Vlangos, C. N., Watson, M., Martin, C. L., & Miller, D. (2017). Recommendations for reporting of secondary findings in clinical Exome and genome sequencing, 2016 update (ACMG SF v2. 0): A Policy statement of the American College of Medical Genetics and Genomics. *Genetics in Medicine*, 19(2), 249–255.
- Kamali, M. (2003). *Principles of Islamic jurisprudence*. Cambridge: The Islamic Texts Society.
- Kamali, M. (2006). Legal maxims and other genres of literature in Islamic jurisprudence. *Arab Law Quarterly*, 20(1), 77–101.
- Kasule, O. (2015). *150430p—Ethics in genetic research*. Retrieved from <http://omarkasule-tib.blogspot.qa/2015/08/150430p-ethics-in-genetic-research.html>. Accessed 15 July 2016.
- Khalidī, T. (1994). *Arabic historical thought in the classical period*. Cambridge University Press.
- Khamrī, 'I. (2015). Marātib al-mundhūb 'inda al-Mālikiyya. *Majallat al-Jāmi'a al-Asmariyya al-Islāmiyya*, 12(24), 207–242.
- Kling, D., Phillips, C., Kennett, D., & Tillmar, A. (2021). Investigative genetic genealogy: Current methods, knowledge and practice. *Forensic Science International: Genetics*, 52(102474), 1–23.
- Korf, B. (2013). Response to Townsend et al. *Genetics in Medicine*, 15(9), 752–753.
- Laklamī, A. (2021). Al-Nasab wa al-khībra: Ishkālāt al-taṣawwur wa al-ta'rīf wa dawābiṭ al-a'mal wa al-tawzīf: Baḥth fī al-tashrīf 'al-usarī wa al-ijtihād al-qaḏā'ī al-Maghribī. *Majallat Al-Fiqh Wa Al-Qānūn*, 99(98), 47–67.
- Lāshīn, M. (2002). *Faṭḥ al-mun'im sharḥ Ṣaḥīḥ Muslim*. Dār al-Shurūq.
- Levey, M. (1963). Fourteenth century Muslim medicine and the *Ḥisba*. *Medical History*, 7(2), 176–182.
- Levey, M. (1967). Medical ethics of medieval Islam with special reference to Al-Ruhawī's 'practical ethics of the physician.' *Transactions of the American Philosophical Society*, 57(3), 1–99.
- Lowe, G., Pugh, J., Kahane, G., Corben, L., Lewis, S., Delatycki, M., & Savulescu, J. (2017). How should we deal with misattributed paternity? A survey of lay public attitudes. *AJOB Empirical Bioethics*, 8(4), 234–242.
- Madhkūr, K., Al-Sayf, 'A., Al-Jundī, A., & Ghudda, 'A. (Eds.). (1985). *Al-Ḥayāh al-insāniyya: Bidāyatuhā wa nihāyatuhā fī al-mafhūm al-Islāmī*. Islamic Organization for Medical Sciences.
- Madhkūr, K., Al-Sayf, 'A., Al-Jundī, A., & Ghudda, 'A. (Eds.). (1995). *Al-Ru'ya al-Islāmiyya li ba'd al-mumārāsāt al-ṭibbiyya*. Islamic Organization for Medical Sciences.
- Marks, J. (2002). *What it means to be 98% chimpanzee: Apes, people and their genes*. University of California Press.
- Marlow, L. (2012). Ḥasab O Nasab. *Encyclopaedia Iranica Online*. Columbia University. Retrieved from [https://doi.org/10.1163/2330-4804\\_EIRO\\_COM\\_2838](https://doi.org/10.1163/2330-4804_EIRO_COM_2838). Accessed 01 May 2023.
- Mauro, M., Allen, D., Dauda, B., Molina, S., Neale, B., & Lewis, A. (2022). A Scoping review of guidelines for the use of race, ethnicity, and ancestry reveals widespread consensus but also points of ongoing disagreement. *The American Journal of Human Genetics*, 109, 2110–2125.
