

## **Genomics in Health and Wellness Meeting**

March 5-6, 2019

Hyatt Regency Bethesda, Bethesda, MD

Executive Summary

The Genomics in Health and Wellness Meeting convened employers to discuss the role of genomics in employee health. The meeting objectives were to determine employers' interest in a genomic medicine 'formulary' and charge a group to develop it, determine employers' interest in a genomic medicine employee health program, explore the potential for developing a consensus around the role of genomics in employee health systems and disseminating recommendations, and explore collaborative opportunities and potential projects to deploy genetic tests and a formulary-based program within employer populations and measure and publish the clinical and health economic impact.

### **Lessons Learned:**

#### Implementation

- Current criteria for testing are insensitive and miss identifying at-risk patients.
- Genetic tests must be implemented along with pre/post-test counseling and a plan for managing the long-term testing results.
- Simply telling employees to request testing from their doctors doesn't work; more effective is a program to which they can opt in, with a robust downstream pipeline for follow-on actions.
- Genomic testing results need to be transferable by patients to other care systems.
- Employers need measurements that assess whether follow-up actions are being implemented and effective, perhaps through third parties.

#### Employer Perspectives

- Employers, in comparison to health insurance companies, are interested in factors other than cost such as employee productivity, morale, and wellbeing.
- A major distinction between insurers and employers is the time span of coverage—1-2 years vs. 10+ years (or even 30 years for pension plans).
- Employers are interested in data on avoidance of health episodes, shortening of episodes, reduction of costs within episodes, and pilot studies that show the effects of early interventions.
- Benefit considerations vary greatly depending on if an employer is implementing regular health insurance benefits or a wellness plan.
- Employers are interested in the time required to achieve benefits from testing; this information can help them decide which interventions to implement first.
- The employee perspective is needed as is the perspective of employee unions.

#### Economics and Assessments of Value

- Economic models need to consider employer data like productivity, lost days of work, role performance, and expected duration of employee-employer relationship.

- Economic models need to be adjustable to reflect different assumptions important to specific employers/employees.
- Published data on the economics of genetics in wellness programs are scant to non-existent.
- The cost per quality of adjusted life year gained (QALY) measurement can be used to assess cost effectiveness of interventions, but may not be the most persuasive measurement for employers.

### **Recommendations:**

#### Implementation

- Offer wellness initiatives through a third party to help avoid real/perceived conflicts of interest.
- Consider incorporating a genetic component to existing wellness programs that already focus on specific disease paradigms.
- Prioritize sharing de-identified aggregate data amongst employer groups while creating a transparent process and rationale for data sharing and uses of data with employees.
- Develop a collaboration amongst employers, with outcome data collected by a third party, to generate the data necessary for insurers and others to assess the value of genetic testing.
- Determine what employers should do vs. what should be ceded to a good healthcare provider.

#### Further Development

- Establish key principles and guidelines for test implementation that address ELSI and policy issues related to genetic testing, such as non-discrimination, privacy, health disparities, and data sharing.
- Conduct a policy review specific to employer programs on the above key ELSI issues.
- Include information in the formulary about who is likely to benefit from each test and the resources necessary for each specific test.
- Rename the formulary with a clearer title that is less likely to be confused with drug treatment.
- Develop a sustainability plan for the formulary beyond volunteer efforts.
- Consider creating a dynamic, web-based implementation guide that includes a suite of materials and allows for “plug-in” guidance based on employers’ unique populations and needs.
- Consider potential role, and possible conflicts, for genomics testing companies in this effort.
- Consider a model of employers supporting testing if tied to evidence generation and evaluation.
- Work to develop options for creating a robust “firewall” between genomic information and employers; making genomics a totally voluntary benefit may help but uptake will differ by demographics.
- Develop a simple categorization of genetic testing to ensure everyone is consistently talking about the same thing; emphasize lumping over splitting.

#### Engagement

- Engage with employees to investigate their value assessments of genomic testing and willingness/motivation to share de-identified data.
- Engage with a number of different types of employers to ensure socioeconomic, racial, and geographic diversity, as well as representation of non-healthcare-based employers.

- Canvas employers that have already implemented genetic testing to get an understanding of their satisfaction and solicit feedback, especially from employees/beneficiaries.