Raising Genomic Citizens: Adolescents and the Return of Secondary Genomic Findings

Maya Sabatello and Paul S. Appelbaum

Whole genome and exome sequencing (WGS/WES) techniques raise hope for a new scale of prediction, prevention, and diagnosis of genetic conditions, and improved care for children. Although still in its early stages, the increased investment in pediatric genomic research, the rapid progress in powerful data analysis technologies, and the plummeting costs associated with DNA sequencing are promising indicators of future introduction of WGS/WES into routine clinical practice. However, the use of WGS/WES in pediatric research settings raises considerable challenges for families, researchers, and policy makers. In particular, the possibility that these techniques will generate genetic findings of medical and nonmedical relevance unrelated to the primary goal of sequencing has stirred intense debate about whether, which, how, and when these secondary or incidental findings (SFs) should be returned to parents and minors.[1]

Scholarly work to date has focused largely on adults' perspectives on return of SFs in pediatric research settings. This attention resonates with the traditional presumptions that parents and other adults know what is in their children's "best interests," and that minors lack the capacity to provide informed consent. However, these presumptions do not easily apply to adolescents (ages >13). Adolescents constitute a developmental category that is separate from children,[2] and their competence to make genetic-related decisions may resemble that of adults' more than is commonly assumed (see below). Moreover, adolescents are more likely than younger children to develop health preferences and views about their "best interests," perspectives that may be different than those of their parents.[3]

How to balance these potentially conflicting views is challenging; however, given that parental authority is not unlimited and that adolescents will bear the long-term consequences of decisions about return of SFs, consideration of adolescents' preferences is important. We suggest that the growth of WGS/WES research on pediatric conditions should lead to the emergence of what we term "genomic citizenship." This concept — which originated in sociological scholarship but evolved into a not-yet-fully-defined set of normative expectations — builds on the intersection among science, medicine, social movements and policy-making. It merges finance, governance, technoscience, and stakeholder engagement,[4] and, importantly, it vests individuals with genomic rights and responsibilities to information and participation in decision making that

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extend beyond themselves and their families to the community and nation at large. Indeed, the presidential Precision Medicine Initiative rests on an appeal for citizens' sharing of genetic, environmental, and lifestyle data in exchange for partnership and engagement to further advance individual, community, and population health.[5] As adolescents are genomic citizens in the making, their involvement in decisions about return of genomic SFs is worth consideration.

In this article, we consider the complexities of return of genomic SFs to adolescents in research settings. After discussing the rise of genomic citizenship and its significance for adolescents, we consider the challenges that arise. Recognizing that the scarcity of studies of adolescents limits the database on which discussion of these issues can draw, we highlight areas for future research. We argue that adolescents' involvement in decisions about return of SFs acknowledges their status as valuable stakeholders, without detracting from broader familial interests, and promotes more informed genomic citizens.

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Genomic Citizenship

The discussion about genetics and citizenship is not new: it emerged from the social sciences in the 1990s and reflects the intersection of 2 developments. The first development is the social reconceptualization of citizenship within the paradigms of the feminist, children's, and disability rights movements. Accordingly, citizenship is increasingly understood as encompassing not only public activity but also involvement in the private sphere,[6] and as contingent not on rigid and fixed degrees of participation but on individual capacity and lived experiences.[7] This concept of citizenship is further recognized for its valuing of a plurality of viewpoints in decision-making processes and its expectation that stakeholders participate in and share the benefits arising from the programming, planning and implementation of relevant policies.[8] This reconceptualization subsequently extended the recognition that "science is politics by other means" to molecular genetics[9] and enabled the conception of minors' interactions and negotiation of their positions in various spaces (family, medical treatment, etc.) as a form of citizenship.[10]

The second development is the upsurge of scientific knowledge of genetics. As sociological and anthropological scholars have observed, since the inception of the Human Genome Project, both medical practice and popular perception are increasingly "geneticized."[11] Advances in genetic testing have led to the much-debated notion of "genetic identity" as an individual and collective attribute,[12] and to the emergence of voluntary networks of individuals with genetic conditions (and their families) as key partners in scientific endeavors and policy-making. Although these patient- and family-based associations originated to provide members with education and support, they began to engage with lobbying for additional funding for research about their conditions and with efforts to find treatments and cures.[13] The combined effect of these processes transformed patients' empowerment and collective mobilization into a "genetic citizenship" that encompasses rights and obligations.[14] Although informed consent and free choice remain the cornerstones of the decision-making process, individuals increasingly have been expected to engage in testing and adopt self-surveillance methods if they are at-risk for a genetic condition.[15]

The extent of the obligations associated with genetic citizenship, as well as the normative basis on which the concept rests, have not been definitively articulated. However, the use of WGS/WES modifies the discussion on genetic citizenship in 3 important

ways. First, it shifts from the traditional research focus on individuals with a diagnosed genetic condition to multi-gene clinical diagnostic and population-based preventive screening programs,[16] which are likely to generate far more extensive data relevant to the health of the adults and children involved. Concurrently, because sequencing produces a great deal of data with unknown or varying degrees of significance as well as potentially yielding nonmedical data (e.g., regarding predispositions to behavioral traits), it encourages a broader inquiry into *which* genomic findings individuals have a right, and a responsibility, to know. Moreover, the increase of genomic data underscores the complexity at stake. Post-sequencing, it is clear that the phenomenon of one gene encoding one genetic product is the exception and not the rule for genetic expression, and that expression of individual genes is the result of multiple epistatic, gene-environment, and epigenetic processes and interactions that are extremely difficult to decode. Thus, delineating the emerging rights and responsibilities of genomic citizens with regard to a given set of findings, is particularly challenging.

