

2015 Biennial Report to the Oregon State Legislature

Advisory Committee on Genetic Privacy and Research (ACGPR)

June 2015



Executive summary

The Advisory Committee on Genetic Privacy and Research (ACGPR), created in its current form by the Oregon Legislature in 2001 (Senate Bill 114), studies the effect of Oregon's regulation of the use and disclosure of genetic information and the rights of individuals regarding their DNA samples and genetic information. The ACGPR also creates opportunities for public education on scientific, legal and ethical developments within the fields of genetic privacy and research and elicits public input on these matters. The ACGPR is staffed, without funding, by the Oregon Genetics Program within the Public Health Division of the Oregon Health Authority.

As in the 2013 biennium report, the committee does not recommend changes to Oregon's current genetic privacy statutes. However, it does recommend the legislature make funding available to the Oregon Health Authority to staff the ACGPR with a 0.25 FTE program analyst (PA3) position.

In this report, the ACGPR:

- Reviews the major activities in the 2013 biennium, including a survey of professional stakeholders regarding their use and understanding of the Oregon Genetic Privacy Laws (ORS 192.531 to 192.549).
- Summarizes the major challenges the committee sees for the 2015–17 biennium.
- Describes the capacity and changing focus of the committee, as well as their continuing inability to fully achieve the duties mandated by Oregon law (ORS 192.549).
- Proposes four focus areas for the committee for the 2015 biennium (July 1, 2015–June 30, 2017).

The full 2015 biennial report is posted on the Oregon Genetics Program website on the Oregon Genetic Privacy Law Web page at www.healthoregon.org/genetics.

Background

The Advisory Committee on Genetic Privacy and Research (ACGPR), created by the Oregon Legislature in 2001 (Senate Bill 114), studies the effect of Oregon's regulation of the use and disclosure of genetic information and the rights of individuals regarding their DNA samples and genetic information. The ACGPR also creates opportunities for public education on scientific, legal and ethical developments in the fields of genetic privacy and research, and elicits public input on these matters.

Please see Appendix 1 for the Advisory Committee on Genetic Privacy and Research Statute (§192.549) and Appendix 2 for the contact information of the 2013 biennium ACGPR members, interested parties and OHA staff. The ACGPR is staffed, without funding, by the Oregon Genetics Program of the Public Health Division of the Oregon Health Authority.

As in the 2013 biennium report, the committee does not recommend changes to Oregon's current genetic privacy statutes. However, it does recommend that the legislature make funding available to the Oregon Health Authority to staff the ACGPR with a 0.25 FTE program analyst (PA3) position.

2013 Biennium update

The ACGPR proposed ongoing work in four areas in our last report, noted below in italics. The proposed recommendations and a summary of activities for the 2013 biennium (July 1, 2013–June 30, 2015) are as follows:

- *Monitor the landscape of national legislation as it affects the Oregon Genetic Privacy Law (OGPL); especially changes to the Common Rule and any emerging interpretation or challenge of Genetic Information Nondiscrimination Act of 2008 (GINA) or other federal laws relating to the use or disclosure of genetic information.*

The ACGPR continues to monitor the national landscape as it relates to ensuring Oregonians' genetic privacy, preventing misuse of genetic information and keeping the legal environment amenable for genetic research and genetic health services in the state. Due to the broad scope of genetic privacy and research issues and the limited resources of the committee, the committee is not able to monitor federal laws and laws from other states in depth. Anticipated changes at the federal level to the Common Rule (45 CFR part 46), and interpretations of GINA have not occurred; the OGPL remains unreconciled with these federal laws.

- *Assess and formulate solutions to the identified problems with current legislation, including other laws that apply to use and retention of tissue samples or test results.*

During the 2011 biennium, the committee identified problems in the current legislation, but could not achieve an adequate reconciliation of the OGPL with the federal laws through consensus and did not recommend legislative changes to the laws. During the 2013 biennium, the committee designed, implemented and analyzed a convenience sample survey to examine the areas of the laws highlighted as most confusing during the committee reconciliation discussions. Please see below for further description of the survey and results.

