

Should we test DNA? Balancing technology & human values

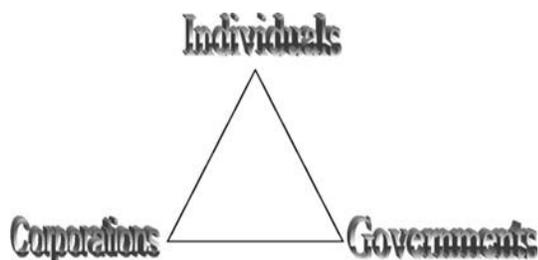
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Two years ago at Genealogy Jamboree, attorney and genetic genealogist Judy Russell condensed the ethical guidelines that had generally sufficed for 20th century genealogist to these three:

1. Tell the truth;
2. Play nice with others; and
3. Don't tell tales out of school.¹

When any new technology is developed, social norms governing its appropriate use often lag far behind. These new technologies have both intended and unintended consequences. Honest and intelligent individuals can differ about the proper/ethical use of that technology. DNA testing is no exception. Should we test? Should we urge others to test?

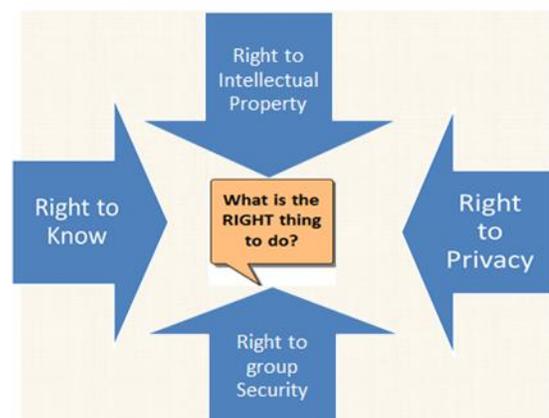


power/increase their accountability.

In the simple model at left, three “players” often have competing views of what the use of a new technology should be. Each of these groups wants maximum freedom for themselves and maximum accountability for the other two players. However, this is a zero sum game. One player can increase power/lessen accountability only if others reduce their

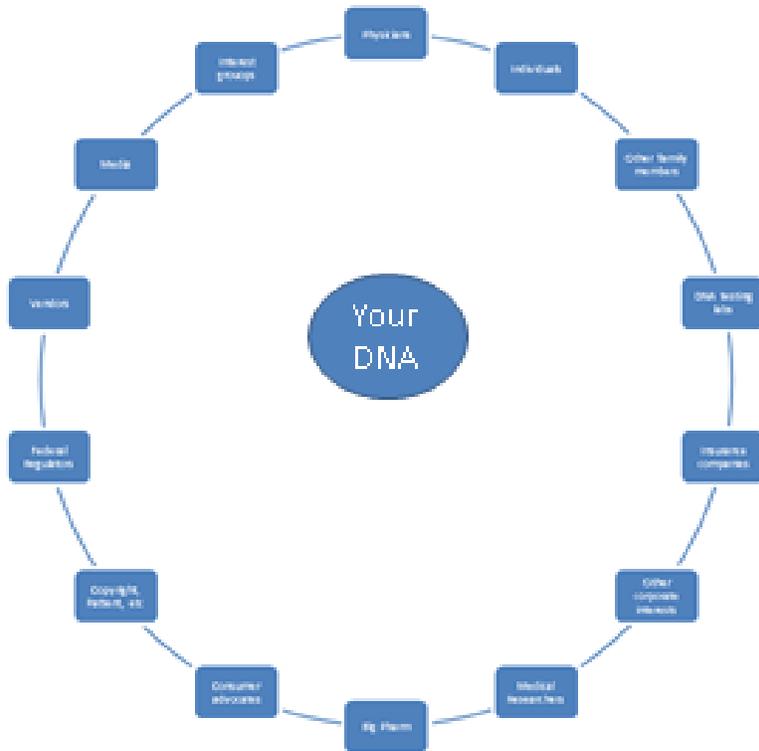
What is the *right thing to do* when “rights” collide?

