
How Much Control Do Children and Adolescents Have over Genomic Testing, Parental Access to Their Results, and Parental Communication of Those Results to Others?

Ellen Wright Clayton

Both researchers and clinicians are increasingly offering genomic testing for children and adolescents, a practice which parents have generally endorsed in numerous studies.¹ By contrast, much less effort has been devoted to understanding what minors think about genetic and genomic testing. While a small number of investigators have shown that minors with or at risk for cancer generally concur with their parents and favor testing,² other studies reveal that minors are less willing to participate in genomics research.³ Regardless, genetic and genomic testing of minors raises a host of potential legal questions. Key issues are: (1) To what extent can minors obtain genomic tests without involvement of parents or guardians? (2) To what extent can minors refuse genomic testing? and (3) To what extent can minors obtain their own results, keep their parents from getting access to them, and limit what their parents do with their genomic test results? While a number of authors have written about legal issues in genetic testing of minors,⁴ remarkably little has been written about the legal protections of minors' choices about genomic analysis and return of results.

In contrast, the ethical dimensions of these genetic and genomic questions have been and continue to be discussed at length. In documents that build upon two decades of previous analysis, the American Academy of Pediatrics (AAP) and the American College of Medical Genetics and Genomics (ACMG) concluded in 2013 that diagnostic genetic testing in minors should be treated as other medical diagnostic interventions requiring full informed consent, that carrier testing should be discouraged except where being a carrier has immediate health consequences for the minor or where the minor is considering reproduction, and that predictive genetic testing for adult-onset diseases is to be discouraged except in limited circumstances and then only with genetic counseling.⁵ Based in part on earlier statements by the AAP about the role of children in health care decision making, these authors asserted that a child's assent is usually required for predictive genetic testing and that the results ultimately belong to the child. As a result, they concluded that parental requests to keep genetic test results from children should be viewed cautiously and may at times be overridden. A statement issued by the American Society of Human Genetics Workgroup on

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Pediatric Genetic and Genomic Testing made similar recommendations.⁶

The ACMG, in a report also released in 2013, opined that when any patients undergo whole genome sequencing, the laboratory must also analyze and report to the clinician the results of 56 other predisposition genes. In the case of minors, they concluded

and should not, always do what parents ask, particularly if the clinician believes that the parents' request could cause greater harm than benefit to the child. The discussion that follows focuses almost entirely on the rights of minors under the age of 18 who have not been emancipated from their parents' control, since emancipated minors¹¹ are treated legally as adults.

Genetic and genomic testing of minors raises a host of potential legal questions. Key issues are: (1) To what extent can minors obtain genomic tests without involvement of parents or guardians? (2) To what extent can minors refuse genomic testing? and (3) To what extent can minors obtain their own results, keep their parents from getting access to them, and limit what their parents do with their genomic test results? While a number of authors have written about legal issues in genetic testing of minors, remarkably little has been written about the legal protections of minors' choices about genomic analysis and return of results.

these results should be returned regardless of the age of onset of the disorder,⁷ in contrast to earlier recommendations of caution in testing for adult-onset disorders. They reasoned that the interests of the family in learning about their own genetic risks superseded the potential interest of the minor in making his or her own decision upon reaching adulthood as well as the potential harms to the minor of returning these results, an analysis that raised questions about the nature of the best interests of the child and the weight that concept deserves.⁸ The ACMG revisited these recommendations in 2014, and concluded that patients and parents should have the option to opt out of receiving the additional results after counseling, but that they could not elect to receive some of the extra results but not others. The views of the child about testing for these additional results were not mentioned in either of these two papers.⁹

So what does the law have to say about these contested issues? The default position is that, for many reasons, parents are presumed to be the appropriate health care decision makers for children and to have access to their children's medical information. Justifications for this position include that parents are free within very broad limits to decide how to bring up their children, parents are thought to be most likely to act in their child's best interests, children generally lack the capacity to make fully competent decisions so someone else must, and state intervention is rarely appropriate.¹⁰ At the same time, however, it is clear that parental authority is not unlimited: health care providers do not,

Minors' Rights to Obtain Genomic Testing

The simple answer is that unemancipated minors have virtually no legal rights to obtain genetic or genomic testing without parental permission. The law does provide a limited set of circumstances in which minors can make their own health decisions. The U.S. Constitution has been interpreted by the Supreme Court to allow minors to procure nonprescription contraceptives,¹² and to a lesser extent to choose abortion without parental permission; in the latter case, judicial approval may be required by state statute in lieu of parental permission or notice.¹³ A few state courts have explicitly held that their state constitutions protect adolescents' right to privacy, especially in regard to abortion.¹⁴ Others have focused on whether parents' constitutional rights superseded those of children.¹⁵

Statutes provide some rights to minors as well. At the federal level, Title X,¹⁶ the family planning program established in 1970, requires the provision of confidential services to teenagers,¹⁷ although providers are required to encourage family involvement for family planning services.¹⁸ All states have statutes that permit minors to obtain certain clinical services without parental permission.¹⁹ These typically include treatment for sexually transmitted infections, drug and alcohol abuse, and mental health. Neither the Constitution nor these statutes, however, are applicable to minors' ability to obtain genetic or genomic testing on their own.