- *Solicit stakeholder input to determine if the Oregon Genetic Privacy Laws are understood and whether understanding affects compliance with the law and allows for adequate protection of the genetic privacy of Oregonians.*

The ACGPR designed, implemented and analyzed a survey of health care system and research staff intended to assess the understanding and interpretations of the current OGPL. The committee directed the survey towards professionals directly affected by the legislation, concentrating on specific problems identified within the current legislation by the committee in the previous biennium. The survey centered around two questions: “Do stakeholders understand the Oregon Genetic Privacy Law?” and

“Does stakeholder understanding affect their ability to comply with the law and adequately protect the genetic privacy of Oregonians?” The committee collected 125 responses, mainly from the Portland metro area. Findings indicate professionals who conduct work within the purview of the OGPL largely find the laws difficult to understand. Please see Appendix 3 for the ACGPR Health System Survey instrument, methods and key findings.

- *Monitor major events in national genetic privacy and research, including developments in direct-to-consumer testing, implementation of student sickle cell trait testing, and the development of health information exchanges.*

Due to the broad scope of genetic privacy and research issues and the limited resources of the committee, the committee is not able to conduct the level of review of events in the field required of them under statute, nor use their findings to tailor needed education of the public.

Genetic privacy in health care and medical research is a common topic in the news and access to genetic and genomic testing is becoming readily available to Oregon consumers with or without collaboration of a physician or genetic specialist. President Obama’s Precision Medicine Initiative (see www.nih.gov/precisionmedicine) may spur even more interest and availability of personal genetic testing and personal genetic information. Issues around the genetic privacy of Oregonians who participate in direct-to-consumer

testing by companies based outside of Oregon remain a significant concern to the committee. However, under the current structure, the committee is unable to take action or lead education efforts on the topic.

Major challenges for the next biennium

- In the face of this rapidly changing field, the committee’s legislative charge to foster public education of genetic privacy and research seems crucial, but likely unachievable without the support of a designated part-time program analyst (PA3).
- The committee has concern that Oregonians, including the state Legislature, will have difficulty creating, refining and evaluating sound public policy, such as the OGPL, without a better understanding of the burgeoning field of medical genetics.

ACGPR capacity and focus

As set forth in ORS 192.549(5), the Oregon Health Authority,¹ through the Oregon Genetics Program, provides nonfunded staff for ACGPR, while members and alternates on the committee volunteer their time and personal resources. It is clear that the full charge of the committee is not adequately met through volunteer and nonfunded OHA capacity.

The committee intends to spend more of their time on the mandate set forth in ORS 192.549(8), to “create opportunities for public education on the scientific, legal and ethical development within the fields of genetic privacy and research.” The committee is exploring ways to expand understanding of current developments related to genetics.

This increased knowledge will help the committee as it moves forward to meet the educational goals set by legislation. A broad understanding of current developments in genetics as they are happening in Oregon and nationally will help the committee identify specific public education topics.

The committee also intends to recruit additional members in the 2015 biennium. The committee hopes to attract a broad membership to help better meet the full charge of the committee.

Proposed focus during the 2015 biennium

Moving into the next biennium, the committee recommends that activities focus on four areas:

- Continue to monitor the landscape of national legislation as it affects the OGPL, especially changes to the Common Rule and any emerging interpretation or challenge of GINA or other federal laws relating to the use or disclosure of genetic information.
- Continue to keep abreast of major events in national genetic privacy and research, such as developments in direct-to-consumer testing, health information exchanges and student sickle cell trait testing.
- Keep abreast of local events in genetics, genetic privacy and genetic research, including activities of the Oregon Genetics Program.
- Identify mechanisms to create educational opportunities for Oregonians on the scientific, legal and ethical developments in genetic privacy and research.

¹ During the 2009–2011 biennium, the Oregon Health Authority (OHA) was established, and the Public Health Division, formerly a part of the Department of Human Services (DHS), became a part of OHA.

