Views of Nonmedical, Health System Professionals Regarding the Return of Whole Genome Sequencing Incidental Findings

Kimberly A. Strong, PhD; Kaija L. Zusevics, PhD, MPH; David P. Bick, MD; Regan Veith, MS

ABSTRACT

Background: Use of genome sequencing in the clinic continues to increase. In addition to its potential to provide findings of clinical benefit, it also has the potential to identify findings unrelated to the indication for testing (incidental findings). Incidental findings are the subject of considerable debate, particularly following the publication of recommendations by the American College of Medical Genetics and Genomics. This debate involves how and which results should be returned as well as stakeholders' desires for such results. Part of the difficulty in determining best practice in relation to returning incidental findings is the dearth of empirical data available regarding laypersons' attitudes and desire for the sometimes controversial information.

Methods: In an effort to contribute data on views regarding the return of incidental findings following genome sequencing in a clinical setting, a survey specifically designed around the various types of incidental findings that occur, ranging from clinically actionable to nonactionable, was administered to a nonmedical population of medical coders working at a medical school (N = 97). Almost all (98%) of the respondents were women, 80% had 6 or more years of experience as a medical coder, and about three-fourths (74%) of participants reported that they had children.

Results: The group surveyed was considerably more interested in receiving all types of results for both themselves and their children than previously surveyed genetics professionals.

Conclusion: Results from this study offer a snapshot of opinions beyond those of the professional genetic community and demonstrate a striking difference between genetic professionals and a more lay population in terms of their attitudes and desires regarding the return of incidental findings. Additional research is needed to explain the nuances in the perspectives motivating these variations.

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Author Affiliations: Program in Genomics and Ethics, Center for Bioethics and Medical Humanities, Institute for Health and Society, Medical College of Wisconsin, Milwaukee (Strong, Zusevics); Human and Molecular Genetics Center, Medical College of Wisconsin, Milwaukee (Strong, Bick, Veith); Section of Genetics, Department of Pediatrics, Medical College of Wisconsin, Milwaukee (Bick); Children's Research Institute, Children's Hospital of Wisconsin, Milwaukee (Bick); Genetics Center, Children's Hospital of Wisconsin, Milwaukee (Veith); Genomics Medicine Clinic, Children's Hospital of Wisconsin, Milwaukee (Veith).

Corresponding Author: Kimberly A. Strong, PhD, Program in Genomics and Ethics, Center for Bioethics and Medical Humanities, Medical College of Wisconsin, 8701 Watertown Plank Rd, Milwaukee, WI 53226; phone 414.955.8460; fax 414.955.6511; e-mail kstrong@mcw.edu.

INTRODUCTION

Sequencing of the exome and of the entire genome (together referred to as clinical sequencing in this report) has entered clinical practice.[1,2] It is able to diagnose rare genetic disorders,[3] suggests treatments for cancer patients,[4] and rapidly identifies inherited disorders in newborns.[5] Use of clinical sequencing in direct-to-consumer (DTC) genetic testing also may expand.[6]

When clinical sequencing is used in medical practice, testing may uncover incidental (or secondary) findings. Incidental findings (IFs) in this context are DNA changes (variants) of varying clinical significance that are unrelated to the indication for testing. Some will be pathogenic variants, while many will be benign variants or variants of uncertain significance.[7] As our understanding of these variants increases, the number of IFs that could alter medical management (actionable findings) will increase. (Actionable findings are defined as gene variants that are associated with an increased risk for a particular disease or condition for which there are "established therapeutic or preventative interventions, or other available actions, that have the potential to change the clinical course of the disease."[8])

In addition, an increase is expected in the number of IFs for conditions for which there are no interventions currently available that may change the disease prognosis (nonactionable findings). Laboratories rely on several important elements when determining whether or not a variant will be reported as actionable or nonactionable, including medical reports, policy statements, lab regulatory bodies, and state and federal statutes. Additional factors or influences include personal utility or degree to which the individual may use the information to take action regarding a

specific portion of their lifestyle, reproductive decision-making, or employment. One such policy statement was issued by the American College of Medical Genetics and Genomics (ACMG), which aimed to provide guidelines for physicians and laboratories involved in genomic sequencing.[9] However, this practice statement was not universally accepted, particularly its recommendation that certain incidental findings should be reported "without reference to patient preference."[9] Criticisms regarding this approach were raised[10-12] and the ACMG subsequently released a revision stating "patients should have an opportunity to opt out of the analysis of medically actionable genes when undergoing whole exome or genome sequencing."[10] At present, there is little empirical data to help physicians and laboratories decide how best to involve patients in this decision making.[13] Yet, it has been suggested that clinicians may face liability if they fail to disclose an IF that could result in an intervention that improves health outcome.[14]