- Mbarek, H., Gandhi, G., Selvaraj, S., Al-Muftah, W., Badji, R., Al-Sarraj, Y., & Qatar Genome Program Research Consortium. (2022). Qatar genome: Insights on genomics from the Middle East. *Human Mutation*, 43(4), 499–510.
- Mbarek, H., & Ismail, S. (2022). Mapping the Arab genome. *Nature Genetics*, 54(12), 1761–1763.
- McEwen, J., Boyer, J. T., Sun, K., Rothenberg, K., Lockhart, N., & Guyer, M. (2014). The Ethical, legal, and social implications program of the National Human Genome Research Institute:



- Reflections on an ongoing experiment. *Annual Review of Genomics and Human Genetics*, 15, 481–505.
- Meslin, E., Thomson, E., & Boyer, J. (1997). The Ethical, legal, and social implications research program at the National Human Genome Research Institute. *Kennedy Institute of Ethics Journal*, 7(3), 291–298.
- Miller, D., Lee, K., Gordon, A., Amendola, L., Adelman, K., Bale, S., & ACMG Secondary Findings Working Group. (2021a). Recommendations for reporting of secondary findings in clinical exome and genome sequencing, 2021 update: A Policy statement of the American College of Medical Genetics and Genomics (ACMG). *Genetics in Medicine*, 23(8), 1391–1398.
- Miller, D., Lee, K., Chung, W., Gordon, A., Herman, G., Klein, T., & ACMG Secondary Findings Working Group (2021). ACMG SF v3. 0 list for reporting of secondary findings in clinical exome and genome sequencing: A Policy statement of the American College of Medical Genetics and Genomics (ACMG). *Genetics in Medicine*, 23(8), 1381–1390.
- Miller, D., Lee, K., Abul-Husn, N., Amendola, L., Brothers, K., Chung, W., & ACMG Secondary Findings Working Group. (2022). ACMG SF v3. 1 list for reporting of secondary findings in clinical exome and genome sequencing: A Policy statement of the American College of Medical Genetics and Genomics (ACMG). *Genetics in Medicine*, 24(7), 1407–1414.
- Mineta, K., Goto, K., Gojobori, T., & Alkuraya, F. S. (2021). Population structure of indigenous inhabitants of Arabia. *PLOS Genetics*, 17(1), e1009210.
- Mitwallī, I. (2018). Al-Majālat al-dilāliyya bayna al-Khuwārizmī wa al-Jurjānī. *Majallat Kulliyat Al-Adāb*, 87(8), 239–262.
- Möller, L. M. (2022). Marital choice and “suitability” in a heterogeneous society: Some reflections on *Kafā’a* in the United Arab Emirates. In J. Rehman, A. Shahid, & S. Foster (Eds.), *The Asian yearbook of human rights and humanitarian law* (pp. 134–147). Brill.
- Moosa, E. (2007). “Neuropolitics and the body.” In *Religion and society: An Agenda for the 21st century* (pp. 47–59). Brill.
- Muflih, M. I. (n.d.). *Al-Ādāb al-shar‘iyya wa al-minaḥ al-mar‘iyya*. ‘Ālam al-Kutub.
- Murphy, T. (2012). In defense of irreligious bioethics. *The American Journal of Bioethics*, 12(12), 3–10.
- Musa, K. (2014). Legal maxims as a genre of Islamic law: Origins, development and significance of *Al-qawā’id al-fiqhiyya*. *Islamic Law and Society*, 21(4), 325–365.
- Muṣliḥ, ‘A. (2021). Al-Sirr al-ṭibbī bayna al-ifashā’ wa al-kitmān fī al-fiqh al-Islāmī wa al-qānūn. *Majallat Ittijāhāt Siyāsiyya*, 14, 86–102.
- Muslim. (2003). *Ṣaḥīḥ Muslim*. Dār Iḥyā’ al-Turāth al-‘Arabī.
- Nash, C. (2004). Genetic kinship. *Cultural Studies*, 18(1), 1–33.
- Noohi, F., & Ross, L. (2022). Clarifying the blurry boundaries between research and clinical care. *The American Journal of Bioethics*, 22(10), 96–98.
- Oxford Business Group. (2009). *The Report: Saudi Arabia 2009*. Oxford Business Group.