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Appendix 1: §192.549 Advisory Committee on Genetic Privacy and Research Statute

- (1) The Advisory Committee on Genetic Privacy and Research is established consisting of 15 members. The President of the Senate and the Speaker of the House of Representatives shall each appoint one member and one alternate. The Director of the Oregon Health Authority shall appoint one representative and one alternate from each of the following categories:
 - (a) Academic institutions involved in genetic research;
 - (b) Physicians licensed under ORS chapter 677;
 - (c) Voluntary organizations involved in the development of public policy on issues related to genetic privacy;
 - (d) Hospitals;
 - (e) The Department of Consumer and Business Services;
 - (f) The Oregon Health Authority;
 - (g) Health care service contractors involved in genetic and health services research;
 - (h) The biosciences industry;
 - (i) The pharmaceutical industry;
 - (j) Health care consumers;
 - (k) Organizations advocating for privacy of medical information;
 - (l) Public members of institutional review boards; and
 - (m) Organizations or individuals promoting public education about genetic research and genetic privacy and public involvement in policymaking related to genetic research and genetic privacy.
- (2) Organizations and individuals representing the categories listed in subsection (1) of this section may recommend nominees for membership on the advisory committee to the President, the Speaker and the director.
- (3) Members and alternate members of the advisory committee serve two-year terms and may be reappointed.
- (4) Members and alternate members of the advisory committee serve at the pleasure of the appointing entity.
- (5) Notwithstanding ORS 171.072 (Salary of members and presiding officers), members and alternate members of the advisory committee who are members of the Legislative Assembly are not entitled to mileage expenses or a per diem and serve as volunteers on the advisory committee. Other members and alternate members of the advisory committee are not entitled to compensation or reimbursement for expenses and serve as volunteers on the advisory committee.
- (6) The Oregon Health Authority shall provide staff for the advisory committee.

- (7) The advisory committee shall report biennially to the Legislative Assembly in the manner provided by ORS 192.245 (Form of report to legislature). The report shall include the activities and the results of any studies conducted by the advisory committee. The advisory committee may make any recommendations for legislative changes deemed necessary by the advisory committee.
- (8) The advisory committee shall study the use and disclosure of genetic information and shall develop and refine a legal framework that defines the rights of individuals whose DNA samples and genetic information are collected, stored, analyzed and disclosed.
- (9) The advisory committee shall create opportunities for public education on the scientific, legal and ethical development within the fields of genetic privacy and research. The advisory committee shall also elicit public input on these matters. The advisory committee shall make reasonable efforts to obtain public input that is representative of the diversity of opinion on this subject. The advisory committees recommendations to the Legislative Assembly shall take into consideration public concerns and values related to these matters. [2001 c.588 §7; 2003 c.333 §6; 2009 c.595 §172; 2011 c.272 §4]

Appendix 2: 2013 biennium ACGPR members, interested parties and OHA staff

During the 2013 biennium, the committee was composed of 10 volunteer members and alternates, serving two-year terms. The President of the Senate appointed Senator Elizabeth Steiner Hayward to the committee. No representative of the House was appointed. Whenever possible, the Oregon Health Authority appointed a member and alternates from the following:

- Academic institutions involved in genetic research – one member
- Physicians licensed under ORS chapter 677 – one member
- Voluntary organizations involved in the development of public policy on issues related to genetic privacy – no members
- Hospitals – one member
- The Department of Human Services – one member
- The Department of Consumer and Business Services – one member, one alternate
- Health care service contractors involved in genetic and health services research – no members
- The biosciences industry – no members
- The pharmaceutical industry – no members
- Health care consumers – one member

- Organizations advocating for privacy of medical information – one member, one alternate
- Public members of institutional review boards – one member
- Organizations or individuals promoting public education about genetic research and genetic privacy

and public involvement in policymaking related to genetic research and genetic privacy – no members

Individuals classified as “interested parties” receive ACGPR emails, including meeting announcements and may join ACGPR meetings in accordance with meeting rules.

ACGPR member roster for the 2013 biennium

Member	Alternate
Senate President’s representatives	
Elizabeth Steiner Hayward, M.D. Oregon State Senator (D) 900 Court St. NE, S-403, Salem, OR 97301 Phone: 503-986-1717 Email: sen.elizabethsteinerhayward@state.or.us	Vacant
Speaker of the House’s representatives	
Vacant	Vacant
Academic institutions involved in genetic research	
Kara Manning Drolet, Ph.D. — Co-chair Research and Institutional Integrity Manager Oregon Health & Science University 3181 SW Sam Jackson Park Road — L106RI Portland, Oregon 97239 Phone: 503-494-6727 Fax: 503-494-5081 Email: manningk@ohsu.edu	Vacant
Licensed health care providers	
Ken Gatter, M.D., J.D. Associate Professor and Vice Chair, Anatomic Pathology Oregon Health & Science University Pathology 3181 SW Sam Jackson Park Road — L471 Portland, Oregon 97201 Phone: 503-494-3562 Email: gatterk@ohsu.edu	Vacant

