

Clinical Use Guidelines

Genetic Presymptomatic and Predictive Testing for Adult-Onset Conditions in Minors

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Introduction

Genetic presymptomatic and predictive testing of minors for adult onset conditions is addressed by this guideline.

Description

Inherited disorders display a range of symptom onset, from congenital to adult. Some adult onset conditions have surveillance or medical intervention recommendations that are initiated in childhood, while for others there is no change in medical management. The National Society of Genetic Counselors (NSGC) states that individuals should be able to make the decision to have testing for themselves, after understanding and assessing the risks, benefits, and limitations of the test. In their 2018 position statement entitled “Genetic Testing of Minors for Adult-Onset Conditions,” NSGC “encourages deferring predictive genetic testing of minors for adult-onset conditions when results will not impact childhood medical management or significantly benefit the child.”¹

According to the Genetics Home Reference, presymptomatic testing “can determine whether a person will develop a genetic disorder,” while predictive testing “can identify mutations that increase a person’s risk of developing disorders with a genetic basis.”² Predictive testing should be limited to disorders for which the genetic contribution is strong. Testing of minors for genetic variants that are not causative but confer susceptibility to disease is not medically necessary; and therefore, is not reimbursable.

Certain individual medical circumstances (such as consideration of a minor for organ/tissue donation or pregnancy in a minor with a family history of adult-onset disease) may present sufficient clinical utility to outweigh the criteria presented in this guideline. Such rare cases should be carefully considered on an individual basis.

Criteria

Introduction

Requests for genetic presymptomatic and predictive testing for adult-onset

conditions in minors are reviewed using these criteria.

Criteria: General Coverage Guidance

Predictive molecular testing of minors (members under the age of 18 years) for X-linked or autosomal dominant disorders will be approved when the following criteria have been met:

- **Genetic Counseling:**
 - **Pre and post-test genetic counseling by an appropriate provider (as deemed by the Health Plan policy), AND**
- **Previous Testing:**
 - **No previous testing for the condition, and**
 - **A familial disease-causing mutation has been identified in a 1st or 2nd degree biological relative who is affected with an adult onset autosomal dominant or X-linked condition, AND**
- **Predictive Testing for Asymptomatic Individuals:**
 - **The minor is at risk for inheriting the familial disease-causing mutation, and**
 - **The condition may have onset in childhood, or**
 - **The condition has recommendations for surveillance that begin in childhood, AND**
- **Rendering laboratory is a qualified provider of service per the Health Plan policy.**

Note Testing of any minor who is symptomatic for a condition, regardless of typical circumstances of onset, is considered diagnostic testing and should be reviewed using *Genetic Testing to Diagnose Non-Cancer Conditions* or the appropriate test-specific guideline.

Limitations and Exclusions

Testing of minors for genetic variants that are not causative of inherited disease is not medically necessary; and therefore, is not reimbursable. Examples of mutations or variants that are not causative include:

- **variants assessed by a testing laboratory to be of uncertain clinical significance**
- **variants that confer susceptibility for disease**
- **variants in genes of uncertain clinical significance.**

Criteria: Test-specific Guidelines

Test-specific guidelines are available for some tests that may be requested for minors. For tests without a specific guideline, use the General Coverage Guidance in Section 1.

References

1. **National Society of Genetic Counselors. Genetic testing of minors for adult-onset conditions. Adopted 2012; Updated: 2018. Available at: <https://www.nsgc.org/Policy-Research-and-Publications/Position-Statements/Position-Statements/Post/genetic-testing-of-minors-for-adult-onset-conditions>**
2. **What are the types of genetic tests? (Last Updated July 2021). In: MedlinePlus Genetics US National Library of Medicine (database online). Copyright, National Institutes of Health. 1993-2022. Available at: <https://medlineplus.gov/genetics/understanding/testing/uses/>**