Society of Medical Education & Research

2022, Volume 2, Page No: 36-43
ISSN: 3108-5059

Asian Journal of Ethics in Health and Medicine

Navigating Incidental Findings in Genomic Research: Professional Attitudes and Practices

Noriya Masamura[1], Takanori Nishiyama[2*], Tadasu Sugimori[3]

[1] Uehiro Research Division for iPS Cell Ethics, Center for iPS Cell Research and Application (CiRA), Kyoto University, The Kyoto Technoscience Center #3, 14, Yoshidakawara-cho, Sakyo-ku, Kyoto, 606-8305, Japan.
[2] Office for Promoting Medical Research, Showa University, 1-5-8 Hatanodai, Shinagawa-ku, Tokyo, 142-8555, Japan.
[3] Department of Biomedical Ethics, The University of Tokyo Graduate School of Medicine, 7-3-1 Hongo, Bunkyo-ku, Tokyo, 113-0033, Japan.

***E-mail** ✉ takanorinishi@outlook.com

Abstract

Clinical genomics professionals frequently encounter decisions regarding the disclosure of incidental findings (IFs) arising from genetic research. While previous studies suggest that research participants are generally interested in receiving IFs, there is ongoing debate about the extent of researchers' obligations to return such findings. This study aimed to investigate the attitudes and perspectives of clinical genomics professionals toward returning IFs in genomic research. A national survey was conducted among 113 clinical genomics professionals using convenience sampling. A self-administered questionnaire assessed participants' attitudes toward IF disclosure, perceived responsibilities for returning IFs, and perceived barriers to disclosure. Descriptive statistics were used to summarize the responses. Of the respondents, 65 (57.5%) had encountered IFs in their practice, while 31 (27.4%) expressed discomfort discussing IFs with research participants. Fewer than one-third reported the existence of formal guidelines for managing IFs. A majority indicated willingness to disclose IFs depending on disease risk: 84 participants (80%) for risks ≥50%, and 69 participants (62.7%) for risks between 6–49%. Notably, 36 respondents (31.9%) reported feeling no obligation to return IFs. Clinical genomics professionals generally hold positive attitudes toward the return of IFs, although a subset perceives no duty to do so. The development of detailed, standardized guidelines is essential to support professionals in managing incidental findings responsibly.

Keywords: Incidental findings, Genomic research, Saudi Arabia, Disclosure, Attitudes, Perceptions, Barriers

Background

Advances in genomic technologies have transformed medicine, providing clinicians with powerful tools for prevention, prediction, and diagnosis across a wide range of health conditions [1]. Genomic research generates vast amounts of data, offering significant potential benefits, but it also frequently uncovers information unrelated to the primary objectives of the study.

Incidental findings (IFs) are defined as "discoveries about an individual research participant that have potential health or reproductive significance, identified during the course of research but beyond the study's original aims" [2]. The return of IFs in genomic research remains ethically and legally debated. Central to this debate is whether researchers should disclose such findings, and if so, which types of results should be shared and by whom. Additional complexities arise from issues such as misattributed paternity or clinically actionable variants [3]. IFs may reveal a participant's genetic predisposition to disease, susceptibility to future

Access this article online https://smerpub.com/

Received: 14 January 2022; **Accepted:** 22 March 2022

How to cite this article: Masamura N, Nishiyama T, Sugimori T. Navigating Incidental Findings in Genomic Research: Professional Attitudes and Practices. Asian J Ethics Health Med. 2022;2:36-43. https://doi.org/10.51847/bIf5NmI7Ju

conditions, or sometimes unexpected information about family members [2].

Studies indicate that many research participants wish to receive IFs, regardless of their clinical significance or actionability [4–7]. Providing clinically relevant information is argued to respect participants' autonomy, demonstrate concern for their well-being, and reinforce the fiduciary relationship between researchers and participants. However, some scholars contend that, unlike physicians, researchers do not have a duty to act in participants' health interests. Unlike clinical settings, researchers typically do not maintain ongoing responsibility for participants' health [8–10].