Second, the landscape of activism has been transformed from patient and family-based associations, usually focused on rare disorders attributable to variations in single genes,[17] to a much broader range of stakeholders.[18] In addition to patients and their family members, stakeholders in WGS/WES research initiatives include, among others, researchers, technologists, healthy volunteers, an increased volume of "patients-in-waiting,"[19] and customers of direct-to-consumer (DTC) genetic testing companies who may utilize these services for nonmedical reasons (e.g., ancestry) and whose genetic data may be used to promote research endeavors (e.g., 23andMe,[20] Gene By Gene, Ltd.[21]). For these reasons, the value of informed stakeholders' engagement in developing genomic-related clinical and research policies has been uniquely recognized in the context of WGS/WES.[22] Importantly, the shift from an exclusive quest for genomic knowledge as part of bedside medicine to include genome sequencing as an educational or recreational activity also reflects the more mundane experience (at least among those who already have utilized these services and the plethora of scholars, journalists, and bloggers who are invested in this issue) of genomic citizenship.

Finally, WGS/WES shifts the focus of work from small clinically based research programs to larger-scale research conducted through biobanks. Although biobanks have existed for a long time, advances in genomics and bioinformatics have led to a steep rise in the number of biobanks[23] and noticeable changes have occurred in their design, operation, and practices. Today, most biobanks generate and store genome-scale sequencing data and their research mission is notably broader than interest in only one particular disorder.[24] Moreover, because biobanks are viewed as a powerful resource in the effort to advance precision medicine, recruitment across age, sex, and racial groups has become a major goal of researchers, governments, private corporations, and advocacy groups (e.g., Genetic Alliance).[25] Although public voluntarism remains key for participation, the potential benefit of WGS/WES for public health outcomes may lead to an evolution in individuals' perceived genetic obligations to encompass broader societal interests. As an example, most of the 752 participants in a genetic epidemiology study of colon cancer risk factors endorsed a concept of genomic responsibility that embraces individuals regardless of their risk status. They embraced a belief that their contributions to the genomic effort are part of a reciprocal exchange aimed at benefiting closer and distant kin and the community at large.[26] Although the concept of genomic citizenship remains to be fully developed, at a minimum it suggests a responsibility to become educated about issues related to the use of genomic data and, when possible, to participate in shaping policy.

President Obama's announcement of the Precision Medicine Initiative epitomizes this development, and the possible range of obligations associated with genomic citizenship. The Initiative's explicit aim is to "[develop a] new research effort to revolutionize how we improve health and treat disease."[27] It calls for a "national, patient-powered research cohort of one million or more Americans who volunteer to participate in research," and who will be involved in the design of the Initiative and "have the opportunity" to contribute, among other data, full medical and genetic profiles.[28] The national interest embodied in the Initiative and the need for a "coordinated and sustained national effort"[29] to translate initial success to a larger scale are highlighted. These include a budgetary allocation, collaborative public/private efforts to leverage advances in genomics, engagement of stakeholders from multiple scientific, medical, and advocacy groups, and a commitment to develop regulatory frameworks "to ensure secure data exchange with patients' consent, to empower patients and clinicians and advance individual, community, and population health."[30] The Initiative's reliance on next generation sequencing and its rhetoric of empowerment, individual choice, blurred public-private boundaries, and an (implicit) obligation of the citizenry to contribute to the genomic effort to advance the national interest suggest an effort to frame a new rhetoric of participation in genomic research. Even if it falls short of call-

ing for mandatory participation, the language of the PMI highlights the evolving normative expectations of the public to become informed and engaged "genomic citizens."

Adolescents: Genomic Citizens in the Making

Adolescents are particularly poised to fulfill the role of informed and engaged genomic citizens. Unlike young children, adolescents are increasingly recognized for their growing autonomy and right to have a voice in medical (and other) decisions relating to them.[31] Notwithstanding some criticism,[32] there is agreement that adolescents' evolving capacity requires nurturing and an opportunity to be exercised before decision-making can be fully developed.[33] Moreover, this trend is supported by empirical research with minors and studies of brain development showing that when given sufficient time and information upon which to reflect, adolescents' (>13 years old) medical decision-making capacity is comparable to adults.[34]

Insofar as there is a preference for decisions about return of genomic SFs to be made by informed patients, adolescents' disposition is ever more promising. Not only do studies show that adolescents' knowledge of genetics is at least as good as adults',[35] but they are also more likely than any other age group to be exposed to genomic information in schools[36] and to access it online. As ubiquitous surfers of the Internet[37] and seekers of health information online,[38] adolescents are prone to encounter the surge of news, blogs, and other websites about advances in genomic sequencing. Adolescents are also heavy users of mobile devices and other new technological gadgets[39] and may be more likely to come across mobile health apps, including those on genomic data. Illumina Inc., e.g., developed an iPad and iPhone app allowing users to explore a real human genome,[40] and 23andMe Inc. created a mobile app that gives people access to their DNA and other related educational material "at people's fingertips."[41]