- Padela, A. (2021). Jurists, physicians, and other experts in dialogue: A Multidisciplinary vision for Islamic bioethical deliberation. In *Medicine and Shariah: A dialogue in islamic bioethics* (pp. 227–234). University of Notre Dame Press.
- Pāshā, Ḥ. (2017). Al-Wirāthah wa al-handasa al-warāthiyya fī al-jīnūm al-basharī. *Majallat Al-Thaqāfa Al-Islāmiyya*, 13(1), 199–270.
- Peters, T. (2014). *Playing god? Genetic determinism and human freedom*. Routledge.
- Philippidis, A. (2018). Patient investment: GSK, 23andMe Forge \$300 million alliance to develop drugs via genetics. *Clinical OMICS*, 5(5), 8–10.
- PLOS One Staff. (2014). Correction: Genome at juncture of early human migration: A Systematic analysis of two whole genomes and thirteen exomes from Kuwaiti population subgroup of inferred Saudi Arabian Tribe Ancestry. *PLoS ONE*, 9(7), e103691.
- Presidential Commission for the Study of Bioethical Issues. (2013). *Anticipate and communicate: Ethical management of incidental and secondary findings in the clinical, research, and direct-to-consumer contexts*. Washington, DC.

- Qoronfleh, M. W., Chouchane, L., Mifsud, B., Al Emadi, M., & Ismail, S. (2020). The Future of medicine, healthcare innovation through precision medicine: Policy case study of Qatar. *Life Sciences, Society and Policy*, 16(1), 1–20.
- Rafī, B. M. (2012). Al-Binā' al-maqāṣidī li al-baḥṡ al-'ilmī fi al-ṭibb. *Majallat Kuliyyat Al-Ādāb Wa Al-'ulūm Al-Insāniyya Bi Fās*, 17–18, 301–314.
- Razali, R., Rodriguez-Flores, J., Ghorbani, M., Naeem, H., Aamer, W., Aliyev, E., & Mokrab, Y. (2021). Thousands of Qatari genomes inform human migration history and improve imputation of Arab haplotypes. *Nature Communications*, 12(1), 5929.
- Reardon, J. (2017). *The Postgenomic condition: Ethics, justice, and knowledge after the genome*. University of Chicago Press.
- Reinhart, K. (1983). Islamic law as Islamic ethics. *The Journal of Religious Ethics*, 11(2), 186–203.
- Roberts, J., & Foulkes, A. (2020). Genetic duties. *William & Mary Law Review*, 62(1), 143–212.
- Rodriguez-Flores, J., Fakhro, K., Hackett, N., Salit, J., Fuller, J., Agosto-Perez, F., Agosto-Perez, F., Gharbiah, M., Malek, J. A., Zirrie, M., Jayyousi, A., Badii, R., Al-Marri, A. A., Chouchane, L., Stadler, D., Mezey, J. G., & Crystal, R. (2014). Exome sequencing identifies potential risk variants for Mendelian disorders at high prevalence in Qatar. *Human Mutation*, 35(1), 105–116.
- Saad, M., Mokrab, Y., Halabi, N., Shan, J., Razali, R., Kunji, K., Syed, N., Temanni, R., Subramanian, M., Ceccarelli, M., Qatar Genome Programme Research Consortium, Tabrizi, A. R., Bedognetti, D., & Chouchane, L. (2022). Genetic predisposition to cancer across people of different ancestries in Qatar: A Population-based, cohort study. *The Lancet Oncology*, 23(3), 341–352.
- Sachedina, A. (2008). Defining the pedagogical parameters of islamic bioethics. In J. Brockopp & T. Eich (Eds.), *Muslim medical ethics: From theory to practice* (pp. 241–251). The University of South Carolina Press.
- Sachedina, A. (2009). *Islamic biomedical ethics: Principles and application*. Oxford University Press.
- Sachedina, A. (2008). Defining the pedagogical parameters of Islamic bioethics. *Quarterly Journal of Medical Ethics*, 2(5), 25–44.