Conversely, other experts argue that researchers do have a general duty to return IFs when specific conditions are met [11, 12]. Proposed criteria for this obligation include:

- Analytical validity of the findings
- Compliance with applicable laws for disclosure
- Participant consent for receiving individual findings
- Findings indicating a substantial risk for a serious health or reproductive condition
- Clinical actionability of the results

Several guidelines address the return of IFs. The American College of Medical Genetics and Genomics (ACMG) recommends that clinically actionable secondary findings from sequencing be returned to patients, with an option to opt-out [1]. In research contexts, the National Heart, Lung, and Blood Institute (NHLBI) advises returning genetic results when disease risk is significant, morbidity is high, and effective interventions exist [13]. These recommendations imply that researchers may bear an ethical obligation to return certain results meeting these criteria.

Despite extensive literature on IFs, there is a notable gap regarding the perspectives of clinical genomics professionals in Saudi Arabia. This study aims to explore their attitudes toward disclosing IFs, their perceived responsibilities in returning these findings, and the barriers encountered in practice.

Methods

This cross-sectional study employed both online and paper-based self-administered questionnaires to collect data from clinical genomics professionals. Eligible participants were identified through the Saudi Society of Medical Genetics membership database and by searching for genomic scientists employed at healthcare institutions and universities across Saudi Arabia. Professionals involved in genomic research or testing were recruited using a convenience sampling approach. Clinical genomic professionals in this context are defined as clinicians who generate differential diagnoses, manage treatment for patients with genetic conditions, and provide genetic counseling.

Potential participants were contacted up to three times. The initial invitation, followed by two reminder emails for non-respondents, included a link to the online questionnaire. For those unreachable via email, paper-based questionnaires were distributed. Data collection occurred from March to October 2019.

The questionnaire (see Additional file 1) was developed based on a comprehensive literature review and consisted of four sections. The first section captured demographic information. The second assessed participants' attitudes toward factors influencing the disclosure of incidental findings using a 5-point Likert scale; these questions were adapted from Lohn *et al.* [14] and Berg *et al.* [14, 15]. The third section evaluated participants' perceptions of their duties regarding IF disclosure, informed by consultations with two internal genomics professionals and a bioethicist, and based on Ewuoso *et al.* [16]. The final section explored barriers to returning IFs, adapted from Ramoni *et al.* [17]. For analysis, responses of "strongly agree" and "agree" were combined into a single "acceptance" category, and "strongly disagree" and "disagree" were grouped as "non-acceptance."

The questionnaire underwent face and content validation by four experts who assessed readability, clarity, and comprehensiveness. Items identified as unclear or ineffective were revised. Internal consistency was high, with Cronbach's alpha values of 0.805 for the attitudes scale, 0.769 for the perception scale, and 0.702 for the barriers scale.

Descriptive statistics, including frequencies, percentages, means, and standard deviations, were used to summarize participant characteristics and study outcomes. The study protocol was approved by the Institutional Review Board of King Fahad Medical City. Completion of the questionnaire implied informed consent.

Results

Out of 180 invited clinical genomics professionals in Saudi Arabia, 113 completed the survey, yielding a response rate of 62%. Respondents had a mean age of

39.6 ± 8.0 years. Most participants were male (n = 69, 61.1%). Educational backgrounds and workplaces varied, with the majority holding a Ph.D. (n = 66, 58.8%) and 78 participants (69%) reporting employment in healthcare settings **(Table 1)**.

Table 1 Participants' characteristics

Variables	n (%)
Age (mean ± SD)	39.6 ± 8.00
Sex	
Male	69 (61.1)
Female	44 (38.9)
Level of education	
Bachelor	13 (11.5)
Master	34 (30.1)
PhD	66 (58.4)
Years of experience (mean ± SD)	11.11 ± 10.00
Affiliation	
Health	78 (69)
Academic	35 (31)
Country in which you received your most senior training	
Saudi Arabia	41 (36.3)
USA	25 (22.1)
Canada	15 (13.3)
Europe	25 (22.1)
Others	7 (6.2)
Guidelines on IFs available in your workplace	
Yes	34 (30.1)
No	46 (40.7)
I do not know	33 (29.2)
Did you encounter IFs in your research practice or by your colleague?	
Yes	65 (57.5)
No	48 (42.5)
Comfort in discussing IFs with research participants	
Comfortable	82 (72.6)
Uncomfortable	31 (27.4)

When questioned about the existence of guidelines for reporting incidental findings, over two-thirds of respondents either reported a lack of guidelines or were uncertain of their availability. Nonetheless, 65 participants (57.5%) indicated that they had encountered IFs in their own research or through colleagues, while slightly more than one-quarter expressed discomfort in discussing these findings with research participants.