In addition, adolescents are a growing group of genomic consumers. Studies of single-gene testing have found that genetic testing of minors is becoming increasingly common[42] and that many adolescents wish to learn about their genetic status.[43] Three recent studies with small samples of adolescents (mostly in clinical settings) support these findings also with regard to WGS/WES.[44] The burgeoning of DTC genetic testing is likely to further increase the number of adolescents who undergo WGS/WES. A study of social networkers found that most believe that parents should be able to test their children through DTC companies and are considering it themselves,[45] and, in reality, once parents/legal guardians provide consent, these companies rarely limit the age of their customers.[46] In fact, some DTC companies specifically target young consumers. The services of 23andMe Inc., for example, are "designed for, intended to attract, and directed toward" children over the age of 13, and more generally, the company aims to "pump up" people's education about the science around genetics … in a way that is fun and engaging."[47] Besides the likely attraction of adolescents to services that are marketed as "fun,"[48] DTC companies create a unique niche and may be particularly appealing for adolescents who want genomic testing done without parental knowledge.[49] Thus, although there is currently a freeze on the health-oriented services provided by American DTC companies,[50] adolescents are increasingly likely to access this market as WGS/WES techniques produce more accurate results at lower costs.

Adolescents are also the most vulnerable link in the familial chain of return of genomic SFs in research settings. Although adolescents may benefit from increased knowledge of their genetic propensities, they are typically not the ones to decide about genetic testing or access to results; that power resides with their parents/legal guardians. This may be particularly challenging for adolescents. Adolescence is characterized by a natural shift away from family- to peer-centered interactions,[51] and viewing adolescents merely as embedded within families may subject them to unwanted and unwarranted familial dynamics regarding genomic decisions. These include biased parental determinations of the minor's (im)maturity[52] and "best interests," and broad dissemination of adolescents' genomic data without their permission.[53] The latter also makes adolescents more likely to experience negative personal and social repercussions (e.g., stigma, discrimination, identity-related issues) with the majority of their lives still ahead of them. Thus, although parents are vested with the legal authority to make genetic-related decisions for their children, consideration of adolescents' preferences is important.

Finally, adolescents' genomic data are already widely available for research. A national survey found that 44% of biobanks in the US store specimens from children under the age of 18 and that 2% are exclusively dedicated to pediatric specimens.[54] In addition, private companies conduct research using pediatric DNA samples obtained independently through parental consent[55] or in collaboration with researchers and medical institutions (e.g., Regeneron Pharmaceuticals, Inc.[56]). As biobanks frequently share biosamples and data —indeed, federal regulations may require them to do so — pediatric genomic specimens are likely to be disseminated widely. As a matter of rights and justice, adolescents should have a voice in decisions about their genomic SFs.

Key Challenges

The increasing use of WGS/WES in pediatric clinical[57] and research settings[58] raises a number of legal and ethical challenges for families, researchers and policymakers. The issues are closely interwoven and reflect the components of the emerging concept of genomic citizenship.

Adolescents' Decision-Making Role

Notwithstanding the growing recognition of adolescents' medical decision-making capacity, their involvement in return of SFs or genetic results more generally to date has been limited. There is no specific guidance about how adolescents should be engaged in clinical genetics and genetic counseling settings, and the few published articles on this issue do not document the prevalence of adolescent involvement.[59] In the US, laws and policies provide little protection for adolescents' involvement in genomic clinical and research settings. Rather, parental prerogatives of giving consent are maintained and adolescents are merely requested to acquiesce or assent.[60]

Notwithstanding the growing recognition of adolescents' medical decision-making capacity, their involvement in return of SFs or genetic results more generally to date has been limited. There is no specific guidance about how adolescents should be engaged in clinical genetics and genetic counseling settings, and the few published articles on this issue do not document the prevalence of adolescent involvement.

Arguably, the general medical and genomic contexts are different. As scholars have observed, adolescents' expanded role in medical decision-making in the US has not been based on notions of children's rights as much as on societal interests in avoiding negative long-term consequences (e.g., higher risk for adolescent pregnancy if parental consent is required for sexual healthcare).[61] Although genomic knowledge may increase adolescents' sense of control over their lives and ability to make long-term plans,[62] genomic testing often lacks the urgency that characterizes other medical contexts. Also, the nature of the data differs. Unlike other adolescent-friendly medical contexts, which are temporary if addressed and predominantly individual-centered, genomic data have long-term consequences[63] and may have implications for other family members. Professionals' satisfaction with the existing policy of acquiescence and assent, and parents' desire to manage their children's genomic data[64] may be grounded in these differences.

Although these rationales make sense for young children, they are weaker, and fail to justify the consent/assent distinction, when applied to adolescents in genomic research. As scholars point out, the scope of assent is unsettled (i.e., is it quasi-consent or does it only require respect for children as subjects?); nor is it stipulated in federal guidelines what procedures are required for obtaining assent or how to determine capacity to assent.[65] Scholars thus criticize assent for its ambiguity and dependence on individual judgments of adult decision-makers.[66] Others decry assent for its arbitrary age threshold and disregard of minors' competence, which develops through direct social and personal experiences rather than mere age and physical growth.[67] They suggest that assent be tailored to the individual child ("personalized") or that it be abandoned in favor of full consent by competent adolescents.[68] Some even charge that debates about consent/assent are ultimately merely reflective of a concern about the loss of adult prerogatives to control their children rather than about protection of children's interests.[69]

