Business and Breakthrough

Framing (Expanded) Genetic Carrier Screening for the Public

@averyholton | Heather E. Canary | Bob Wong
University of Utah
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ECS?
Professional Focus

(1) guidelines for determining what conditions should be included in test panels
(2) knowledge health care providers have about the tests, conditions, and results
Professional Focus

(3) adequate counseling or education for patients, both before and after test administration
the benefits and drawbacks of ECS. Medical professionals have urged the development of widely recognized, formal guidelines for what to include in ECS panels (Benn et al., 2014; Edwards et al., 2015; Grody et al., 2013; Langlois, Benn, & Wilkins-Haug, 2015)
Media Focus
Let’s Look

2010-2015
Let's Look

<table>
<thead>
<tr>
<th>Variable</th>
<th>Value</th>
<th>Bar Length</th>
</tr>
</thead>
<tbody>
<tr>
<td>A business organization/representative</td>
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<td>124</td>
</tr>
<tr>
<td>Medical research company/representative</td>
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<td>110</td>
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<tr>
<td>Screening advocacy organization/representative</td>
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<tr>
<td>Individual Physician</td>
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<tr>
<td>Individual Researcher</td>
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<td>A government organization/representative</td>
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<td>Current parents</td>
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<td>A religious organization/representative</td>
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<tr>
<td>Genetic Counselor</td>
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<tr>
<td>Expecting parents</td>
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<tr>
<td>Pharmaceutical company/representative</td>
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Let’s Look

- Genetic Carrier Screening: 197
- Specific Lab/Test Name: 176
- Expanded Genetic Carrier Screening: 167
- Breakthrough or Research: 123
- Business Issues: 89
- Cost: 70
- Innovation: 63
- Legal/Ethical Issues: 53
- Pre-Pregnancy Issues: 50
- Treatment: 48
- Pregnancy Health: 32
- Religious Issues: 13
- Political Issues: 10

Chart showing the frequency of various topics.
Let’s Look

Thematic >

Episodic
Let’s Look

Gain > Loss
Let’s Look

Parents < 2%

Genetic Counselors < 6%
Let’s Look

Business Rep > 54%

Research Rep > 48%
Let’s Look

Parents = Episodic

Advocacy = Loss
Let’s Look

Pre-Pregnancy = Gain

Legal/Ethical = Loss
The Voices

Business/Breakthrough

Counselors/Parents
Future Considerations

National Institutes of Health and National Human Genome Research Institute
RM1 funding

Primary Investigator, Jeffrey Botkin. Co-Investigator/Project Lead.

$3,880,000
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