Survey information concerning the return of IFs found through clinical sequencing is starting to emerge. Green et al[15] questioned 16 specialists in clinical genetics and/or molecular medicine. They were asked to select variants in 99 common conditions that they would return to the ordering physician if discovered incidentally through clinical sequencing. In only 21 conditions did all 16 agree in favor of disclosure—for adult-onset conditions with a known pathogenic mutation. Another survey of 279 clinical genetics professionals examined attitudes towards IFs identified through clinical sequencing.[8] The authors found that the vast majority of respondents were interested in learning about actionable IFs in themselves (96%) and in their child (99%). There was far less agreement concerning nonactionable findings. Just 44% wanted to know about IFs related to adult-onset nonactionable disorders in themselves, and 31% wanted to know such information about their child. A recently published study of 258 primary care providers demonstrated very similar results.[16]

Lohn et al[17] distributed an online questionnaire to 496 geneticists and genetic counselors in Canada to ascertain their views concerning disclosure of IFs from clinical sequencing. Responses from the 210 participants varied depending on the nature of the finding; 95% recommended disclosure of an IF pertaining to a serious and treatable condition, while only 12% recommended disclosure of an IF with only social implications (eg, nonpaternity). It is important to note that the majority of genetic counselors (84%) and geneticists (79%) indicated that families should be given a choice as to which kinds of IFs are returned to them.

In addition to the survey data above, a recently published study involved focus groups of 35 genetics health professionals.[18] While participants demonstrated a diverse range of views regarding the return of genomic results, overall, patient autonomy was deemed a vital component in the decision-making process.

Data also exists concerning patient/family preference regarding return of genomic research results[19] as well as the public's preference concerning informatin about ancillary risk associated with particular pharmacogenetic test results.[20] However, with regard to clinical sequencing, there is a paucity of data pertaining to the views of the general population and individuals who are likely to be the beneficiaries of IFs. Townsend et al[21] used 3 focus groups—genetics health care professionals, the general public, and parents whose children have experienced genetic testing—to explore attitudes about the disclosure of IFs in clinical sequencing. A significant divide was identified. Professionals expressed a preference to limit analysis in order to avoid IFs as much as possible and focus pretest discussions primarily on medical relevance. In contrast, the lay groups in this study emphasized autonomy and patients' rights to choose what findings they receive and felt that patients would accept the consequences of any potential anxiety and uncertainty engendered by the results.

Continued guidance on IFs from the medical and ethics community is essential; however, more information is needed from the general population and individuals who are the likely beneficiaries of this technology. To further survey attitudes toward the return of IFs, we engaged nonmedical health system professionals (lay professional members of an academic department in a medical school) around this issue as a step towards evidence-based guidelines that involve all stakeholders.

MATERIALS AND METHODS

Study Sample and Recruitment

Following a 45-minute presentation about basic genetics concepts and clinical genetics care presented by one of the authors (DB), attendees at the Medical College of Wisconsin's (MCW) Billing and Collections Team (BCT) meeting in February 2013 were invited to participate in a voluntary, anonymous survey. This method was similar to a previous administration of the same survey.[16] The purpose of the lecture preceding the survey was to provide a broad overview of genetics and genomics in clinical practice to a general audience. Lecture topics included the definition of basic genetic concepts (gene, chromosome, inheritance), examples of patient populations that would benefit from genetic testing, overview of how genetic diseases are cataloged, inheritance patterns (autosomal recessive, autosomal dominant, x-linked, mitochondrial, chromosomal), penetrance, variability, prenatal genetic topics (age-related risk, fertility, preconception risk assessment, screening, diagnostic testing, chorionic villus sampling, amniocentesis, ultrasound examination, reproductive options, preimplantation genetic diagnosis), genetic screening, ethnic-related disease incidence, disease specific examples that highlight the previous definitions (cystic fibrosis, Tay-Sachs disease, thalassemia, sickle cell anemia, Down syndrome), example