Member	Alternate
Voluntary organizations: Genetic privacy policy development	
Vacant	Vacant
Hospitals	
Anne T. Greer Assistant General Counsel, Legacy Health System 1919 NW Lovejoy Street, Portland, Oregon 97209 Phone: 503-415-5426 Fax: 503-415-5780 Email: agreer@lhs.org	Vacant
Oregon Health Authority, Public Health	
Hillary Booth FoodNet Special Studies Coordinator Acute and Communicable Disease Prevention Office of Disease Prevention and Epidemiology 800 NE Oregon Street, Suite 772, Portland, Oregon 97232 Phone: 971-673-1111 Fax: 971-673-1100 Email: hillary.booth@state.or.us	Vacant
Department of Consumer and Business Services	
Gayle Woods Operations Manager Oregon Insurance Division Dept. of Consumer and Business Services 350 Winter Street NE, 440-2 Salem, Oregon 97301 Phone: 503-947-7217 Email: gayle.woods@state.or.us	Rhonda I. Saunders-Ricks Manager, Rates and Forms Oregon Insurance Division Department of Consumer and Business Services 350 Winter Street NE, 440-2 Salem, Oregon 97301 Phone: 503-947-7270 Fax: 503-378-4351 Email: Rhonda.i.saunders-ricks@state.or.us
Health care service contractors: Genetic and health services research	
Vacant	Vacant
Biosciences industry	
Vacant	Vacant
Pharmaceutical industry	
Vacant	Vacant

Member	Alternate
Health care consumers	
Vacant	Vacant
Organizations advocating for privacy of medical information	
Stuart Kaplan, Ph.D. – Co-chair Board Member, ACLU of Oregon 9615 SW View Point Terrace Portland, Oregon 97219 Phone: 503-246-3498 Email: skaplan@lclark.edu	Vacant
Public members of institutional review boards	
Steven J. Nemirow, Esq – Alternate-chair Director, Kartini Clinic for Disordered Eating 2800 N Vancouver, Suite 118 Portland, Oregon 97227 Phone: 503-249-8851 Email: snemirow@kartinclinic.com	Vacant
Education and ethics	
Vacant	Vacant

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 Email: summer.l.cox@state.or.us

ACGPR interested parties

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<p>Casey Bush Research Regulatory Specialist Legacy Research Institute Phone: (503) 413-2474 Email: cbush@lhs.org</p>	<p>Gwen M. Dayton, J.D. Senior Counsel, Office of Legal Affairs Northwest Permanente P.C., Physicians and Surgeons Permanente Dental Associates, Inc. Phone: (503) 813-3708 Email: gwen.m.dayton@kp.org</p>
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<p>Paul Newton, J.D., CIP Email: pnewton@pdx.edu Email: pwnewton@lhs.org</p>	<p>John Salmon Associate General Counsel, Office of General Counsel University of Oregon Phone: 541-346-3082 Email: jsalmon@uoregon.edu</p>
<p>Robert C. Shoemaker, Jr., J.D. Member, Public Health Advisory Board Principal author of Oregon's original genetic privacy statute, 1995 Former Oregon State Senator Phone: 503-206-6190 Email: rcshoe@aol.com</p>	

Appendix 3: ACGPR Health System Survey

Background

During the 2011 biennium, the Oregon Health Authority (OHA) provided funds for the committee to reconcile Genetic Information Nondiscrimination Law (GINA), federal and state Health Insurance Portability and Accountability Acts (HIPAA) and Oregon Genetic Privacy Law (OGPL).

With this goal in mind, the Oregon Genetics Program asked Shannon O’Fallon, J.D., Senior Assistant Attorney General, to review the OGPL in reference to GINA and HIPAA. Draft legislation for a reconciliation of the OGPL to these other laws and draft legislation for a selective repeal of the OGPL were both considered. Please see Appendix 1 of the ACGPR 2011 Biennial Report for a summary report from Shannon O’Fallon including draft legislation.

