Exploring the Current Landscape of Consumer Genomics

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Bronx, NY

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The Bronx, NYC
# The Bronx, NYC

**Population estimates, July 1, 2018, (V2018)**

<table>
<thead>
<tr>
<th>Race and Hispanic Origin</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>White alone, percent</td>
<td>44.9%</td>
</tr>
<tr>
<td>Black or African American alone, percent (a)</td>
<td>43.6%</td>
</tr>
<tr>
<td>American Indian and Alaska Native alone, percent (a)</td>
<td>2.9%</td>
</tr>
<tr>
<td>Asian alone, percent (a)</td>
<td>4.5%</td>
</tr>
<tr>
<td>Native Hawaiian and Other Pacific Islander alone, percent (a)</td>
<td>0.4%</td>
</tr>
<tr>
<td>Two or More Races, percent</td>
<td>3.7%</td>
</tr>
<tr>
<td>Hispanic or Latino, percent (b)</td>
<td>56.4%</td>
</tr>
<tr>
<td>White alone, not Hispanic or Latino, percent</td>
<td>9.1%</td>
</tr>
</tbody>
</table>

**Population Characteristics**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Veterans, 2013-2017</td>
<td>27,604</td>
</tr>
<tr>
<td>Foreign born persons, percent, 2013-2017</td>
<td>35.3%</td>
</tr>
</tbody>
</table>
## The Bronx, NYC

### Computer and Internet Use
- Households with a computer, percent, 2013-2017: 82.4%
- Households with a broadband Internet subscription, percent, 2013-2017: 70.4%

### Education
- High school graduate or higher, percent of persons age 25 years+, 2013-2017: 71.5%
- Bachelor's degree or higher, percent of persons age 25 years+, 2013-2017: 19.4%

### Health
- With a disability, under age 65 years, percent, 2013-2017: 10.9%
- Persons without health insurance, under age 65 years, percent: 8.9%

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US Census Bureau - https://www.census.gov/quickfacts
## The Bronx, NYC

### Income & Poverty

<table>
<thead>
<tr>
<th>Description</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Median household income (in 2017 dollars), 2013-2017</td>
<td>$36,593</td>
</tr>
<tr>
<td>Per capita income in past 12 months (in 2017 dollars), 2013-2017</td>
<td>$19,721</td>
</tr>
<tr>
<td>Persons in poverty, percent</td>
<td>27.9%</td>
</tr>
</tbody>
</table>
Consumer Genomics

- Direct to consumer
- Patient driven

Prenatal

Cancer

Montefiore
Albert Einstein College of Medicine
Prenatal Genetics – Clinical Guidelines

• Aneuploidy Screening & Diagnosis
  – Cell free DNA
  – First trimester screening
  – CVS and Amniocentesis

• Carrier Screening
  – Hemoglobinopathies
  – Cystic Fibrosis
  – Spinal Muscular Atrophy
  – Fragile X Syndrome
Prenatal Genomics – Clinically Available

• Detection of Microdeletion Syndromes
• Expanded Carrier Screening
Prenatal Genomics – Consumer Driven

Gender Reveal

Teddi Mellencamp
Prenatal Genomics – Consumer Driven

Gender Reveal

View More on Instagram

It's a girl! Of course, we would have been equally excited either way, as @tedwinator, the kids and I are just blessed to have a healthy baby no matter the gender. Although I did promise Cruz he could help name her so not sure she'll be too thrilled being called “Catboy” Arroyave. 😊 Thank you to @ocoballoonsbar for the pop we needed, @204events for the rad background and @jegephoto for capturing this moment so perfectly. 🥰

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Prenatal Genomics – Consumer Driven

Alexa and Carlos PenaVega

"Mommy’s outnumbered, but can I say that I love it?” the Spy Kids star said in a March 2019 video after revealing the sex of her baby with a colorful cake. “The idea of two boys is so exciting. It’s such a blessing. I have a beautiful momma’s boy already, and now I get two!”
Prenatal Genomics – Consumer Driven

A: Magic cake says it's a boy!
Prenatal Genomics – Gender Reveal

• Patients want early information and are often under pressure ... because the party is already planned.
• Patients want the results to be given to someone else – sister, bakery, etc.
• Patients frequently embark on the “gender test” with little consideration that the aneuploidy screening test results might be high risk.
• The patient interface – My Chart – does not display ”send out” labs and so patients often misinterpret the Fragile X screening result as the gender.
Prenatal Genomics – Paternity Testing

- Many mothers are interested – prospectively
- Home DNA kits are advertised for holiday gifts and stocking stuffers:
  - Blogs and current books discuss family issues raised by unexpected results
Cancer Genomics – Consumer Driven

• How to get the right patients to Genetics?
  – Often see the worried well
  – Some individuals from high risk families are never seen in Genetics

• Patients are quite interested in multi-gene panels
  – May find something unexpected
Cancer Genomics – Consumer Driven

- Variants of Uncertain significance
  - Surgeons might plan to operate based on a VUS
- What to do with a VUS?
  - Patients often report that they will eat a healthier diet and exercise
Cancer Genomics – Consumer Driven

• When it is believed that there is something in the family …

• It’s hard to get copies of previous testing results from family members

• Patients or family members can’t always remember the results from testing they undertook previously

• There can be confusion as results are conveyed from one family member to another
  - PALB2 vs BRCA2
Cancer Genomics – Consumer Driven

- Lab reports are scanned into EPIC as “send out” lab reports and are not easily accessible to other providers or to patients via MyChart
The Current Landscape of Consumer Genomics

• Clinical Utility
  – Planning a party
  – Evaluating an ultrasound anomaly
  – Eating healthy

• Communicating and keeping track of results
  – Reports are hard to understand & keep track of
  – Sharing information within families
  – EMRs and interoperability
Thank you!