of the clinical diagnostic considerations for a disease category exemplified by neurodevelopmental disorders, examples of how a known genetic diagnosis or risk can be used to benefit patients, definition of whole exome/genome sequencing and when they are clinically indicated, definition of primary and secondary results, and definition and examples of both adult- and childhood-onset medically actionable and nonactionable diseases. The same diseases used as examples in the survey were used in the lecture. The BCT is composed largely of support staff members who fall in the category of "professional health care support occupation." They are responsible for coding the professional component of evaluation and management services and/or procedures rendered by MCW faculty, serving as liaisons for patient complaints, responding to insurance organization inquiries, and/or providing education to faculty. The group's leader stated that overall, these professionals have an intermediate to advanced knowledge of coding conventions and functionalities, anatomy and physiology, and medical terminology, suggesting a potential aptitude for medical topics such as genetics. The BCT meets regularly to offer continuing education credits for staff members who are accredited by the American Academy of Professional Coders (AAPC).

Survey Development and Data Collection

A 23-item questionnaire (by Lemke and colleagues[8]) that was previously developed, vetted, and used by internal and external experts was administered to assess participants' attitudes regarding whole genome sequencing (WGS) for themselves and their children, as well as their views about the return of results in 3 distinct areas: (1) types of WGS results they would want about themselves; (2) types of WGS results they would want for their children; and (3) the management of incidental findings in adults and minors in clinical settings. The questionnaire also gathered demographic information about the participants. For nondemographic questions, participants were asked to respond on a 4-point Likert scale ranging from "strongly disagree" to "strongly agree."[8] Although we did not assess participants' baseline knowledge of genetics/genomics, we administered the questionnaire immediately after the educational session about genetics and genomics in order to establish that all participants were exposed to similar information about topics addressed in the survey prior to responding to the questions. For consistency, the same wording, definitions of terms (incidental findings, etc), and examples were used in both the presentation and survey administration.

The survey was administered using Turning Technologies (Turning Technologies LLC, Youngstown, Ohio), which uses PowerPoint-imbedded surveys and enables the collection of anonymous responses through a hand-held device. The questionnaire was read aloud by one of the authors (RV) as participants responded using their hand-held devices, and the anonymous responses were documented immediately. Results for each question were shown to participants after the devices received and tabulated responses from all participants. This study was approved by the Human Research Protections Program, the Institutional Review Board at MCW.

Table 1. Participant Characteristics

Characteristics, N=97	%	(n)
Gender		
Female	97.7	(83)
Male	2.4	(2)
Age		
18-25	1.2	(1)
26-35	16.7	(14)
36-45	23.8	(20)
45-55	27.4	(23)
56 +	31	(26)
Educational Level		
High school diploma or GED	4.8	(4)
Certificate program	43.4	(36)
2-year associate degree	24.1	(20)
Bachelor's degree	24.1	(20)
Master's degree	3.6	(3)
Other advanced degree (MD, JD, PhD)	0	(0)
Length of Time Practicing in Primary Work Role		
Still in training	2.4	(2)
0-5 years	16.7	(14)
6-10 years	27.4	(23)
11-15 years	19.1	(16)
16-20 years	15.5	(13)
21 or more years	19.1	(16)
Number of Children		
0	26.2	(22)
1	16.7	(14)
2	32.1	(27)
3	19.1	(16)
4	1.2	(1)
5 or more	4.8	(4)

Abbreviation = GED, General Educational Development

Statistical Analysis

The survey response data were downloaded from the Turning Technologies software and exported to SPSS Statistics (IBM, Armonk, New York) for statistical analysis. Descriptive statistics were conducted on all survey questions. For the questions with Likert scale responses, "strongly" and "somewhat," categories were combined to result in two categories rather than one for ease of reporting and to be able to compare results with the first administration of the survey and maintain statistical procedural consistency.[8] Valid percentages for each question are reported. (Missing responses are excluded; therefore, response rates vary for each question.) Cross tabulations were conducted to examine differences in responses between categories of respondents, such as age, having children, and wanting one's genome sequenced.