The legal notion of "mature minor,"²⁰ which has been endorsed by statute or case law in less than half

of the states, comes closest to allowing minors to obtain genetic or genomic tests without parental permission. This concept has emerged primarily through tort litigation, typically acting to provide immunity to clinicians from lawsuits brought by parents when the clinician treated a child without parental permission or when the minor attempted to disavow their prior consent.²¹ To the extent that the concept of “mature minor” is based on the common law, its contours are necessarily fact-specific. The criteria generally appear to include requirements that the clinician have a reasonable belief that the minor is an older adolescent with capacity to make the decision and that the care offered not be high risk, is within mainstream care, and meets the standard of care. A few states have specifically rejected this doctrine by statute or judicial opinion, while a small number of states have passed statutes allowing minors to give effective consent if they are above a certain age or have “sufficient intelligence to understand and appreciate the consequences of the proposed surgical or medical treatment or procedures,”²² a standard that may under rare circumstances permit minors to obtain genetic or genomic tests.

In most cases, parents would know about genomic testing conducted in the clinical context since the charges for testing would be included in any bill to the parent and the insurance company’s explanation of benefits, thereby giving them the opportunity to object at least after the fact. The clinician who conducted such tests without parental permission would have to rely on the uncertain protection of the mature minor rule. Thus, the adolescent who wants genomic testing on her own may have an incentive to turn to direct-to-consumer testing, which could more easily be done without the parent’s knowledge.²³ The downside, of course, for the minor who turns to direct-to-consumer testing is the lack of the kind of expert interpretation available in research and clinical testing.

A few states have enacted laws that specifically provide that parental permission is required for genetic and genomic testing of a minor. Arizona and Oklahoma, for example, each enacted a “Parents’ Bill of Rights” that protects their rights to make health care decisions for their children as well as specifically requiring written parental consent before any genetic or genomic tests are conducted.²⁴ Statutes like these preclude any ability of minors to obtain these tests on their own, even if they are pregnant or are considering reproductive genetic testing.

Minors would almost never be able to enroll in research involving genomic testing on their own as parental permission is required unless the conditions for waiver of consent are met.²⁵ Even in the case of

biobanks, some sort of consent (and hence parental permission for minors) is increasingly required, especially if individual results are being returned,²⁶ and it has been proposed that any research using biological materials containing DNA will require consent.²⁷

Minors’ Rights to Refuse Genomic Testing

Unemancipated minors have virtually no access to the courts to enjoin parental behavior and so have little independent legal basis to obtain an injunction to stop genetic or genomic testing for which their parents have given permission. They are not even able individually to seek damages from their parents after the fact, as parents are generally immune from liability for actions that are deemed to be within their latitude to discipline or control, a concept that courts have interpreted very broadly to protect parents except in cases of car accidents.²⁸ As a result, whether a minor’s desire not to have clinical genetic or genomic testing is honored turns on the actions of others in the clinical or research setting. Many clinicians will not test a minor who objects if the minor is late school age or older, acting in accordance with professional ethical standards²⁹ and recognizing the challenge of obtaining samples from an unwilling teenager. Physicians may also refuse to perform tests that they think are inappropriate.³⁰ Parents, however, are free to seek other clinicians who will perform the desired tests.

Governmental child protection agencies are unlikely to step in to uphold the minor’s refusal of clinical testing since genetic or genomic testing is unlikely to pose a serious risk of harm to the child,³¹ the statutory basis for state intervention in cases of abuse or neglect. The fact that parents may seek to benefit themselves, their other children, and the family unit as a whole in addition to or even without regard for promoting the individual interests of the child who is being tested is largely irrelevant for purposes of state intervention to prevent child abuse, so long as there is no direct and serious, usually physical, harm to the child. Particularly given the deference that is generally given to parental choices, whether and under what conditions receiving unwanted genetic or genomic information can rise to this level of harm to a minor is an open question.

By contrast, honoring a minor’s objection to participation in medical research is much more firmly entrenched in the Common Rule, even though parents and minors may differ in their views about what role the child should play in deciding about research participation.³² The fact that IRBs are required to make “adequate provision...for soliciting the [affirmative] assent of the children, when in the judgment of the IRB the children are capable of providing assent”³³

may allow some adolescents to place limits on genetic or genomic testing or to forgo it altogether as a condition of participating.³⁴

Minors' Rights to Obtain Test Results, to Prevent Others from Having Access, and to Control What Others Do with the Results

Regulations promulgated under the Health Information Technology for Economic and Clinical Health (HITECH Act) generally provide that individuals have the right to “inspect and obtain a copy of protected health information” in “a designated record set,” which may extend to some research results as well.³⁵ Yet minors are legally entitled to access their medical records only under limited circumstances.

