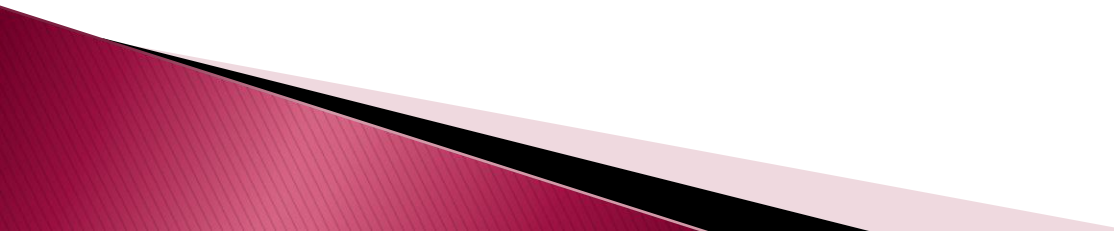
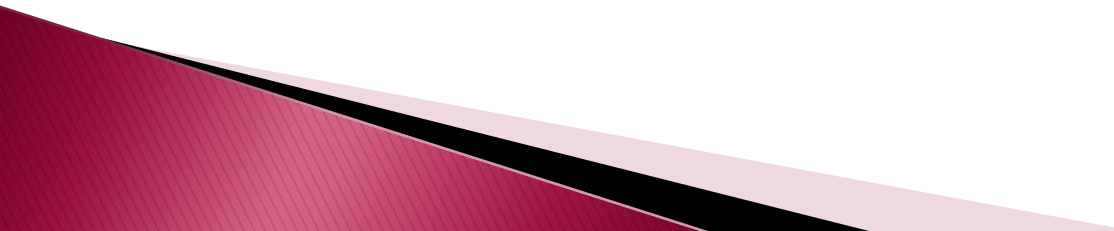


Genomics:
What Kind Of Information Do Consumers
Want?



What Kind of Information Do Consumers Want?

- What can we test for?
 - What will the information mean for me?
 - What will the information mean for my family?
 - Will I have access to the information?
 - Is the information actionable?
 - Where can I go for more information?
- 

What Kind of Information Do Consumers Want?

What can we test for?

- List of available tests and profiles

- Is there more than one type of test for a particular trait?

- Which one is best for me?

- What are the differences?

What Kind of Information Do Consumers Want?

What will the information mean for me?

- My risk for disease (relative and absolute)
- Risk for passing on disease to children
- Response to treatment/prognosis
- Best choice of medications to treat or prevent disease
- Reaction to medications
- Quality of life/lifestyle factors
- What is the likelihood that I have this variant/factor?

What Kind of Information Do Consumers Want?

- What will the information mean for my family?

- Might carrying this trait effect my family planning decisions?

- Might I have passed this on to my children?

- Might other relatives share these traits?

What Kind of Information Do Consumers Want?

- Will I have access to the information?

 - How do I order the test?

 - How much does the test cost?

 - Will my insurance pay for the cost of the test?

What Kind of Information Do Consumers Want?

Is the information actionable?

- Does the information make new options available to me?

- What are the benefits and risks of each option?

- Do experts agree on the best course of action?

- Will insurance pay for the options?

- Will I have to make decisions based on the information?

- What do other people choose to do with the information?



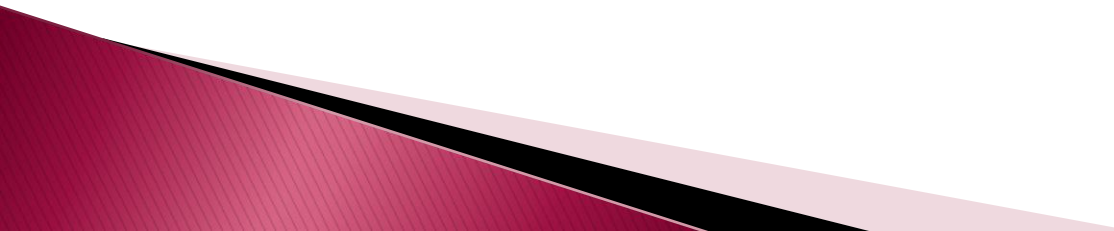
What Kind of Information Do Consumers Want?

Where can I go for more information?

- Is there a trusted/credible/complete/unbiased source of information?
- Are there particular experts that I should consult with?
- Are there guidelines on what to do with the information?
- Can I talk with others who are like me?

What Kind of Information Do Consumers Want?

Barely on the radar

- How do these different factors and options work together to effect my personal health and choices I might make?
 - Is there a good timeline for what stages of life I might consider exploring each aspect of my genomic profile and a roadmap for best interventions by age/phase of life
 - How personalized are the interventions
- 

Other considerations

- Consumers are making decisions right now based on these tests
- How do we assure consumers are getting full information?
- How do we assure consumers understand the information?
- How do we provide updates to consumers?
- Consumers believe that once a test is available it has been validated and has clinical utility
- Consumers trust that their doctors will have expertise and understanding about these tests

"I'm 38 and carry a BRCA mutation and I'm at high risk for ovarian cancer. My mother died at age 42 of the disease. I'm booked for a prophylactic bilateral salpingo-oophorectomy next Tuesday. I've been told by my gynecologic-oncologist that they don't really know what the long term implications are of doing this at my age. In my record he wrote:

'There are probably increased risks of osteoporosis and heart disease from premature removal of the ovaries.'

Both are diseases that I'm at risk for. Should I wait and do this closer to menopause? It's a horrible, hard thing, because no matter what I do there seems to be substantial risk."