The committee recognized problems in the current legislation, but could not achieve an adequate reconciliation of the OGPL with the federal laws through consensus. The committee decided to look further into the areas of the law that were highlighted as most confusing during the committee discussions on the reconciliation effort. Some specific problems identified within the current legislation include:

- Differing definitions of genetic test in GINA and OGPL;
- The lack of clarity between distinguishing characteristics of clinical and research tests;

- The lack of clear separation between clinical, research, insurance and employment requirements;
- Differing interpretations of how to carry out the requirement of notification in practice;
- Overlap with other laws that apply to the use and retention of samples and information obtained in clinical settings.

During the end of the 2011 biennium and in the 2013 biennium, the committee created and conducted a survey of health care system and research staff to get a better understanding of the questions:

1. Do stakeholders understand the Oregon Genetic Privacy Law?
2. Does stakeholder understanding affect their ability to comply with the law and adequately protect the genetic privacy of Oregonians?

Methods

An introduction to the survey and the survey link was sent out in April 2014 to ACGPR members and interested parties. This initial group consisted of 30 individuals representing 10 distinct groups:

- American Civil Liberties Union of Oregon
- Kaiser Permanente NW
- Legacy Health Services and Legacy Research Institute
- Oregon colleges and universities
- Oregon genetics advocacy groups

- Oregon Health & Science University
- Oregon health care clinics
- Oregon Insurance Division
- Oregon law firms
- Public Health Division of the Oregon Health Authority

Members and interested parties forwarded the introduction and survey link to their organization and to colleagues in other organizations. (The introduction email is on the following page of this appendix.) The Oregon Genetics Program and others also distributed the link to the Oregon Bar Health Law section list serve,

the Oregon Pathology Association, the Oregon Association of Hospitals & Health Systems, the Oregon Institutional Review Board registry list and all Oregon Genetics Program professional contacts and others.

Ninety-nine respondents completed the survey by the end of May 2014. The ACGPR conducted a second push of the survey in September 2014. This second push elicited another 26 respondents, for a total of 125 respondents. While most respondents worked in the Portland Metro area, many respondents practiced in other areas throughout Oregon (please see page A20 for survey responses by ZIP code).

Cox Summer L

From: Cox Summer L
Sent: Friday, April 25, 2014 4:15 PM
To: BOOTH Hillary; Zukowski Laura A; WOODS Gayle; Backlar, Patricia; Drolet, Kara; Franks, Jenny; Gatter, Ken; Goddard, Katrina; Greer, Anne; Kaplan, Stuart; Nemirow, Steven; SAUNDERS-RICKS Rhonda I; Becky Straus; Beth Crane; Dorsey, Paul; Fowler, Gregory; Klein, Eran; Naleway, Allison; Bland, MaryPat; Bush, Casey; Dayton, Gwen; Hartzell, Marilyn; 'mab@healthlawoffice.com'; 'marcumr@ohsu.edu'; 'marencom@pacificu.edu'; 'rcshoe@aol.com'; 'peter.jacky@kp.org'; John Salmon; Karen Kovak
Cc: Nystrom Robert J; Kane Kristin A; George Rani M
Subject: The Advisory Committee on Genetic Privacy and Research (ACGPR) Needs Your Help!

Dear ACGPR members and interested parties:

Please take this survey (<https://www.surveymonkey.com/s/OGPL>) AND distribute it to ALL of your colleagues for whom the Oregon Genetic Privacy Laws have professional relevance. We are using a convenience sample, so getting the word out on this survey will really help.

Please help us!

My apologies if you have received this invitation multiple times. We are trying to reach a broad base of individuals.

Please help us by taking our 10 – 15 minute survey (<https://www.surveymonkey.com/s/OGPL>) and forwarding this email to your contacts who may use or be aware of the Oregon Genetic Privacy Laws in their work.