A few small studies of adolescents indicate that a more nuanced approach is required. Although a common strand in these studies is adolescents' desire to engage in the decision-making process — in effect, supporting the participatory role envisioned in the concept of genomic citizenship — more research is needed to understand its various components. For instance, studies of healthy (n=11)[70] and at-risk adolescents found that they believe they should be able to decide about diagnostic single-gene testing.[71] However, adolescents' views may differ for genomic testing, especially as the scope of results to be returned in WGS/WES may be unpredictable. And although studies show that adolescents want greater control over their participation in genomic research,[72] whether and at what age they want to play a determinative role in decisions about return of genomic SFs is unclear. A recent (not genomic-related) study of a diverse group of adolescent participants in clinical research (n=177) found that the majority expressed overall satisfaction with their assent and parental permission, and were gener-

ally reliant on and positive about their parents' support and judgment.[73] In the genomic context, a Belgian study about storage and use of biological tissue from pediatric research conducted 5 focus groups with adults and 5 with adolescents ages 15-19 year-olds.[74] It found that adolescents viewed their parents as the most suitable people to decide about participation in research. Adolescents also proposed a generally higher age threshold for consent compared to their parents (16 vs. a range of 10-18), although they often thought themselves capable of making the relevant decisions and preferred to receive "medically important information" together with their parents. A second focus-group study of 7 adolescents diagnosed with disorders that may have had a genetic cause found that they strongly preferred shared decisions regarding both participation in WGS/WES and return of genomic SFs.[75]

These few studies suggest, first, that adolescents' expectations of involvement in the decision-making process may be context-dependent. Adolescents may be more willing to relinquish responsibility in decisions about participation in genomic research, which may be viewed as harmless and as having less direct bearing on their lives,[76] but more invested in medically-related decisions, where they are the primary beneficiaries and can assume greater responsibility for their healthcare. Second, although adolescents want to be involved in genomically relevant decisions, they may not want to make such decisions on their own.[77] Indeed, the small-scale studies of adolescents and WGS/WES indicate that they prefer a *shared* – not an independent – decisional role, and that *some* adolescents look to parents for guidance and support.[78] Possibly, these views reflect adolescents' recognition of the role of parents in their lives, and the interdependence of family members in making complex medical decisions. However, further research will be needed to establish whether these suggestions are correct and what adolescents' rationales are for these preferences.

With regard to a shared decision-making process, there are yet other issues to consider. As shown in other medical contexts, such a process may be beneficial, as it is associated with improved familial communication, treatment adherence and outcomes.[79] This may be critical, for example, in returning genomic results related to cardiac conduction disorders, which are low-penetrance and typically inherited in a dominant fashion, but present the risk of (rare) fatal outcomes that require significant restrictions on adolescents' daily activities.[80] But even if a shared decision-making process is adopted, disagreements among parents, adolescents, and physicians/researchers may arise. Parents' expectation of receiving SFs before their children – found in studies of parents with children of all ages[81] and specifically with adolescents with medical conditions who participated in genomic research [82] – may conflict with adolescents' preference for receiving the results together with their parents. Parents and adolescents may also disagree about which SFs should be returned or to whom these data should be disclosed (see below). Although encouraging parents to engage in genomic-related conversations with their children could be a first step in addressing this challenge, a skillful conflict-resolution process that provides optimal care and privacy for adolescents and recognizes the interdependence of family members will be needed.

Types of Genomic SFs to Be Returned

As WGS/WES techniques generate extensive medical and nonmedical data with varying levels of significance, scholars have increasingly emphasized that knowing one's genetic makeup should be a matter of choice. This is especially true for decisions about return of genomic SFs in research settings, where the findings are unsolicited. The right (not) to know is thus grounded in notions of individual autonomy and privacy, and the fiduciary duty of physicians to respect the person's right to decide what information to receive.[83]

The challenge for adolescents, however, is that although they are the subjects of research, they are not the decision makers. Although parents commonly make decisions for their children, the return of genomic SFs – which can comprise not only immediately relevant medical information but also predictive, carrier, and nonmedical data – is unique. First, parental decisions to receive predictive and nonmedically relevant SFs (e.g., Huntington disease and behavioral traits, respectively) may limit adolescents' options in the future and hamper their right based in anticipatory autonomy to decide which genetic data to receive (the "right to an open future").[84] Experts also caution that the knowledge of carrier status and genetic propensity for disorders (rather than presence of a medical diagnosis) may adversely affect adolescents' life planning, family relations, and sense of identity and self-worth that are being formed in this period.[85] Finally, lack of adolescents' involvement raises the risk that parents will conflate their interests and their adolescent's interests, leading to SF-related decisions that reflect parents' preferences (and anxieties) rather than those of the adolescent. Even if parents' decisions about the return of immediately relevant medical SFs relating to their child may resemble those made in conventional pediatric medical contexts, decisions about other SFs may not. The difficulty is thus in determining which

among the types of pediatric genomic SFs should be returned.

