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Honey, I Sequenced the Kids: Preventive Genomics and the Complexities of Adolescence

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How much control should individuals have over their genomic data? Although this question has been extensively discussed in debates about return of genomic incidental findings (IFs), Lazaro-Munoz and colleagues consider it in another putative context: population-based preventive genomic sequencing (PGS) programs that would target rare, highly penetrant, and medically actionable genetic (MAG) conditions. The authors advocate for a "menu" rather than a "panel" approach to the management of genomic information—allowing participants greater discretion regarding genes to be analyzed—because it better resonates with prevalent notions of patients' autonomy, choice, and patient-centered decision making in medical contexts. This is an important discussion, which will likely continue. However, the article does not address the implications of either approach for minors; indeed, it does not mention minors at all. Although steering away from genomic dilemmas in minors may simplify the discussion, it misses important considerations for this substantial group of stakeholders. As genetic testing in pediatrics increases, knowledge of adolescents' genetic propensities may have substantial positive and negative impact on their life plans, identity, and other aspects of their development. Consideration of their interests in this evolving context is consistent with the increasing recognition of children, especially adolescents, as active participants in medical decision making. In this commentary, we highlight the complexities involved with the management of genomic findings of adolescents and offer possible ways to enhance their autonomous choices in such processes.

Public health surveillance programs to improve quality of life through prevention and treatment of diseases or other medical conditions are, of course, not new. Such programs can be traced back to the Renaissance and have developed with varying levels of success as scientific knowledge has increased. Thus, a PGS program could be seen as the most up-to-date and precise initiative to improve public health. However, the management of genomic data evokes new dilemmas as the "source" of the threat to health is internal to the individual and the "public risk" is limited to other family members who may share a genetic proclivity for medical conditions. The conventional premise that public health interests justify limitations on individual rights is thus weakened, and as we shift from public health surveillance to a personal risk assessment program it seems reasonable for individuals to have greater choice about the generation, use, and handling of their genetic data.

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The challenge for adolescents (and minors in general), however, is that they are *not* conventional decision makers. Although genetic testing of minors is becoming increasingly common, including for adult-onset conditions without known treatments (Duncan et al. 2005), decisions about genetic testing or access to the results typically are not made by adolescents themselves but by parents or legal guardians. Further, because children, including adolescents, are often viewed as embedded within families rather than as autonomous individuals, family dynamics play a significant role in genomic decisions. The implications for the discussion of PGS are manifold.

Part of the rationale in favor of a menu approach is that it is more compatible with the modern conceptualization of a person's best interests, which favors interests expressed by autonomous people over physicians' or others' decisions on their behalf. Although this is true for adults, it is hardly applicable for adolescents: the common practice is for parents to determine what is in their children's best interests, with adolescents at most asked to acquiesce. Even if we assume that most parents strive to make decisions that promote their children's best interests, the lack of adolescents' involvement raises the risk that parents' views and anxieties—rather than those of the adolescent—will dominate the decision. Further complicating the situation is that as minors mature, they may hold values and preferences different from their parents'. How to balance parental authority against adolescents' growing autonomy is not always clear. Encouraging parents to engage in genomic-related conversations with their children could be a first step in addressing this challenge, although other measures will be needed. Existing law provides very little protection to minors' wishes (Clayton in press), and parents may be unable or unwilling to acknowledge their children's perspectives and differentiate between their values and emotions and those of their children.

This observation highlights the challenge in determining the scope of genes to be included in a PGS program. Lazaro-Munoz and colleagues suggest sequencing genes related to a limited list of MAGs and leave physicians to determine the list. However, experience from debates about return of genomic IFs suggests that parents and physicians often disagree about which genomic data would serve the child's best interests. Whereas many parents show a desire, a sense of duty and a right to learn *all* about their children's genetic makeup (Levenseller et al. 2013; Townsend et al. 2012), expert panels and professionals are concerned that full disclosures may hamper children's "right to an open future," violate their right (not) to know, and adversely affect their sense of self-worth and family relations (Green, et al. 2013; Levenseller et al. 2013). Data about adolescents' views are largely missing, although a focus group of adolescents in a clinical setting found that most wanted to know all their genomic IFs, including those relating to non-MAGs (Levenseller et al. 2013). Although this study provides limited data about the (dis)similarities in adolescents', parents', and physicians' views, it is clear that, especially if a menu approach is adopted, a mechanism for resolving disagreements among these stakeholders will be needed.

Of course, whether adolescents' choices as to which genes to analyze as part of a PGS program will have any weight will also depend on their decision-making capacities. Traditionally, the constituents of such capacities—persons' abilities to understand the options presented, appreciate their implications, balance risks and benefits, and make a

choice—have been presumed to be lacking in legal minors. Over the past several decades, there has been a visible movement beyond reliance on an arbitrary "age of consent," recognizing that competency is not merely age-dependent but, more importantly, experience and ability contingent (Alderson 2007). Moreover, as studies show that adolescents' (>13 years old) medical decision-making capacity is comparable to adults' (Santelli et al. 2003), some childhood scholars have charged that debates about minors' consent are ultimately an effort to preserve adults' powers rather than protect children (Alderson 2007). This cautionary note may be particularly relevant in the context of genomic data. Studies show that while adults' understanding of genetic testing and its risks and benefits is limited, adolescents' knowledge of genetics is at least as good as adults' (Rew 2010). Thus, rather than exclude adolescents from PGS discussions, measures could be taken to enhance their participation by requiring adolescents' assent (the golden rule for research), extending efforts to develop simple-language communication of genomic information to include adolescent-friendly initiatives, and establishing a shared decision-making process.

Shared decision-making is preferable for another reason: it could safeguard adolescents' genomic privacy from succumbing to familial pressures and disregard for their preferences regarding sharing of information. There is evidence that the concept of genetic privacy is applied asymmetrically within families. Whereas many parents disclose genetic data about their children to extended family members, friends, neighbors, and others (Gallo et al. 2008), studies of adults who have undergone predictive testing show that they are wary of disclosing their own genetic results (Klitzman 2012). Mechanisms enabling adolescents' involvement in decisions about sequencing could also allow their voices to be heard regarding decisions about disclosure of their data. With so much of their lives ahead of them, adolescents have particularly strong interests in not having their genetic information used as a basis for foreclosing their life options—a concern that might warrant greater protections against discrimination as part of any PGS program that is implemented.

There is much to hope for from a well-designed PGS program, and Lazaro-Munoz and colleagues' advocacy for a menu approach to the selection of genes to be sequenced provides a good starting point. But as these discussions move forward it will be crucial to consider adolescents' role in genomic screening decisions, and to revisit the restrictions to which their participation has traditionally been subject. In the current constellation of limited adolescent involvement in decision making, from adolescents' perspective the differences between the panel and menu approaches are minimal, since the only approach currently available is a paternalistic one: whether the decision follows parents' or professionals' preferences, adolescents have no control over the generation or dissemination of their genomic information. Although approaches that confer ultimate decision-making authority on adolescents might require changes in law or regulation, considerable enhancement of adolescents' roles is entirely compatible with existing law (e.g., soliciting adolescents' informed preferences for genetic sequencing as part of joint adolescent-parental decision making). Development of such approaches could alleviate some of the challenges for adolescents in the genomic era with regard to public health-based genomic screening and medical uses of genomic information, as well.

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