The Advisory Committee on Genetic Privacy and Research (ACGPR) was created in its current form by the Oregon Legislature in 2001 (Senate Bill 114). One of the ACGPR's charges is to study the effect of Oregon's laws for the use and disclosure of genetic information and the privacy rights of individuals regarding their DNA samples and genetic information. In the 2013 biennium, the committee is soliciting stakeholder input to determine if the Oregon Genetic Privacy Laws (OGPL) are understood and the goals of the Oregon Legislature regarding genetic privacy are being accomplished. The ACGPR needs your help in identifying possible problems with the current Oregon law and other laws that apply to use and retention of tissue samples or test results. Please fill-out this survey, which should take about 10 - 15 minutes. Having your professional perspective in this survey will be of great service to us. At the end of the survey, there will be an opportunity to provide your contact information, if you would prefer to remain anonymous, simply skip this question.

This survey will be a convenience sample, so please forward this 10 – 15 minute survey (<https://www.surveymonkey.com/s/OGPL>) invitation to your contacts within and outside of your institution. It will be helpful to get responses from a broad base of individuals, across Oregon.

We are interested in hearing from:

- Admitting/Patient Access staff,
- Corporate Compliance staff,
- Genetics health care providers,

- Other health care providers,
- Health Information Management/Medical Records/HIS staff,
- Hospital administrators,
- Hospital counsel,
- IRB staff/IRB members,
- Pathologists,
- Research administrators,
- Researchers,
- and others for whom the Oregon Genetic Privacy Laws have professional relevance.

If you would like to learn more about the ACGPR, please contact Summer Lee Cox in the Oregon Genetics Program, in the Oregon Genetics Program, summer.l.cox@state.or.us, 971.673.0273.

Your participation in this survey will be of great value to us, thank you so much!

Kind regards, Summer

Summer Lee Cox, MPH | Genetics Program Coordinator | Oregon Health Authority | 800 NE Oregon St, Suite 370 | Portland, OR 97232 | E: summer.l.cox@state.or.us | P: 971.673.0273 | F: 971.673.0997 | **Check out the Oregon Genetics Program at** <http://www.healthoregon.org/genetics>

Advisory Committee on Genetic Privacy and Research (ACGPR) Health

Advisory Committee on Genetic Privacy and Research (ACGPR) Health System Su...

The Advisory Committee on Genetic Privacy and Research (ACGPR) is interested in the Oregon Genetic Privacy Laws (OGPL) in the context of current federal law. Having your professional perspective will help ACGPR members:

- determine if the OGPL are understood,
- determine whether stakeholder understanding affects compliance with the laws, and
- determine whether stakeholder understanding allows for adequate protection of the genetic privacy of Oregonians.

This survey should take about 10 - 15 minutes. The progress bar located below the header of each page will tell you how far along you are.

At the end of the survey, there will be an opportunity to provide your contact information, if you would prefer to remain anonymous, simply skip this question.

This survey will be a convenience sample, so please forward this survey to your contacts within and outside of your institution.

The survey link is: <https://www.surveymonkey.com/s/OGPL>

It will be helpful to get responses from a broad base of individuals, across Oregon. We are interested in hearing from:

- Admitting/Patient Access staff,
- Corporate Compliance staff,
- Genetics health care providers,
- Other health care providers,
- Health Information Management/Medical Records/HIS staff,
- Hospital administrators,
- Hospital counsel,
- IRB staff/IRB members,
- Pathologists,
- Research administrators,
- Researchers,
- and others for whom the Oregon Genetic Privacy Laws have professional relevance.

If you would like to learn more about the Advisory Committee on Genetic Privacy and Research (ACGPR) or discuss any matters, please contact Summer Lee Cox in the Oregon Genetics Program, summer.l.cox@state.or.us, 971.673.0273.

Your participation in this survey will be of great value to us, thank you so much.

1. What is the primary ZIP code in which you work?

Advisory Committee on Genetic Privacy and Research (ACGPR) Health

2. What is your professional role? (select all that apply)

- Admitting / Patient Access
- Corporate Compliance
- Genetics Healthcare Provider
- Other Healthcare Provider (non-genetics)
- Health Information Management / Medical Records / HIS
- Hospital Administrator
- Hospital Counsel
- IRB Staff / IRB Member
- Pathologist
- Research Administration
- Researcher
- Other (please specify)

The Oregon Genetic Privacy Laws (OGPL)

The next three questions are about the Oregon Genetic Privacy Laws (OGPL). Please see the bottom of this page for a short summary of the OGPL.