Table 2 summarizes participants' attitudes regarding factors influencing IF disclosure. Approximately two-thirds of respondents identified the participant's age and the potential psychosocial impact of the findings as important considerations in deciding whether to disclose IFs. Additionally, a majority (n = 57, 75.9%) agreed that IFs should be returned to research participants if they had expressed a desire to receive such information during the informed consent process.

Table 2. Attitudes toward factors associated with disclosure of incidental findings

	Strongly agree + agree	Neutral	Strongly disagree + disagree
Age of research participant	75 (66.4)	31 (27.4)	7 (6.2)
Psychosocial impact of the IFs	79 (69.9)	26 (23)	8 (8.1)
The test is analytically valid	84 (75.7)	21 (18.9)	6 (5.4)
The study participant wanted to receive the IFs during informed consent	57 (75.9)	12 (10.7)	13 (13.4)
Severity of the condition			
Serious and preventable/treatable[a]	97 (85.8)	9 (8)	7 (6.2)
Serious and not preventable/treatable[a]	65 (57.5)	30 (26.5)	18 (15.9)
Serious, late-onset and preventable/treatable[a]	92 (81.4)	14 (12.4)	7 (6.2)
Not-serious and preventable/treatable	92 (81.4)	13 (11.5)	8 (7.1)
Not-serious and not preventable/treatable	54 (48.2)	39 (34.8)	19 (17)
Likelihood of disease threat			
The chance < 1% (rare)	30 (27.3)	34 (30.9)	46 (41.8)
The chance 1–5% (few)	46 (41)	31 (27.7)	35 (31.2)

The chance 6–49% (some)	69 (62.7)	24 (21.8)	17 (15.5)
The chance ≥ 50% (most)	84 (80)	12 (11.4)	9 (8.6)
Burden of intervention			
Very low burden	40 (47.6)	34 (32.4)	21 (20)
Somewhat burdensome	59 (54.7)	37 (34.3)	12 (11.1)
Moderately burdensome	74 (69.2)	25 (23.4)	8 (7.4)
Highly burdensome	81 (75)	18 (16.7)	9 (8.3)

Not serious: not life threatening

[a] Serious: life threatening

Participants were asked about their willingness to return incidental findings based on factors such as disease severity (serious versus non-serious), availability of prevention or treatment, likelihood of disease occurrence, and the burden of intervention. Most respondents considered it acceptable to disclose IFs regardless of disease severity or whether the condition was preventable or treatable. Acceptance of disclosure increased as the probability of disease occurrence rose: 84 participants (80%) indicated they would return IFs when the risk was ≥50%, and 69 participants (62.7%) would do so for a risk of 6–49%. Additionally, around three-quarters of respondents supported returning IFs even when the associated intervention carried a high burden.

Over two-thirds of participants agreed that IFs from genomic studies should generally be available to research participants, and 81 respondents (71.6%) believed participants should have the option to select which IFs are disclosed to them. Notably, 36 participants (31.9%) felt they could independently determine which IFs to return, and an equal proportion (31.9%) reported feeling no obligation to disclose incidental findings **(Table 3)**.

