

Genetic Notice and Opt Out

This script simplifies a very complicated subject matter; while as accurate as possible it should not be seen as a complete summary of the new law or of genetic research.

Script for Admissions Personnel

We have a new law in Oregon that allows you to make a decision about whether you are willing to allow medical information about you to be used for coded or anonymous genetic research. Anonymous genetic research is research that may use your medical information but does not identify you as the source of the information. Coded genetic research also does not identify you but the researcher may ask for special permission to identify you if necessary.

You have a right, however, to say you do not want your information used in that way. If you **do not** want your information used for future coded or anonymous genetic research, you need to mark the box, sign the form, and return it to OHSU. If you have no objection to use of your information or specimen, you do not need to do anything.

You may take it with you and fill out this form later and send it back to us if you wish.

Possible patient questions and sample answers:

- 1. Don't researchers have to obtain my consent in order to use my information for research?* Yes, researchers must obtain your consent if your information is identified as belonging to you. In the case of anonymous or coded research, however, they are not necessarily required to.
- 2. What is genetic research? Can you give me an example?* Genetic research is the study of whether there are genetic reasons for certain health conditions, such as obesity or Alzheimers. Genetic research furthers scientific understanding of disease and helps develop new tests and treatments.

3. *If I do not sign this form, will my insurance company or employer be able to discriminate against me based on my genetic information?* No. This form only indicates whether you want or do not want your information used for coded or anonymous genetic research.
4. *Why would genetic researchers want my information?* We don't know what information researchers may later deem useful as they explore better understanding of particular diseases.
5. *Is there any way researchers could later identify me or even contact me?* Coded genetic research does provide a way for researchers to identify you but the researcher would require the permission of an Institutional Review Board to do so.
6. *I don't get this coded/anonymous research thing. Can you explain it to me further?* The Notice we gave you should help with those sorts of questions. If you have more questions about genetic research, however, you may call our Integrity Office at 503-494-8849.
7. *I don't want to be bothered with this now. Can I think about this later?* Yes. You may send this form back to us after you return home from your hospital stay.