Although law, professional guidelines and principles of medical ethics require that decisions about return of SFs be "driven by the best interests of the child,"[86] this concept is notoriously malleable. The result is that both parents and professionals may view their decisions as promoting the child's best interests, but hold fundamentally different understandings of what it means and of their corresponding responsibilities. In particular, parents' desires to receive their adolescents' genomic information for conditions that are treatable during childhood are undisputed. It is commonly viewed as integral to parents' right to care for their children and generally broad freedom to decide how to raise them.[87] Some also suggest that it is a parental *duty* with a corresponding physician obligation to disclose such data even against parents' own preferences.[88]

Opinions are split, however, about returning SFs for carrier status with reproductive implications (e.g., carrier state for cystic fibrosis), disorders for which interventions will be deferred to adulthood (e.g., BRCA1/2), and adult-onset conditions without treatments that offer clear clinical benefit (e.g., Alzheimer disease). Whereas expert panels and professional guidelines generally suggest that these be deferred until adolescents reach maturity and can decide for themselves,[89] studies indicate that many parents desire to learn *all* about their children's genetic makeup.[90] Although parents believe that it is their right and duty to access and manage their children's genomic data,[91] professionals often view themselves as the guardians of adolescents' genomic-related rights in decisions that are intrinsically family-oriented.[92] And whereas professionals call for distinctions based on medical utility and scientific validity, studies indicate that parents' rationales may include not only personal and familial medical interests but also mere curiosity.[93] Even if we assume that most parents (and professionals) strive to make decisions that promote children's best interests, there is a risk that adolescents' right (not) to know will not only be in conflict with familial interests, but also subjugated to parents' (or others') rights, interests and whims.

Given this controversy, it may be useful to consider adolescents' preferences and rationales. However, only 3 small-scale studies have explored this issue,[94] and only 2 of them distinguished among types of results. The first study involved a focus group with 7 adolescents diagnosed with disorders that may have a genetic cause. It found that *most* adolescents wanted to receive all medically relevant SFs from clinical sequencing, including those relating to their current conditions, carrier status and adult-onset conditions even if untreatable.[95] The second study recorded consent sessions of families with children with unexplained cardiac arrhythmias or mitochondrial disease who were offered WES and return of *actionable* SFs in a research setting. It found that adolescents aged 12-14 generally focused on concrete details (e.g., blood draws). However, adolescents aged 15 and older typically appeared to understand the implications of learning SFs for the present (e.g., sports, medical treatment) and for the future (e.g., reproductive decisions), but some of these older adolescents were uncertain about their readiness to receive results.[96]

Although these studies indicate that adolescents may be interested in more information about SFs than currently recommended by professional guidelines, the data are insufficient to establish adolescents' preferences and to develop policy guidelines. Adolescents in these studies were symptomatic and may hold views that are different than the general adolescent population that is likely to be included in genomic studies.[97] Moreover, these studies focused only on medical, mostly actionable, genomic findings, which do not capture the scope of information WGS/WES produces. Further research should thus explore adolescents' preferences about return of medically *and* non-medically relevant genomic SFs and the extent to which their views coincide with those of parents and professionals.

A further complicating factor is that while both parents and professionals may raise protection-based claims to justify their respective positions, there are very limited empirical data to support either view. One such claim is the concern that knowledge of genomic risks will negatively impact adolescents' psychosocial wellbeing and family relations.[98] As a result, parents often wish to shield their children from receiving genomic data (but to receive the data themselves), and professionals want to shield children from their parents' knowing this information.[99]

To date, the few small-scale studies that examined this question focused on clinical, single-gene testing for specific conditions (e.g., cancer, Huntington disease) among adolescents at risk and their findings did not substantiate the concerns.[100] Moreover, qualitative studies with at-risk 14-25 year-olds who underwent predictive single-gene testing for adult onset conditions (e.g., BRCA1, Huntington disease, familial adenomatous polyposis (FAP)) call attention to potential benefits from this knowledge.[101] Recognizing the complexity of the information, many participants nonetheless considered the pre-testing uncertainty to be a major burden on their psychosocial wellbeing and expressed relief post-testing, regardless of the

results. Participants also identified both positive and negative impacts on the family, including improved family relationships, notwithstanding the experience of stress on the family as a whole.[102] Clearly, these findings are not immediately applicable to WGS/WES scenarios involving SFs, where adolescents do not expect the findings and may not have the lived experience of growing up in a family with a genetic condition. However, they highlight the need for further research in this area, including explorations of the short- and long-term implications of adolescents' knowledge of their genomic risks for their wellbeing and family relations.

Another related issue is whether adolescents' knowledge of their genomic risks will motivate them to engage in preventive behaviors – an issue that is at the heart of genetic and genomic citizenship. In this regard, a few studies of healthy adolescents about single-gene testing for breast cancer, heart disease, hypercholesterolemia and Tay-Sachs disease give hope: they found that many adolescents, especially those with a family history, report that they are willing to make behavioral changes if the condition is actionable.[103] But it is hard to assess whether adolescents will translate genetic risk information into action.

Studies suggest that behavioral changes in response to genetic data depend on various factors, including an individual's risk assessment, belief in one's ability to mitigate the risk, perceived costs of that behavior, and others,[104] but there is very little research with adolescents on any of these facets. Several studies with *adults* at risk for genetic conditions (e.g., diabetes) do not offer much reason for optimism: their findings mostly suggest that genetic data has little or no effect on health-risk behaviors.[105] Nonetheless, engaging adolescents in decisions about return of genomic SFs may be fruitful. Because genomic SFs are unexpected, adolescents may not feel "doomed," as those with a family history of a disorder may feel,[106] and they may have greater motivation to act on these data. Also, because adolescents are in the process of developing their health habits, they may be more amenable to changes in health practices than adults who need to alter long-standing behaviors. Still, as multiple sources influence adolescents' health practices (including parents, peers, social media, and health professionals),[107] empirical studies will be needed to establish which sources of influence are particularly critical and whether the promise of genomically informed practices will materialize.

