Shhh, or tell the world

one family’s experience with genetic test results

IPDLN Conference Science Slam 2018
Alison Paprica and Juliet Di Carlo
Doctor: “Given your family history of cancer, I recommend you undergo genetic screening to see if you are positive for BRCA1 or BRCA2 mutations”
Section C  Medical Declaration (continued)

3. Have you, your co-applicant or any listed dependant(s) ever been advised to have an investigation, hospitalization or surgery which has **not been completed**, or are awaiting any tests or test results?

Somebody other than us cares about these genetic test results....
Angelina Jolie undergoes double mastectomy

By Ed Payne, CNN

Updated 8:09 AM ET, Thu May 16, 2013

Actress Angelina Jolie announced in a New York Times op-ed article on Tuesday that she underwent a preventive double mastectomy after learning that she carries a mutation of the BRCA1 gene, which sharply increases her risk of developing breast cancer and ovarian cancer.

"My doctors estimated that I had an 87 percent risk of breast cancer and a 50 percent risk of ovarian cancer, although the risk is different in the case of each woman," Jolie wrote. "Once I knew that this was my reality, I decided to be proactive and to minimize the risk as much I could. I made a decision to have a preventive double mastectomy."
What are we going to do?

I don’t know. I don’t feel ready to tell the girls. I don’t know what we’d say.

Well, I guess this confirms your mum had the mutation. We should let your brother and sister know, so they can get tested too.

[Sigh]
Of course, that’s not the only possible outcome
Husband’s Uncle
Husband’s Aunt
Husband’s Father
Husband’s Mother
Me
Husband
Eldest Daughter
Youngest Daughter
accident
Husband’s Uncle
Husband’s Aunt
Husband’s Father
Husband’s Mother
Me
Husband
Eldest Daughter
Youngest Daughter
cancer
Husband’s Uncle
Husband’s Aunt
Husband’s Father
Husband’s Mother
Me
Husband
Eldest Daughter
Youngest Daughter
cancer
Some day, someone is going to ask you about your medical history.

Say that your grandma on dad’s side died of ovarian cancer at a young age, but dad has been tested for the breast cancer gene mutations, and the tests were negative.

It’s important that you tell this to anyone that asks.
Shhh or tell the world

Based on a true story, this ~3 minute one-woman play highlights how one individual's genetic test information unavoidably provides information about the genetic risks for other family members.

When it comes to breast cancer genes, what do you want to know/not know and who else needs to be told? The answer, of course, depends on the results.
This September, get the BRCA Test for $99

Learn your risk for hereditary breast and ovarian cancer
Plus free phone counseling to help you understand your results

Get Started

Take the first step with this easy saliva test for BRCA1 and BRCA2.

Color's BRCA Test
$149   $99

What's included in your Color test
- Saliva collection kit & prepaid return label
- BRCA1 and BRCA2 test report
- Expert genetic counseling
- Latest genetics news that matters to you
- All Color tests are physician-ordered. Learn more.

Buy Color
Pay with PayPal

*You must be at least 18 to use Color.
Door will open to genetic discrimination if act protecting Canadians is overturned, genomics expert says

Canada's Genetic Non-Discrimination Act is being challenged by the province of Quebec

Brandie Weikle · CBC News · Posted: May 14, 2018 4:00 AM ET | Last Updated: May 14

The act, which became law May 4, 2017, makes it a criminal offence to enter into any kind of contract that requires a person to disclose the result of a genetic test.

The Quebec government is challenging the constitutionality of the act by referring it to the Court of Appeal of Quebec, arguing that by making it illegal to deny a service based on someone's genetic test results, the act infringes on the regulation of the insurance industry — a provincial jurisdiction.
A Major Drug Company Now Has Access to 23andMe’s Genetic Data. Should You Be Concerned?

By JAMIE DUCHARMÉ  July 26, 2018

For more, visit TIME Health.

Consumer genetic testing company 23andMe announced on Wednesday that GlaxoSmithKline purchased a $300 million stake in the company, allowing the pharmaceutical giant to use 23andMe’s trove of genetic data to develop new drugs — and raising new privacy concerns for consumers.

The “collaboration” is a way to make “novel treatments and cures a reality,” 23andMe CEO Anne Wojcicki said in a company blog post. But, though it isn’t 23andMe’s first foray into drug discovery, the deal doesn’t seem quite so simple to some medical experts — or some of the roughly 5 million 23andMe customers who have sent off tubes of their spit in exchange for ancestry and health insights.
Many of us are thinking a lot about privacy, consent, public engagement and how people feel about their data being used.

Genetic test results may add a new wrinkle because of the personal impact that test results can have, e.g., on identity and because one individual’s genetic profile isn’t solely their information, it unavoidably provides information about people related to them.