Table 3. Study participants' perception of the duties to return IFs

	Strongly agree + agree	**Neutral**	**Strongly disagree + disagree**
IFs from genome studies should be made available to research participants?	77 (68.1)	23 (20.4)	13 (14.5)
Research participants should have a choice on what IFs are disclosed to them?	81 (71.6)	18 (15.9)	14 (12.4)
Research participants alone should make the decision on what IFs are disclosed to them?	61 (55)	27 (24.3)	23 (20.7)
I can decide what IFs are disclosed to research participants (e.g. only serious and treatable conditions)?	36 (31.9)	29 (25.7)	48 (42.4)
Research participants have the right to make decisions about receiving IFs if they have no prior knowledge or family history of the conditions listed?	61 (55)	27 (24.3)	23 (20.7)
I can override the research participant's wishes if they consider it is not in their best interest to disclose a particular IF?	36 (31.9)	29 (25.6)	48 (42.5)
I can override the research participant's wishes if they consider it is not in the best interest of their family members to disclose a particular IF?	35 (31)	34 (30.1)	44 (38.9)
I have no obligation to return Ifs	36 (31.9)	39 (34.5)	38 (33.6)

Participants identified a range of obstacles to returning incidental findings. The most frequently cited barrier was the uncertain clinical utility of genetic research results, reported by 93 respondents (83%). Other notable barriers included the requirement to use clinically certified laboratories (n = 75, 66.4%), the risk that research participants might misinterpret the findings (n = 73, 64.6%), the potential for causing emotional distress (61%), concerns about the adequacy of clinical follow-up (n = 73, 64.6%), and the necessity of ensuring access to trained clinicians after disclosure (51%) **(Table 4)**.

Table 4. Barriers to the return of IFs

Barriers	Major barrier	Minor barrier
Uncertain clinical utility of IFs	93 (83.0)	19 (17.0)
Possibility that participants will misunderstand IFs	73 (64.6)	40 (35.4)
Potential for causing emotional harm to the study participants	63 (55.8)	50 (44.2)
Need to ensure access to trained clinician after disclosure of IFs	70 (61.9)	43 (38.1)
Potential for loss of confidentiality	72 (63.7)	41 (36.3)
Possibility that association with IFs may not be valid	68 (60.7)	44 (39.3)
Need to use a clinically certified lab	75 (66.4)	38 (33.6)
Concern about adequacy of clinical follow-up	73 (64.6)	40 (35.4)
Potential to distort the line between research and clinical care	54 (47.8)	59 (52.2)
Possibility of social discrimination	65 (57.5)	48 (42.5)
Concern over liability for adverse outcomes of IFs disclosure	65 (57.5)	48 (42.5)
Time commitment required to return IFs	52 (46.0)	61 (54.0)
Possibility that genotyping may be inaccurate	75 (66.4)	38 (33.6)
Need to keep contact patients information update	56 (50.0)	56 (50.0)
Need to keep up to date with relevant associations of IFs with the disease	64 (56.6)	49 (43.4)
Cost of returning IFs to participants	64 (56.6)	49 (43.4)

Discussion

The return of incidental findings (IFs) in genomic research remains a complex and evolving issue, with recommendations continuing to develop in response to emerging ethical, clinical, and societal considerations. This study examined the attitudes of clinical genomics professionals toward factors influencing the disclosure of IFs. While over half of respondents reported experience encountering IFs, approximately one-quarter expressed discomfort discussing these findings with research participants. This suggests that many professionals may feel unprepared to address the challenges posed by Next Generation Sequencing technologies, which increasingly identify clinically relevant IFs [18, 19].

There was broad agreement that IFs should be disclosed regardless of participant-specific factors such as age or potential psychosocial impact. These attitudes align with the American College of Medical Genetics and Genomics (ACMG) recommendations, which emphasize the return of IFs without restricting disclosure based on age, psychosocial status, or patient preference [1]. However, questions remain particularly for adult-onset conditions discovered in children, where the potential harms of disclosure and the benefits of parental intervention are not well defined, fueling ongoing debate. Our findings also indicate consensus among clinical genomics professionals regarding thresholds for returning IFs based on disease severity and clinical actionability. Most participants supported disclosing findings associated with a high risk of severe disease or where effective interventions exist. This reflects a perceived ethical duty to offer IF results to participants and, where relevant, their family members, especially when findings are preventable or treatable.