Table 2. Survey Results

Question	Response % (n)
I would want to know about an incidental finding that indicates a genetic association with an:	**Somewhat or Strongly Agree**
Adult-onset disease that is "clinically actionable."	96.5 (82)
Adult-onset disease that is NOT "clinically actionable."	80.7 (67)
Adult-onset disease with uncertain clinical significance.	74.2 (66)
I would want to know about an incidental finding about my child that indicates a genetic association with a/an:	**Somewhat or Strongly Agree**
Childhood-onset disease that is "clinically actionable."	98.8 (82)
Childhood-onset disease that is NOT "clinically actionable."	83.7 (72)
Adult-onset disease that is "clinically actionable."	95.3 (81)
Adult-onset disease that is NOT "clinically actionable."	77.1 (64)
Disease with uncertain clinical significance.	83.3 (70)
In an adult patient: I think an incidental finding should be made available that indicates a genetic association with an:	**Somewhat or Strongly Agree**
Adult-onset disease that is "clinically actionable."	95.3 (82)
Adult-onset disease that is NOT "clinically actionable."	91.7 (77)
In minor (under 18) patient: I think an incidental finding should be made available that indicates a genetic association with a/an:	**Somewhat or Strongly Agree**
Childhood-onset disease that is "clinically actionable."	98.8 (81)
Childhood-onset disease that is NOT "clinically actionable."	91.4 (74)
Adult-onset disease that is "clinically actionable."	94.9 (74)
Adult onset disease that is NOT "clinically actionable."	84.7 (72)

Chi-square and Fisher exact statistical tests were used to ascertain if there were statistically significant differences in responses between groups. Exact *P*-values were calculated; a significance level of ≤ 0.05 was used throughout analysis.

RESULTS

There were a total of 97 participants in the sample. Participants could abstain from answering any questions; therefore, response rates were calculated based on the number of answers provided for each question. See Table 1 for demographic characteristics of the sample and Table 2 for survey questionnaire results. Over two-thirds of respondents (67.6%, n=50) reported wanting their genome sequenced; 24.3% (n=18) did not want their genome sequenced; and 8.1% (n=6) were unsure at the time of the survey. A slight majority of the respondents (56.2%, n=50) strongly or somewhat agreed that they would want their child's genome sequenced.

Overall, there was a reported desire among study participants to receive information about IFs both for themselves and for their children for all categories of findings. These items asked participants to respond to the questions as though they, or their child, were receiving sequencing for a particular diagnostic indication and an "incidental finding" was detected. There were no significant differences in responses about IFs between participants who had children and those who did not. Data for those who strongly or somewhat agreed with the statements are reported in Table 2.

For several questions, there were statistically significant differences in responses between those who indicated that they would want their genome sequenced and those who would not. Nearly three-fourths (72.9%, n = 35) of respondents who would want their genome sequenced agreed or somewhat agreed that they would also want their child's genome sequenced, which was significantly higher than among those respondents who would not want their genome sequenced or were unsure, χ^2 (3, n = 72) = 38.138, $P < .000$. In addition, 89.6% (n = 43) of respondents who would want their genome sequenced strongly or somewhat agreed that they would want to know about an IF regarding an adult-onset disease that was not clinically actionable, which was significantly higher than respondents who did not want their genome sequenced or were unsure, χ^2 (2, n = 71)=10.13, $P = .006$. Moreover, 87.8% (n = 43) strongly or somewhat agreed that they would want to know about an incidental finding with uncertain clinical significance, which was significantly higher than among those who would not want or were unsure about having their genome sequenced, $\chi^2(2, n = 73) = 15.049$, $P = .001$. Slightly over 85% (85.1%, n = 40) strongly or somewhat agreed that they would want to know about an IF in their child related to an adult-onset disease that was not clinically actionable, $\chi^2(2, n = 70) = 6.942$, $P = .031$. Finally, 91.7% (n = 44) of those who would want their genome sequenced strongly or somewhat agreed that they would want to know about an IF in their child with uncertain clinical significance, which was significantly higher than the comparison group, $\chi^2(2, n = 72) = 7.820$, $P = .020$. There were no significant differences in wanting one's genome sequenced in terms of age of participant, number of children, or having children.

DISCUSSION

This is the second time this survey has been used to explore attitudes regarding the return of incidental findings. Unlike the previous administration of this survey, which involved clinical genetics professionals,[8] this study queried participants who did not have special qualifications regarding genetics and whose edu-

cation levels were similar to that of the general Wisconsin public (http://www.census.gov/compendia/statab/2012/tables/12s0233.pdf). Therefore, this study begins to provide some information on the attitudes of a nonspecialist group regarding WGS and receipt of possible "results" of genomic testing.

