



Fact Sheet for Health Care Consumers Genetic Privacy & Research

Oregon's first genetic privacy laws were passed in 1995 with a goal of trying to help protect your genetic information and prevent possible employment or insurance discrimination to health care consumers like yourself.

In 2005, a few changes were made in Oregon laws about when results of a genetic test, specimens collected (such as blood or tissue), or health care information may be available for certain types of genetic research. You will be asked to make decisions about this starting in 2006.

What is the same?

- If genetic test results, specimens collected or health care information can be linked to you (for example if it includes your name or address or birth date) the researcher must still get your permission before using this information for genetic research.

What is new?

- If genetic test results, specimens collected or other health care information does not include any information that can be linked to you (or there is only a code and the key to the code is kept separately) the new law allows researchers to access these and ask permission of an independent review board (called an IRB) to use the test results, specimens collected or health care information for what is called "anonymous" or "coded" genetic research.
- The new law requires you to make a decision regarding use of your health information in anonymous or coded genetic research.
- As a result, starting July 1, 2006, the new law requires that your doctor or health care provider give you notice and asks you to complete a form at least once and mark if you DO NOT want any of your specimens or health care information available for anonymous or coded genetic research. This is often called an "opt-out" form.

Why was the change made?

- Many people want to keep their health care information, including their genetic information, private. Many people also recognize that medical and genetic research can help develop new information that allows both patients and doctors to learn more about diseases, make good health care decisions, and discover new treatments.
- The new law tries to balance the interests of those who want to keep their genetic information private by allowing them to make a decision to “opt-out” while allowing researchers to do genetic research needed to make good health care decisions by you and your health care providers.

What do I need to do?

- You will need to make a personal decision on whether your genetic test results, specimens collected or health care information will be available for anonymous or coded genetic research.
- If you DO NOT want your results of a genetic test, specimens collected or health care information available for anonymous or coded genetic research you must mark that place on the form provided by your doctor or health care provider
- If you DO want the results of a genetic test, specimens collected, or your health care information available for anonymous or coded genetic research, you don't need to do anything.
- In either case, your health care provider is responsible for providing a notice and form for you to mark. This only needs to happen once, not at every visit.
- If you change your mind in the future, it is YOUR responsibility to inform your health care provider and it would only affect results of genetic tests, specimens collected or health care information from that date forward.

Where can I get more information?

Talk to your doctor or health care provider.

The Oregon Genetics Program – (971) 673-0271 or

www.oregongenetics.org.