Interestingly, respondents generally accepted returning IFs even when the likelihood of disease occurrence was low, with acceptance increasing alongside rising risk. This is consistent with prior research suggesting that returning IFs is ethically acceptable regardless of disease probability [20–22]. Respecting participant autonomy remains a central ethical principle. Despite most participants supporting disclosure, about 31.9% reported they did not feel obligated to return IFs, echoing prior scholarly debate on whether researchers have a duty to disclose incidental findings [11, 12, 23]. Those advocating non-disclosure often adopt a precautionary approach to prevent potential harm from revealing sensitive information [24].

The implications of genomic information extend beyond the individual to families, offspring, and, in some cases, broader social groups. In the Saudi context, cultural, religious, and social structures—including extended and tribal family systems and high rates of consanguinity—necessitate careful consideration. Disclosure of IFs could inadvertently result in stigmatization or discrimination,

highlighting the ethical tension between respecting autonomy and minimizing harm. Therefore, culturally sensitive systems for IF disclosure should be established, aligning with Islamic principles, Saudi social norms, and international ethical standards.

Previous studies in Saudi Arabia indicate that returning IFs is generally perceived as a moral and ethical obligation [25, 26]. Accordingly, ACMG recommendations, which focus on reporting pathogenic or likely pathogenic variants among a set of actionable genes, must be interpreted cautiously within this cultural context [27].

Given the scale and complexity of genomic data, questions about how, when, and by whom IFs should be returned persist [28]. Developing legislative frameworks that integrate international human rights standards with local social and cultural contexts is crucial. Such frameworks should be supported by education, training, and public engagement. ACMG and NHLBI guidelines provide internationally recognized criteria for returning actionable IFs, including analytical validity, clinical actionability, substantial risk for serious conditions, and participant preference [13, 28]. Building on these standards, we recommend incorporating culturally sensitive assessments to evaluate the potential benefits and harms of returning each IF on a case-by-case basis, ideally through interdisciplinary review processes [29].

Clinical implications of incidental findings

Genomic incidental findings (IFs) identified in clinical settings can carry significant clinical relevance, directly affecting the health of patients and their families, informing reproductive decisions, and aiding future healthcare planning [30]. Consequently, the return of IFs, along with access to follow-up care and treatment, constitutes a fundamental clinical responsibility. In a recent qualitative study conducted in Saudi Arabia, researchers generally agreed on the importance of disclosing research results. However, some participants argued that returning IFs is not strictly the researcher's responsibility [26]. Notably, a portion of respondents considered it acceptable to override a participant's wishes if disclosure was deemed beneficial for the participant's family, raising potential legal and ethical issues surrounding confidentiality [8]. This perspective mirrors findings from Williams (2012), where researchers and institutional review board (IRB) members supported informing family members if the condition was inheritable [31]. Similarly, some participants believed overriding the participant's preferences is justified if disclosure is not in the participant's best interest. Prior studies by Williams (2012), Simon (2011), and Dressler (2012) emphasize the importance of predicting potential IFs and explicitly detailing in informed consent how they would be managed [31–33]. Moreover, research shows that serious and preventable IFs should be disclosed to participants, even against their preferences, highlighting the precedence of clinical utility [30, 34].

When IFs provide clear clinical utility—such as identifying carrier status or predicting future disease risk for family members—this can ethically outweigh the principle of non-disclosure [22]. The main barriers to returning IFs, including uncertain clinical utility, validity concerns, and the potential for participant misunderstanding, align with prior reports [17, 20].

Study Limitations

Although the study employed both online and paper-based recruitment to maximize national reach, the use of convenience sampling limits generalizability to the broader population of clinical genomic professionals in Saudi Arabia. While the findings provide insight into attitudes and perceptions regarding IF disclosure, actual clinical practice may differ. Further investigation is needed to objectively evaluate how professionals implement IF disclosure in practice. Additionally, contextual factors such as limited healthcare resources, challenges in interpreting IFs, and institutional constraints may influence actual practices despite reported support for disclosure.