- Şāliḥ, A. (2020). *Al-Tahquq min al-nasab bi faḥṡ al-baṡma al-wirāṡhiyya wa al-kashf 'an nata'ijih al-'aradiyya: Naẓarāt fiḥiyyah jadīda*. Qatar University Press
- Samin, N. (2015). *Of sand or soil: Genealogy and tribal belonging in Saudi Arabia*. Princeton University Press.
- Samin, N. (2012). *Kafā' a fi l-Nasab* in Saudi Arabia: Islamic law, tribal custom, and social change. *Journal of Arabian Studies*, 2(2), 109–126.
- Sartell, E., & Padela, A. (2015). *Adab* and its significance for an Islamic medical ethics. *Journal of Medical Ethics*, 41(9), 756–761.
- Savulescu, J. (2015). Bioethics: Why philosophy is essential for progress. *Journal of Medical Ethics*, 41(1), 28–33.
- Schuklenk, U. (2018). On the role of religion in articles this journal seeks to publish. *Developing World Bioethics*, 18(3), 207.
- Serour, G., Ghaly, M., Saifuddeen, S., Anwar, A., Isa, N., & Chin, A. (2022). Sunni Islamic perspectives on lab-grown sperm and eggs derived from stem cells–in vitro gametogenesis (IVG). *The New Bioethics*, 1–13.
- Setia, A. (2022). Islamic ethics in engagement with life, health, and medicine. In A. Al-Akiti & A. Padela (Eds.), *Islam and biomedicine* (pp. 79–109). Springer International Publishing.
- Shaddī, F. (2023). Al-Intisāb li ḡhayr al-qabīla bayna al-fiḥ wa al-nizām al-Sa'ūdī. *Abḥāṡh*, 10(1) 416–167.
- Shanti, H., El Chouchane, L., Badii, R., Gallouzi, I., & 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(358).
- Sharaf al-Dīn, A. (1982) Al-Ijrā'āt al-ṭibbiyya al-ḥadītha wa ḥukmuḥā fi ḍaw' qawā'id al-fiḥ al-Islāmī. *Al-Muslim al-Mu'āṡir*, 31, 139–167.

- Sharaf al-Dīn, A. (1983). *Aḥkām al-taṭbīb fī al-fiqh al-Islāmī. Majallat al-'Ulūm al-Ijtīmā'iyya*, 11(2), 47–62.
- Sharaf al-Dīn, A. (1987). *Al-Aḥkām al-shar'iyya fī al-'amāl al-ṭibbiyya*. Unknown publisher.
- Sharaf al-Dīn, A. (2001). *Handasat al-injāb wa al-wirātha fī ḍaw al-akhlāq wa al-sharā'ī*. Al-Maktaba al-Akādīmiyya.
- Sharīfa, S. (2018). Qaḍāyā iqāf al-in-'āsh al-qalbī al-ri'awī. *Majallat Al-Hikma Li Al-Dirāsāt Al-Islāmiyya*, 10, 26–60.
- Shepard, A., Diamond, D., Willard, L., Staples, J., Martin, K., & Witherspoon, N. (2022). Discovering misattributed paternity after DNA testing and its impact on psychological well-being and identity formation. *American Journal of Qualitative Research*, 6(3), 189–211.
- Shīwa, F. (2020). Al-Ab'ād al-maqāṣidiyya li al-qawā'id al-kulliyya fī al-fiqh al-ṭibbī. *Majallat Al-'Ulūm Al-Qānūniyya Wa Al-Shar'iyya*, 26, 29–56.
- Tantāwī, M. (1995). Ḥukm bay' al-insān li 'uḍw min a'ḍā'ih. In *Al-Ru'ya al-Islāmiyya li ba'd al-mumārasāt al-ṭibbiyya* (pp. 305–315). Islamic Organization for Medical Sciences.
- Teebi, A., & Teebi, S. (2005). Genetic diversity among the Arabs. *Community Genetics*, 8(1), 21–26.
- Thareja, G., Al-Sarraj, Y., Belkadi, A., Almotawa, M., The Qatar Genome Program Research (QGPR) Consortium, Suhre, K., & Albagha, O. (2021). Whole genome sequencing in the Middle Eastern Qatari population identifies genetic associations with 45 clinically relevant traits. *Nature Communications*, 12(1), 1–10.