3. How relevant is the Oregon Genetic Privacy Laws (OGPL) to your every day position/responsibilities?

- Very Relevant Relevant Moderately Relevant Of Little Relevance Not At All Relevant

4. How would you rate your personal knowledge and understanding of OGPL?

- Very Good Good Adequate Inadequate No Knowledge or Understanding

5. How would you rate your department/work unit's knowledge and awareness of OGPL?

- Very Good Good Adequate Inadequate No Knowledge or Awareness

Advisory Committee on Genetic Privacy and Research (ACGPR) Health

Summary of Law:

The Oregon Genetic Privacy Laws (OGPL) (ORS 192.531 to 192.549) make it a Class A misdemeanor to unlawfully obtain, retain, or disclose genetic information. Oregon law also creates a civil cause of action against anyone who unlawfully obtains or discloses genetic information, with the right to obtain the greater of actual damages or set statutory damages. Oregon law prohibits an employer from obtaining or using genetic information to discriminate against an employee or prospective employee. The law also prohibits insurance companies from using genetic information to price or decline individual policies (ORS 746.135). Oregon law allows the use of genetic information without an individual's consent for: identification of deceased individuals; paternity; newborn screening; genetic information from a decedent for medical diagnoses of blood relatives; and court order. Rules based on the OGPL have established minimum research standards for the collecting and testing of genetic information: all genetic research using information and samples collected in Oregon, whether anonymous, coded, or identified, must be reviewed by an institutional review board that follows strict federal rules for human subject research; the law also requires that individuals be given the option to request their biological sample or health information not be used for anonymous or coded genetic research.

Genetic Information Non-Discrimination Act (GINA)

The next three sets of three questions will assess the level of familiarity with federal laws relevant to genetic privacy and research. This will help us understand the context of your answers to subsequent questions.

The three questions below are about the Genetic Information Nondiscrimination Act of 2008 (GINA). Please see the bottom of this page for a short summary of GINA.

6. How relevant is the Genetic Information Non-Discrimination Act (GINA) to your every day position/responsibilities?

- Very Relevant Relevant Moderately Relevant Of Little Relevance Not At All Relevant

7. How would you rate your personal knowledge and understanding of GINA?

- Very Good Good Adequate Inadequate No Knowledge or Understanding

8. How would you rate your department/work unit's knowledge and awareness of GINA?

- Very Good Good Adequate Inadequate No Knowledge or Awareness

Summary of Law:

The Genetic Information Nondiscrimination Act of 2008 (GINA) is federal legislation designed to prohibit the use of genetic information in health insurance and employment. The Act prohibits group health plans and health insurers from denying coverage to a healthy individual or charging that person higher premiums based solely on a genetic predisposition to developing a disease in the future. The legislation also bars employers from using individuals' genetic information when making hiring, firing, job placement, or promotion decisions.

The Health Insurance Portability and Accountability Act (HIPAA)

The next three questions are about the Health Insurance Portability and Accountability Act (HIPAA). Please see the bottom of this page for a short summary of HIPAA.

9. How relevant is the Health Insurance Portability and Accountability Act (HIPAA) to your every day position/responsibilities?

- Very Relevant Relevant Moderately Relevant Of Little Relevance Not At All Relevant

Advisory Committee on Genetic Privacy and Research (ACGPR) Health

10. How would you rate your personal knowledge and understanding of HIPAA?

- Very Good Good Adequate Inadequate No Knowledge or Understanding

11. How would you rate your department/work unit's knowledge and awareness of HIPAA?

- Very Good Good Adequate Inadequate No Knowledge or Awareness

Summary of Law:

The Health Insurance Portability and Accountability Act (HIPAA) addresses the privacy of individuals' health information by establishing a nation-wide federal standard concerning the privacy of health information and how it can be used and disclosed. This federal standard generally preempts all state privacy laws except for those that establish stronger protections. Generally, HIPAA "covered entities" are required to comply with HIPAA rules for any health or medical information of identifiable individuals, including their medical records, medical billing records, any clinical or research databases, and tissue bank samples. Essentially, a HIPAA covered entity cannot use or disclose protected health information for any purpose other than treatment, payment, or health care operations without either the authorization of the individual or under an exception in the HIPAA regulations.

The Clinical Laboratory Improvement Amendments (CLIA)

The next three questions are about the Clinical Laboratory Improvement Amendments (CLIA). Please see the bottom of this page for a short summary of CLIA.