Conclusions

This study demonstrates broad support among clinical genomic professionals for returning clinically actionable IFs, particularly when disease risk is elevated. IFs are commonly encountered in professional practice, yet many workplaces lack formal guidelines for their management. There is a clear need for comprehensive, culturally tailored guidelines in Saudi Arabia to govern the disclosure of IFs. Ethically, IFs should be returned when results are accurate, interpretable, and clinically relevant to the participant's health. Proper management of IFs can significantly impact patient care and potentially save lives. Hence, ethical frameworks should

balance the participant's and family's best interests with the advancement of genomic research. Empirical exploration of the implications of returning IFs within the Saudi context is warranted to guide best practices and policy development.

Acknowledgments: None

Conflict of Interest: None

Financial Support: None

Ethics Statement: None

References

1. Green RC, Berg JS, Grody WW, Kalia SS, Korf BR, Martin CL, et al. ACMG recommendations for reporting of incidental findings in clinical exome and genome sequencing. Genet Med. 2013;15:565–74.
2. Wolf SM, Lawrenz FP, Nelson CA, Kahn JP, Cho MK, Clayton EW, et al. Managing incidental findings in human subjects research: analysis and recommendations. J Law Med Ethics. 2008;36(2):219–211.
3. Jackson L, Goldsmith L, O'connor A, Skirton H. Incidental findings in genetic research and clinical diagnostic tests: a systematic review. Am J Med Genet Part A. 2012;158(12):3159–67.
4. Clarke AJ. Managing the ethical challenges of next-generation sequencing in genomic medicine. Br Med Bull. 2014;111(1):17–30.
5. Fernandez CV, Bouffet E, Malkin D, Jabado N, O'Connell C, Avard D, et al. Attitudes of parents toward the return of targeted and incidental genomic research findings in children. Genet Med. 2014;16(8):633.
6. Bollinger JM, Green RC, Kaufman D. Attitudes about regulation among direct-to-consumer genetic testing customers. Genet Test Mol Biomark. 2013;17(5):424–8.
7. Harris A, Kelly SE, Wyatt S. Counseling customers: emerging roles for genetic counselors in the direct-to-consumer genetic testing market. J Genet Counsel. 2013;22(2):277–88.
8. Bledsoe MJ, Grizzle WE, Clark BJ, Zeps N. Practical implementation issues and challenges for biobanks in the return of individual research results. Genet Med. 2012;14(4):478–83.
9. Clayton EW, McGuire AL. The legal risks of returning results of genomics research. Genet Med. 2012;14(4):473–7.
10. Ossorio P. Taking aims seriously: repository research and limits on the duty to return individual research findings. Genet Med. 2012;14(4):461.
11. Lockhart NC, Yassin R, Weil CJ, Compton CC. Intersection of biobanking and clinical care: should discrepant diagnoses and pathological findings be returned to research participants? Genet Med. 2012;14(4):417–23.
12. Ma'n HZ, Knoppers BM. International normative perspectives on the return of individual research results and incidental findings in genomic biobanks. Genet Med. 2012;14(4):484–9.
13. Bookman EB, Langehorne AA, Eckfeldt JH, Glass KC, Jarvik GP, Klag M, et al. Reporting genetic results in research studies: summary and recommendations of an NHLBI working group. Am J Med Genet Part A. 2006;140(10):1033–40.
14. Lohn Z, Adam S, Birch P, Townsend A, Friedman J. Genetics professionals' perspectives on reporting incidental findings from clinical genome-wide sequencing. Am J Med Genet Part A. 2013;161(3):542–9.
15. Berg JS, Foreman AK, O'daniel JM, Booker JK, Boshe L, Carey T, Crooks KR, Jensen BC, Juengst ET, Lee K, Nelson DK. A semiquantitative metric for evaluating clinical actionability of incidental or secondary findings from genome-scale sequencing. Genet Med. 2016;18(5):467–75.
16. Ewuoso C. A systematic review of the management of incidental findings in genomic research. BEOnline: J West Afr Bioethics Train Program. 2016;3(1):1.
17. Ramoni RB, McGuire AL, Robinson JO, Morley DS, Plon SE, Joffe S. Experiences and attitudes of genome investigators regarding return of individual genetic test results. Genet Med. 2013;15(11):882–7.
18. Kohane IS, Hsing M, Kong SW. Taxonomizing, sizing, and overcoming the incidentalome. Genet Med. 2012;14:399–404.
19. Johnston JJ, Rubinstein WS, Facio FM, Ng D, Singh LN, Teer JK, et al. Secondary variants in individuals undergoing exome sequencing: screening of 572 individuals identifies high-penetrance mutations in cancer-susceptibility genes. Am J Hum Genet. 2012;91(1):97-108. doi:

10.1016/j.ajhg.2012.05.021. Epub 2012 Jun 14. PMID: 22703879; PMCID: PMC3397257.