Each of these three “players” will assert *rights*, but those *rights* are usually in competition with other *rights*. The point of view one takes often is determined by the *right* one is asserting. Or does one choose to assert the *right* that will support their pre-existing point of view? Where should the balance point be among these competing rights? What is the **RIGHT** thing for us to do? Should we DNA test? Should we expect others to test and share their results? How should we use or protect those results?



As we move into the era of using the information recorded in our DNA for both family history and for personalized genomic medicine, we can identify many more would-be stakeholders who claim they should have a say over the use of that information:

Selected Stakeholders in DNA Testing



- Individuals
- Family researchers
- Other family members
- DNA testing labs
- Physicians
- Insurance companies
- Other corporate interests
- Medical researchers
- Big Pharma
- Consumer advocates
- Copyright & patent holders
- Federal Regulators
- Vendors
- Media
- Interest groups
- DNA counsellors
- Ethicists

Again as with the simpler model on the previous page, it is a zero sum game. Players can gain more control or free themselves from accountability only as others give up some control or are assigned more accountability.

Genetic Genealogy Standards:

Earlier this year a distinguished group of genetic genealogists circulated a list of “Genetic Genealogy Standards”:

<http://www.thegeneticgenealogist.com/wp-content/uploads/2015/01/Genetic-Genealogy-Standards.pdf>

They should be consulted along with existing guidelines such as:

Board for Certification of Genealogists (BCG): “Code of Ethics and Conduct”,
<http://www.bcgcertification.org/aboutbcg/code.html>

The National Genealogical Society has published several Genealogical Standards. Every genealogist, whether beginner or expert, hobbyist or professional, should read these. These Genealogical Standards and Guidelines may be viewed on the society’s website:
http://www.ngsgenealogy.org/cs/ngs_standards_and_guidelines

Individual Responsibility to “do the right thing”

The new Genetic Genealogy Standards state, “it is ultimately the responsibility of those taking a genetic genealogy test (“tester”) to understand and consider these standards before ordering or agreeing to take any genetic genealogy test.” At the time persons are deciding whether to test or not it is unlikely they will be aware of the above documents. However, for a long time each of us who try to do the right thing has used tried and true methods for arriving at the truth for us.

Long before the digital age, an old philosophy professor of mine suggested the following six ways that we can arrive at truth. They remain valid today for those seeking the “truth”. How many different ones do you use?

1. **Rational Thought**—truth comes from logically correct thinking. (Everything grows out of Rene Descartes’ observation, “I think, therefore, I am.”)
2. **Common Sense**—truth comes from what we all know in common.
3. **Sensory Observation**—truth comes from what we can see, touch, smell, taste and hear.
4. **Intuition**—truth comes from within the individual—a sort of sixth sense, an inner voice or consciousness.
5. **Scientific Method**—truth comes from rigorously testing hypotheses and by sharing results with others to see if they can be replicated.
6. **Authoritarian Faith**—truth comes from an authority in which we have faith (e.g. the Pope, *The Bible*, Rush Limbaugh, Nelson Mandela, Dr. Laura, Dr. Martin Luther King, Jr., our parents, Osama bin Laden, the government, a professional body, a mentor, Confucius, etc.).ⁱⁱ

Only if we use *Authoritarian Faith* as our prism for discerning truth are we guaranteed that the *legal answer* will be the same as the *ethical one*. And this will be true only if the authority in which we place our faith is the wisdom of the government. If we use any of the other five means of determining truth or use authority figures other than the government for guidance, we may at times find ourselves in situations where the *ethical* and the *legal* answers can be in conflict.

Should you test? Should you urge others to test? All of us may not arrive at the same answer, and we should learn to respect each person’s right to make that decision.

Additional reading:

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ⁱ Judy G. Russell, “The Ethical Genealogist”. Presentation at Jamboree 2013, Southern California Genealogical Society, June 7-9, 2013.

ⁱⁱ A context for these ways of knowing truth can be found in Denise K. Fourie and David R. Dowell, *Libraries in the Information Age: An Introduction and Career Exploration*. 2nd Edition, Santa Barbara: Libraries Unlimited, 2009, pp. 195-196.