Genomic Privacy

The issue of genomic privacy has generated considerable public debate. In particular, scholars have argued that genetic information is uniquely sensitive and personal, as it may reveal attributes of individuals and family members that are immutable and beyond anyone's control.[108] Others have raised the concern that knowledge of individuals' genetic proclivity to disorders may lead to stigma and discrimination.[109] This concern finds support in a history of misuse of genetic knowledge (e.g., eugenics) and current research on the impact of the geneticization of various conditions, such as epilepsy[110] and psychiatric disorders.[111] Still others cautioned that without unique privacy protection measures, individuals will be discouraged from genetic testing,[112] thus effectively undermining the goal of precision medicine. Thus, the federal government adopted the Genetic Information Nondiscrimination Act of 2008 (GINA),[113] which standardized a ban on genetic-based discrimination in employment and health insurance across US states. Although some have challenged the justifications for this "genetic exceptionalism,"[114] the Presidential Commission for the Study of Bioethical Issues concluded in 2012 that to realize the "enormous promise" that WGS holds for advancing clinical care and the greater public good, "individual interests in privacy must be respected and secured."[115]

Although risks to genomic privacy arise for all research participants, they are magnified for adolescents. A part of the challenge is that the collective fea-

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ture of genomic data may blur the boundaries between individual and family privacy. Studies regarding pediatric genomic SFs show that although parents often worry that their children's participation in research will lead to loss of privacy (and possible stigma and discrimination),[116] they do not view their own access to their children's genomic information as a privacy concern.[117] Many parents in fact disclose genetic data about their children to extended family members, friends, neighbors, and others,[118] suggesting a sense of ownership.

Even if we accept blurred genomic privacy boundaries as natural, adolescents may draw lines around private information differently than their parents. A study of 10-17 year-olds at risk for breast cancer and heart disease explored their attitudes toward enrollment in research and genetic testing.[119] It found that they wanted parents and doctors to know their genetic results, but were concerned about sharing the results with others and wanted to have control over who knew their results.[120] These preferences may conflict with parents' disclosure behaviors, especially when adolescents' rationales for selective disclosure are ignored. The genomic context is further complex because minors may be selective about which genetic findings they would prefer to share with parents. 8-11 year-olds enrolled in a genetic epidemiology study since birth viewed some data as more personal, and less acceptable for sharing, and defined "personal" differently than their parents.[121] Similarly, as the Belgian study on adolescents' participation in genomic research found, although adolescents approved of sharing "medically important information" with parents (the category was not further defined), they were more reluctant with regard to other information.[122] Given the vast medical and non-medical information WGS/WES techniques are likely to produce, where and for what reasons adolescents draw the line of genomic privacy is an important area for inquiry.

Other issues relate to genomic data-sharing by professionals, especially in the context of new informational technologies. One such issue is the increasing incorporation of genomic data in electronic medical records. This development has been intensely debated, given that these records may optimize personalized care, but their "multi-owner and multi-user nature"[123] may increase the risks of privacy breaches and misuses of genomic data.[124] This may be pivotal for adolescents: genomic data may be disseminated to a wide range of caregivers and released to insurers and others who may require access to such records.[125] In reality, advances in technology, regulatory requirements and support by health professionals and the Federal government[126] make it likely that the use of e-medical records will increase in the future. But as there are ongoing efforts to redesign the existing e-health record system and to craft regulations that will curtail the risks,[127] exploring adolescents' views may be important. Studies indicate (and professional guidelines recognize[128]) that adolescents have privacy concerns relating to professionals' data sharing in healthcare and research settings.[129] Knowing whether adolescents view genomic SFs as part of their medical data and how they want such data to be used (and by whom) will assist in protecting adolescents' privacy interests as they mature into adulthood and advance the crafting of privacy regulatory frameworks that are attuned to the preferences of adolescent research participants.

Another issue is the practice of biobanks sharing biological specimens, which may increase the risk of adolescents' re-identification. Since 2008, a few researchers have managed to identify people randomly selected from a research database using only their DNA, and in 2013, this re-identification was extended to family members using only participants' DNA, ages, and states of residence.[130] Even if it is accepted that full protection of research participants' anonymity cannot be guaranteed, parents may not be best at mitigating the risk. Studies suggest that many adults have difficulty grasping what genomic data sharing means, tend to underestimate associated risks, and, in any case, that their actual data sharing decisions are significantly less restrictive than their reported preferences and privacy concerns.[131]

Insofar as parents seek DTC testing for their children or adolescents utilize it independently, the risks to adolescents' genomic privacy are particularly alarming. These companies encourage the sharing of genomic data with all interested parties as part of their claimed agenda to accelerate population-based genomic research through the democratization of information, while conveying the message that individuals should have control over their genomic data.[132] 23andMe, Inc., for example, allows consumers to use an online tool to transfer their genomic data to many individuals at once and promotes a company-sponsored blog and virtual space for discussions among consumers.[133] The company also sells customers' genetic data to other for-profit entities for medical research and product development.[134] The challenge, as these services gain popularity (a study of adult consumers (n=80) found that most shared their genetic data on the company's website or other social networking platforms[135]), is that there are very few measures in place to facilitate consumers' balancing of risks and benefits. Although consumers must give permission to share and sell their genetic data, there

is no informed consent process to ensure that parents and adolescents comprehend the implications of their decisions.[136] As the national cohort and its public-private partnerships gain traction, this should be a concern.