can obtain their children’s test genetic and genomic results.³⁸

Whether research participants or their representatives legally can obtain their individual results of genetic or genomic analysis is a topic of enormous controversy, which is beyond the scope of this paper, although the trend is toward increasing access.³⁹ The HITECH provisions noted above appear to provide access to at least some research results. Assuming that obtaining these results is legally permissible, parents could be asked to waive access to their child’s data, at least during the conduct of the study, if not longer. Numerous empirical studies, however, demonstrate that most parents are interested in getting these results.⁴⁰

State statutes that permit minors to make specific health care decisions (such as obtaining contraceptives or treatment for certain conditions) often protect their related information from disclosure to or access by others, but these statutes do not apply to genetics. Thus, as a general rule, minors have little ability to prevent their parents from obtaining their medical records unless their parents have agreed to honor their child’s confidentiality. Some states, including Arizona and Oklahoma in their Parents’ Bills of Rights, have explicitly stated that parents can obtain their children’s test genetic and genomic results.

The Health Insurance Portability and Accountability Act (HIPAA) provides a floor, permitting access when the minor is legally entitled to give binding consent for the care and has done so; where permission for care has been given by some person or entity other than the parent, typically, a judge; or, most pertinent for this discussion, where the parent has agreed that the minor may have a confidential relationship with a clinician.³⁶ Notably, many health care providers and institutions offer adolescents broader access to their records as a matter of routine. Once minors reach adulthood, of course, they can access their historical medical records.

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As noted above, minors have little direct legal authority to control the actions of their parents. Thus, once parents have their children’s results, they are largely free to tell other relatives or to disclose them.

Minors’ Rights Surviving Death

Given the general lack of control minors have over genetic testing and the resulting information, it is hardly surprising that unemancipated minors have little control over whether their parents can access the child’s genetic information after death. HIPAA and state law generally provide access to medical records to the decedent’s “personal representative” both before and after death.⁴¹ In the case of minors, these representatives are usually the parents. Although courts can change custody or name a different guardian, minors themselves do not have the legal authority on their own to name a different representative or to write a binding document with their wishes.⁴² Thus, only time will tell whether the robust ethical debate about what weight should be given to the wishes of minors in genetic and genomic testing will lead to greater legal recognition of their desires and concerns, including after death.

Conclusion

The American Academy of Pediatrics for the last 20 years has stated that minors should have an increasingly important role in deciding about their own health care as they mature,⁴³ a position the Academy endorsed more specifically regarding pediatric genetic testing in its recent statement with the American College of Medical Genetics and Genomics.⁴⁴ This right to choose limits the ability of others to override. Yet the College, very shortly thereafter, issued guidance that provides no real opportunity for minors to make decisions about secondary findings of clinical genomic tests.⁴⁵ The result is a marked difference in what weight is given to the views of minors.

The questions, then, are how much control minors should have over these tests and whether the law gets the balance right. Are these the kinds of choices minors should be able to make on their own, like obtaining contraceptives and treatment for certain diseases, which are usually justified at least in part on the desire to encourage minors to seek care, sometimes with a nod to the adolescent's privacy and decision-making interests? Or are these choices to undergo genetic and genomic testing so fraught that minors should not be permitted to make these decisions on their own? To what extent should adolescents ever be able to say no to such testing when their parents support it?

The analysis in this paper reveals that the law, for the most part, provides remarkably little protection for minors who wish to make decisions about genetic and genomic testing and to control who has access to the results. This is hardly surprising given our legal system's sweeping deference to parental governance of the family. The mature minor exception provides the only real safeguard for unemancipated minors who seek genetic and genomic testing in the clinical context, and clinicians should be aware that there is no guarantee that a court will find that this exception applies. Ironically, direct-to-consumer genetic testing may be the best option for minors who want information. Minors have a bit more control in the research setting as their assent is required for participation, giving them at least some leverage at the outset.

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these issues at all because they do not raise questions of abuse or neglect that warrant state involvement; instead, these questions would be left for resolution in the ethical space of the child-parent-clinician relationship that so uniquely characterizes pediatrics. Then, if the contrasting American Academy of Pediatrics' and the American College of Medical Genetics and Genomics' positions are seen simply as different ethically acceptable options, the choices available to the minor will depend in significant part on the ethical stance chosen by the clinician.

Law and ethics already structure and largely limit the options of children and adolescents, in both research and clinical care.

Assessment of whether law and ethics have gotten it right may depend on what weight is given to the personal salience of genetic information. I am a vocal critic of genetic exceptionalism, reasoning that genetic information cannot justifiably be distinguished from other kinds of information that shed light on many aspects of who people are and what they do. Yet at this cultural moment, genetic information is broadly understood as shedding particular light on a person's essence, as going to the very heart of who she is. That kind of intimate, personal information, which is so highly valued in our society, is precisely what the law protects in the right of privacy, which already extends even to adolescents. Thus, some legal change is warranted. At a minimum, adolescents should have the right to object to genetic and genomic tests, particularly those that confer no direct benefit to the minor prior to adulthood.

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