While the participants in this study were not genetics professionals, answers to many of the questions demonstrate similar agreement/disagreement percentages. Both the expert and nonexpert study participants reported very similar, nearly unanimous desire for the return of adult-onset "clinically actionable" results for themselves (~96%) and "clinically actionable" childhood-onset conditions for children (~99%). This subset of the lay population was considerably more interested in receiving all types of results for both themselves and their children. Regardless of whether a disease-causing variant was actionable, the majority of participants in this study (>74%) reported that they would want to be informed of findings. This is in contrast to the genetic professionals' survey results, wherein less than half of the respondents reported a desire to know about nonactionable findings. There could be several factors contributing to this contrast, including divergent baseline knowledge and familiarity with potential legal and financial implications of genetics testing (ie, the Genetic Information Nondescrimination Act [GINA] and the Health Insurance Portability and Accountability Act [HIPAA]). Although beyond the scope of the introductory lecture and assessment of this survey, these considerations provide future direction for investigation and should be considered in the context of this comparison. The potential lack of knowledge about this legislation among this study's participants may have contributed to their higher interest in receiving results that may be nonactionable or have uncertain clinical significance.

Interestingly, when questions moved toward the return of results, participants who reported that they would not choose to undergo WGS still indicated they would want to receive the results. Understanding what is driving a desire for disclosure of results once known, when not interested initially in pursuing the technology that would provide those results, requires more study. Once the leap is made (in our hypothetical scenarios) to the situation wherein testing is complete and findings are available, most people do not appear to want those findings withheld. It is possible that—similar to other qualitative studies involving lay populations[21]—these results may represent a desire for involvement in decision making and a resistance to others knowing something they do not. Preferences or opinions are relevant to the discussion; however, consideration must be made for emotion and influence of perception of fact associated with such inquiry. Attempts to exclude patients/parents from taking part in the decision-making process may not be supported by the population itself.

In this study, interest in testing for oneself correlates with a strong reported desire to receive genetic findings for both oneself and children, regardless of potential actionability related to the finding. It is notable that a very high percentage of participants reported a desire for return of results, even when the results have uncertain clinical significance or are not clinically actionable. In contrast, the genetic professional population previously studied was considerably more opposed to the return of such results.[8]

Study Limitations

This study points to differences in attitudes regarding incidental findings between medical and nonmedical audiences; however, there are several limitations. First, the participants may not be representative of a truly "lay" audience given their exposure to medical concepts through their work with medical records. Thus, the findings are not generalizable to other nonmedical populations, and they may be biased because these nongenetics professionals work in an academic medical center where innovative tests and therapies are commonly introduced. Most participants (97.7%) were women; thus, the findings are largely representative of female perspectives on IFs.

The use of Turning Technologies as a data collection mechanism may have limited the degree of participation among survey participants who are not familiar with or comfortable using new technologies.

In addition, this study is limited in the scope of statistical analysis that could be performed due to the overall small sample size and variable number of responses per question. Although we assessed how many children participants had, we did not explore what type of parent (ie, parenting style, characteristics) participants see themselves as being, which could influence their responses in terms of their desires for IF reports for their children.[22,23]

This type of attitudinal survey is not designed specifically to explore participant knowledge, understanding, or thought processes prior to their selection of particular answers. It is noteworthy that this study lacked information about the participants' knowledge and comprehension of factors that influence decision-making about IFs, such as a full grasp of the risks (including the limitations of current privacy regulatory protections) and benefits of genomic testing in various contexts. Methodologies allowing for more in-depth exploration of motivation, such as open-ended and cognitive interview, will be needed to better assess this understanding as well as the disconnect between the lack of desire for the test, but a largely congruent desire for the test result. In addition, the results of this survey are based on hypothetical questions and may not represent how participants would act in the future.

CONCLUSION

There are many clinics and providers that offer a patient-centered approach to diagnostics and medical management. Personalized care has been an emerging theme among institutions across the country. The popularity of direct-to-consumer genetic testing

suggests that some patients/consumers desire a certain level of control or decision-making capacity in their health care diagnosis and management. This is not to say that patients should have the only opinion that matters during the decision-making and policy consideration time; rather, it acknowledges that they are key stakeholders in the genomics era. Further investigation and research is needed among a broader population to increase generalizability; however, this study offers a snapshot of opinions beyond the genetics community. While it is important to acknowledge that empirical data regarding preferences/attitudes/opinions are not in themselves sufficient to direct policy,[24] overwhelming public/professional sentiment that contradicts policy should be a flag for a need to further discuss the basis upon which policy has been set. In order to avoid such a situation, empirical data regarding preferences/attitudes/opinions provide useful contextualization. In the absence of other data, we recommend that clinical discussions and decisions about the return of incidental findings following genome sequencing continue to take account of patient preferences regarding the receipt of such results.

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