20. Middleton A, Morley KI, Bragin E, Firth HV, Hurles ME, Wright CF, et al. Attitudes of nearly 7000 health professionals, genomic researchers and publics toward the return of incidental results from sequencing research. Eur J Hum Genet. 2016;24(1):21–9.
21. Wright MF, Lewis KL, Fisher TC, Hooker GW, Emanuel TE, Biesecker LG, et al. Preferences for results delivery from exome sequencing/genome sequencing. Genet Med. 2014 Jun;16(6):442-7. doi: 10.1038/gim.2013.170. PMID: 24310310; PMCID: PMC4597884.
22. Christenhusz GM, Devriendt K, Dierickx K. To tell or not to tell? A systematic review of ethical reflections on incidental findings arising in genetics contexts. Eur J Hum Genet. 2013;21(3):248–55.
23. Wolf SM, Crock BN, Van Ness B, Lawrenz F, Kahn JP, Beskow LM, et al. Managing incidental findings and research results in genomic research involving biobanks and archived data sets. Genet Med. 2012;14(4):23.
24. Townsend A, Adam S, Birch PH, Lohn Z, Rousseau F, Friedman JM. "I want to know what's in Pandora's box": comparing stakeholder perspectives on incidental findings in clinical whole genomic sequencing. Am J Med Genet Part A. 2012;158A:2519–25.
25. Aloraini T, Abdulrahim A, Karbani GA. Attitudes of geneticists and patients toward incidental findings in Saudi Arabia. J Biochem Clin Genet. 2019;2(2):116–21.
26. Alahmad G, Alzahrany H, Almutairi AF. Returning results of stored biological samples and biobanks: perspectives of Saudi Arabian biomedical researchers. Biopreserv Biobank. 2020;18(5):395–402.
27. Kalia SS, Adelman K, Bale SJ, Chung WK, Eng C, Evans JP, et al. 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. Genet Med. 2017;19(2):249–55.
28. Fabsitz RR, McGuire A, Sharp RR, Puggal M, Beskow LM, Biesecker LG, et al. Ethical and practical guidelines for reporting genetic research results to study participants: updated guidelines from a National Heart, Lung, and Blood Institute working group. Circ: Cardiovasc Genet. 2010;3(6):574–80.
29. Al Shakaki A. Islamic bioethical discourse in incidental findings: research genetic context. Innov Glob Health Prof Educ. 2019:22–23. https://doi.org/10.20421/ighpe2019.01.07.
30. Downing NR, Williams JK, Daack-Hirsch S, Driessnack M, Simon CM. Genetics specialists' perspectives on disclosure of genomic incidental findings in the clinical setting. Patient Educ Couns. 2013;90(1):133–8.
31. Williams JK, Daack-Hirsch S, Driessnack M, Downing N, Shinkunas L, et al. Researcher and institutional review board chair perspectives on incidental findings in genomic research. Genet Test Mol Biomark. 2012;16(6):508–13.
32. Simon CM, Williams JK, Shinkunas L, Brandt D, Daack-Hirsch S, Driessnack M. Informed consent and genomic incidental findings: Irb chair perspectives. J Empir Res Hum Res Ethics. 2011;6(4):53–67.
33. Dressler LG, Smolek S, Ponsaran R, Markey JM, Starks H, Gerson N, et al. Irb perspectives on the return of individual results from genomic research. Genet Med. 2012;14(2):7.
34. Klitzman R, Appelbaum PS, Fyer A, Martinez J, Buquez B, Wynn J, et al. Researchers' views on return of incidental genomic research results: qualitative and quantitative findings. Genet Med. 2013;15(11):888–95.