- Thareja, G., John, S., Hebbar, P., Behbehani, K., Thanaraj, T., & Alsmadi, O. (2015). Sequence and analysis of a whole genome from Kuwaiti population subgroup of Persian ancestry. *BMC Genomics*, 16, 1–14.
- Tok, M. E., Alkhater, L., & Pal, L. (2016). *Policy-making in a transformative state: The Case of Qatar*. Palgrave Macmillan UK.
- Townsend, A., A. S., Birch, P., & Friedman, J. (2013). Paternalism and the ACMG recommendations on genomic incidental findings: Patients seen but not heard. *Genetics in Medicine*, 15(9), 751–752.
- 'Umayrī, R. (2005). Al-Mandūb: Ḥadduh wa aqsāmuh. *Majallat al-Sharī'a wa al-Dirāsāt al-Islāmiyya*, 20(63), 127–161.
- 'Uwayd, T. (2020). Aḥkām al-nasab wa ātharuh fī al-Sharī'a al-Islāmiyya wa mā 'alayh al-'amal fī al-qānūn al-Kuwaytī. *Majallat Kulliyyat Dār al-'Ulūm*, 129, 141–178.
- Veatch, R. & Guidry-Grimes, L. (2020). *Basics of bioethics*. Routledge.
- Walker, R., & Morrissey, C. (2012). Charting ELSI's future course: Lessons from the recent past. *Genetics in Medicine*, 14(2), 259–267.
- Weiss, B. (1978). Interpretation in Islamic law: The Theory of *Ijtihād*. *The American Journal of Comparative Law*, 26(2), 199–212.
- Wiersma, M., Ghinea, N., & Lipworth, W. (2019). Limiting religious contributions—A Response to Schuklenk. *Developing World Bioethics*, 1(2), 1.
- Wilfond, B., Duenas, D., & Johnson, L. (2022). To disclose or not to disclose: Secondary findings of XXY chromosomes. *The American Journal of Bioethics*, 22(10), 87–88.
- Wilson, L. (2004). Ethical, legal and social issues of genomic research: Striking a balance between science and law. *Journal of Legal, Ethical and Regulatory Issues*, 7(2), 119–140.
- Wolf, S., Lawrenz, F., Nelson, C., Kahn, J., Cho, M., Clayton, E., Fletcher, J. G., Georgieff, M. K., Hammerschmidt, D., Hudson, K., Illes, J., Kapur, V., Keane, M. A., Koeing, B. A., Leroy, B. S., McFarland, E. G., Paradise, J., Parker, L. S., Terry, S. F., ... & Wilfond, B. S. (2008). Managing incidental findings in human subjects research: Analysis and recommendations. *Journal of Law, Medicine & Ethics*, 36(2), 219–248.
- Yāsīn, M. (2019). Dawr al-ikhtibār al-jīnī fī ḥifz al-ansāb. *Tabayyun*, 27(7), 107–136.
- Yudell, M. & DeSalle, R. (Eds.). (2002). *The genomic revolution: Unveiling the unity of life*. Joseph Henry Press.
- Yūsuf, A. (1938). *Al-Radd 'alā siyar al-Awzā'ī*. Lajnat Iḥyā' al-Ma'ārif al-Nu'māniyya.
- Zakariyah, L. (2015). *Legal maxims in Islamic criminal law: Theory and applications*. Leiden: Brill.

- Zayed, H. (2016). The Arab genome: Health and wealth. *Gene*, 592(2), 239–243.
- Zhou, W., Kanai, M., Wu, K. H., Rasheed, H., Tsuo, K., Hirbo, J. B., Wang, Y., Neale, B. M. (2022). Global biobank meta-analysis Initiative: Powering genetic discovery across human disease. *Cell Genomics*, 2(10), 100192.
- Zūzū, F. (2002). Wasā'il al-injāb al-isṭinā'iyya: Naḥwa tawjīh al-baḥth al-'ilmī bi al-naẓar al-maqāṣidī. *Al-Muslim Al-Mu'āṣir*, 27(105), 167–201.