Communication of SFs

Communication is key to tackling the challenges for adolescents described so far –decision-making role, types of genomic SFs to be returned, and genomic privacy. Indeed, the expectation of genomically informed and responsible behavior (as embodied in the concept of genomic citizenship) can only be fulfilled when individuals are provided the opportunity to understand and reflect on their genomic risks. However, there are conceptual and practical communication-related challenges that adolescents face in decisions about the return of SFs.

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This observation highlights the broader issue of protecting adolescents' genomic privacy in the era of social networking. Undoubtedly, today's adolescents are "growing up wired."[137] Over 95% of adolescents ages 12-17 access the Internet daily, 81% visit social networking sites (predominantly Facebook but also others, e.g., Instagram, Snapchat, and Twitter), and 71% report using more than one social media site.[138] Because these online forums are viewed as a means of communication with their peers, adolescents use them to express who they are, to form and maintain social relations, and to self-identify.[139] In these processes, adolescents share a wide range of personal information about themselves, including photos, interests, messages about risky behavior, and often identifying information (e.g., name).[140]

Although these practices may challenge the traditional distinctions between private and public information,[141] their implications for adolescents' genomic privacy are unclear. Studies suggest that most adolescents do not embrace a full public approach to social media and that they take measures to restrict and manage their profiles, reputations, and social interactions.[142] However, no study to date has explored how adolescents construct genomic privacy in the informational age. When parents have access to their children's genomic data, they may post messages about SFs on social networks or join online support groups, which may effectively broadcast adolescents' genetic status.[143] Given the limits of GINA in protecting against genetic discrimination,[144] this sharing may increase the risk for misuse of adolescents' genetic information by school officials, future employers, insurers, and others, while undermining adolescents' sense of control over their online profiles and social interactions.

First, adolescents have to overcome the barrier of being perceived by professionals and parents as lacking decision-making capacity. Although not all adolescents' may be equally capable, the starting point of presumed incapacity greatly disadvantages them: it is harder to demonstrate competence than incompetence and to prevail over adults, especially parents, who are more powerful actors in the decision-making process.[145] As mentioned, an individualized assessment of capacity may be a better way to approach adolescents in genomic research, and there is a growing literature about how to assess adolescents effectively.[146] But adolescents' competence to make decisions is also greatly dependent on the support of competent adults.[147]

One intuitive option is for parents to be entrusted with the role of communicating genetic risk information to their children. Support for this position can be found in the little research that exists on parent-child communication of single-gene testing results among at-risk families. Although rates of disclosure vary by context and type of disorder, many parents who are carriers of genetic mutations (e.g., BRCA) feel obliged to and, indeed, do share this information with their adolescents long before preventive interventions are recommended.[148] The Belgian study and one US-based study of WGS/WES further indicate that adolescents expect parents to share SFs with them and are

concerned about parents not fully informing or even misleading them about their genomic data.[149]

Although parents may be a natural choice to communicate SFs to their children, this expectation is fraught with difficulties. Parents may not be the best judges of their children's maturity to understand genomic data,[150] and they may be reluctant to disclose genomic information.[151] Studies also show that adults' understanding of genetic testing and its risks and benefits is limited.[152] Parents may thus lack sufficient medical and genetic knowledge to convey the implications of the findings accurately, and will need professional guidance about how and when to disclose genomic findings to their children.[153] Moreover, there is some evidence from studies about single-gene testing that family discussions about genetic risk are influenced by individual, familial, cultural, and socioeconomic factors, including the nature of relationships among family members and the familial communicative style.[154] How these will play out in decisions about return of genomic SFs in research settings is currently unknown, but given the barriers and the fact that styles of interaction in some families may be less conducive to such conversations, it is important to consider other venues in which information about genomic SFs can be conveyed.

Perhaps the most straightforward alternative is for professionals to assume this role. As in other areas of adolescent-friendly medicine, this would require researchers and healthcare providers who are skilled in engaging with adolescents, who can effectively convey the information to them, and, importantly, who believe in the value of this communication with adolescents.[155] In practice, these professionals may not have the skills, time, or understanding for such SF-related discussions.[156] Indeed, studies indicate that, notwithstanding efforts to adopt adolescent-friendly strategies, some genetic counselors still feel that they lack the relevant skills to work with adolescents.[157] Beside the clear need for additional training for professionals and addressing more systemic issues (e.g., need for longer interactions and more psychosocial support than adults), these limitations circle back to parents' weakness as communicators of genomic SFs. In the lack of professional proficiency, parents may not have the support and guidance they may need, and adolescents are more likely to be left in a communicational vacuum.

Finally, since increased access of individuals to their genomic data underscores the informational barriers that patients and research subjects experience, efforts are ongoing to make genomic data and the return of SFs more patient-friendly. Measures to this effect include suggestions to revise the existing model of informed consent,[158] changes in the format and presentation of genetic reports (e.g., avoiding scientific jargon), and augmentation of verbal communication of results by access to e-medical records and interactive patient portals.[159] However, these discussions so far have only focused on parents or adult research participants. Once adolescents are acknowledged as consumers and valuable contributors of genomic data, it is critical that adolescent-friendly communication protocols be developed in consultation with them. For instance, studies should investigate which means of communicating SFs adolescents believe are most effective (e.g., email, in person), with whom adolescents are most comfortable interacting (e.g., parents, researcher, genetic counselors), their preferences for follow up,[160] and the educational material and formats that would be most useful for them. Given that today's adolescents are the first generation to live in the intersection of the genomic and informational eras, their views may be significantly different than those of adults. Learning about these preferences will be important to developing tailored guidelines about communication of genomic SFs with adolescents.

