July 1, 2006 - Changes in Oregon’s Genetic Privacy Law & its Impact on Health Care Providers

What’s Changed?
1. Beginning July 1, 2006, health care providers must notify their patients that any specimens or health information collected will be available for anonymous\(^1\) or coded\(^2\) genetic research unless the person "opts out."
2. A patient “opts out” by completing an opt-out form in writing and submitting it to their health care provider.
3. The revision changes the types of research that can be done without informed consent using an individual’s (a) biological specimen, or (b) health information.

Implementation at OHSU?
1. In most areas, Admitting and Patient Registration staff will be providing patients with OHSU’s Genetic Notice.
2. Patient’s can opt-out of future anonymous or coded genetic research by completing OHSU’s Genetic Notice opt-out section and returning the form to OHSU.
3. Patients may return the opt-out at any time and may deliver it directly to you as the Health Care Provider. Send all completed opt-outs to Health Information Services, Mail Code OP-17NP.
4. Your questions or patient questions can be referred to the OHSU Integrity Office at 503-494-8849.

Informing Indirect Providers\(^3\) of Opt-outs if Specimens or Health Information are Sent Outside OHSU for Analysis
1. Outside lab or x-ray facilities receiving an order or patient specimen from you (OHSU) must be notified if a patient has opted-out of coded or anonymous genetic research.
2. Here is the process:
   a. If you use Epic, the opt-out is automatically included on the printed external order requisition forms.
   b. If you are not using Epic, the opt-out is documented in A2K and the opt-out should be included with the order or specimen.

If you have questions about the new law or whether the procedures outlined above apply to your area, please contact the OHSU Integrity Office at 4-8849 or oips@ohsu.edu.

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1 “Anonymous” means that the no one can identify the patient from whom the biological specimen or health information was obtained.
2 “Coded” means that the patient from whom a biological specimen or health information was obtained cannot be identified without using a code or other encryption that is kept separately from the specimen or information.
3 “Indirect provider” is a health care provider having a relationship with a patient in which: A) Health care is delivered to the patient based on orders of another health care provider; and B) The health care provider typically provides services or products, or reports the diagnosis or results associated with the health care directly to another health care provider, who provides the services or products or reports to the patient.

Last Updated 6/27/2006
http://ozone.ohsu.edu/cc/gen/providers.pdf