Genomic Citizens across the Board

An overarching limitation in the literature on return of pediatric genomic SFs (and minors' genetic testing in general[161]) is sample bias, that is, existing data are based largely on females, Caucasians, and except for the Belgian study,[162] only patients enrolled in genomic research,[163] whose views may not reflect those of asymptomatic adolescents.

However, a few recent studies with adults found that race, gender, and social class influence parents' views on who should be involved in the decision-making process, the role they want to take in this process, the type of SFs to be returned, and expectations for medical or other benefits from participation in genomic research.[164] Studies also indicate that genomic responsibility is gendered. Women are more likely to undergo predictive genetic testing and to view themselves as the guardians of their families' genetic health.[165] Thus, women collect genetic data about their (and their partner's) families, negotiate with healthcare providers, disclose their and their children's genetic data to other relatives, and communicate the data to their children.

Moreover, studies of adolescents in interfacing areas indicate that sex- and race-based differences exist from early age. For example, a study exploring the views of 10-12 graders (mean age 17±1 years) about single-gene testing for familial breast cancer, Tay-Sachs disease and hypercholesterolemia found that girls are more interested than boys in learning about their genetic

status and making behavioral changes to mitigate the genetic risk, but also more concerned that test results would produce anxiety.[166] A study with adolescents in treatment for substance and conduct disorders[167] and another one with young adults who participated in research relating to mental health and substance use[168] found that minorities are less likely than whites to consent to sharing their DNA with other investigators and more likely to restrict use of their DNA to genetic research about their condition or related medical issues. Similarly, studies found sex and race-based differences in adolescents' use of social media sites and types of data they post online. For instance, girls are more protective of their privacy than boys and African Americans are less likely to provide names and identifying information than whites.[169] Whether and how the findings from these studies will hold with regard to return of genomic SFs has yet to be explored. But given that health and health risks are cultural constructs[170] and that adolescents grow up in different environments and self-identify by sex, race, and ethnicity, exploring how these factors interact with adolescents' preferences about return of SFs will be instrumental for enhancing genomic literacy and responsibility among these rising genomic citizens.

Conclusions

There is much hope that WGS/WES will serve as a game-changer in pediatric clinical care. Next-generation sequencing is also a central component of the Precision Medicine Initiative, which calls for a strong partnership between government and civil society, upholds stakeholders' active engagement as a mark of democratic notions of informed citizenry,[171] and encompasses the newly emerging, if not yet fully defined, rights and responsibilities of genomic citizenry.

As WGS/WES increasingly enter pediatric research settings, adolescents are likely to be an ever-expanding group of research participants. Dilemmas about return of genomic SFs to parents and minors are likely to occur, with the complexities of the decision-making process increasing as minors approach adulthood. Indeed, adolescents are a unique group to investigate. No longer children but not yet adults, they may hold health-related preferences and be cognitively competent decision-makers but have little legal control over decisions about return of genomic SFs. Although adolescents are likely to be greatly impacted by these decisions, there are too few measures in place to protect their genomic privacy from the multiple sources of risk (including parents, professionals, and themselves) while enabling them progressively to assume the responsibilities of genomic citizens.

Whether adolescents will succeed in this goal depends on how well they are nurtured in the genomic era. Emerging studies are indicative of the interest of adolescents in being part of the genomic conversation, but also of the challenges ahead. However, there is a need for a more targeted, systematic, and comparative approach to learn about adolescents' views on return of genomic SFs.

There are many intersecting areas for research that could be helpful in advancing this field. These include qualitative and quantitative data on adolescents' preferred decision-making roles and the implications for family relations, treatment adherence, and the parents/professionals/adolescent triad in delivering genomic care. Studies should also explore the types of SFs adolescents would want to have returned, how adolescents understand the notion of genomic risk, their rationales for their decisions, and the short and long-term behavioral and psychosocial impacts of genomic knowledge. In addition, studies about adolescents' conceptualization of genomic privacy are needed, especially in intersection with informational technologies. Another area to explore is how a culture of adolescent-friendly genomic care can be cultivated, including effective parent-adolescent communication, informed professional engagement, and increased genomic literacy. Finally, research should be mindful of the possible impact of age, sex, and race on each of these aspects of return of genomic SFs to ensure that procedures are tailored to adolescents' characteristics.

Empirical data about adolescents' views on return of genomic SFs can play an important role in policy deliberations and development of professional guidelines. They can highlight areas of concord and discord among relevant stakeholders, contextualize the rationales for adolescents' preferences, and offer alternative policy approaches tailored to this age group.

Empirical data about adolescents' views on return of genomic SFs can play an important role in policy deliberations and development of professional guidelines.[172] They can highlight areas of concord and discord among relevant stakeholders, contextualize the rationales for adolescents' preferences, and offer alter-

native policy approaches tailored to this age group.[173] Although the immutable and collective nature of genomic data inherently calls for balancing stakeholders' competing interests, learning about adolescents' views may mitigate the potential harms arising from SF decisions and provide them the opportunity to begin exercising their genomic citizenship.

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