12. How relevant is the Clinical Laboratory Improvement Amendments (CLIA) to your every day position/responsibilities?

- Very Relevant Relevant Moderately Relevant Of Little Relevance Not At All Relevant

13. How would you rate your personal knowledge and understanding of CLIA?

- Very Good Good Adequate Inadequate No Knowledge or Understanding

14. How would you rate your department/work unit's knowledge and awareness of CLIA?

- Very Good Good Adequate Inadequate No Knowledge or Awareness

Summary of Law:

The Centers for Medicare & Medicaid Services (CMS) regulates all laboratory testing (except research) performed on humans in the U.S. through the Clinical Laboratory Improvement Amendments (CLIA). In total, CLIA covers approximately 225,000 laboratory entities. The Division of Laboratory Services, within the Survey and Certification Group, under the Office of Clinical Standards and Quality (OCSQ) has the responsibility for implementing the CLIA Program. The objective of the CLIA program is to ensure quality laboratory testing. Although all clinical laboratories must be properly certified to receive Medicare or Medicaid payments, CLIA has no direct Medicare or Medicaid program responsibilities.

Oregon Genetic Privacy Law (OGPL) Definitions

NOW BACK TO THE OREGON GENETIC PRIVACY LAWS (OGPL). These questions are about the definitions used in the OGPL.

Advisory Committee on Genetic Privacy and Research (ACGPR) Health

15. How well do you understand the definition of genetic...

	Extremely Well	Very Well	Moderately Well	Not Very Well	Not At All Well
INFORMATION in the OGPL?	<input type="radio"/>				
CHARACTERISTIC in the OGPL?	<input type="radio"/>				
TEST in the OGPL?	<input type="radio"/>				
RESEARCH in the OGPL?	<input type="radio"/>				

Oregon Genetic Privacy Law Opt-Out Provisions

In 2005, the OGPL established opt-out requirements for anonymous and coded genetic research:

Changes were made in the Oregon Genetic Privacy 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.

If such genetic information cannot be linked to an individual (or there is only a code and the key to the code is stored separately) the new law allows researchers to ask permission from an institutional review board to use the test results, specimens collected or health care information for "anonymous" or "coded" genetic research. The new law requires patients to make a decision regarding use of their health information in anonymous or coded genetic research.

As a result, starting July 1, 2006, doctors and healthcare providers must provide patients a notice and ask them to complete a form (at least once) if they do not want any of their specimens or health care information available for anonymous or coded genetic research. This is often called an "opt-out" form.

16. For affected departments, how would you rate your institution's understanding of the 2005 opt-out requirements?

- Excellent
 Good
 Fair
 Poor
 Not Sure / Not Applicable

17. Please explain your answer to the above question.

18. How would you rate your institution's understanding of ALL parts of the OGPL?

- Excellent
 Good
 Fair
 Poor
 Not Sure / Not Applicable

19. Please explain your answer to the above question.

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20. What is the primary way your Institution meets the one-time opt-out provision in the OGPL? (select one)

- By mail active opt-out (must return to opt-out)
- By mail active choice (must return with opt-in or opt-out choice)
- Institution blanket opt-out (everyone is automatically opted out)
- In person, part of routine signatures, no separate education on OGPL
- In person, part of routine signatures, includes separate education on OGPL
- Don't know / Not applicable to my role
- Other (please specify)

Are Changes to the Oregon Genetic Privacy and Research Laws Needed?

The next two questions are required to move forward with the survey. Your thoughtful answer will be especially helpful to us.

* AN ASTERISKS INDICATES THAT YOU MUST ANSWER THE QUESTION BEFORE MOVING ON TO THE NEXT QUESTION.

THE ASTERISKED QUESTIONS IN THIS SURVEY ARE ESSENTIAL for us to determine if the Oregon Genetic Privacy Laws (OGPL) are understood and the goals of the Oregon Legislature regarding genetic privacy are being accomplished.

* 21. Do you think the OGPL needs to be changed?

- No, no changes needed Yes, some provisions should be changed The OGPL should be repealed in its entirety Unsure / Don't Know

* 22. Please explain your answer to the question above. This is important, your comments are valuable to our committee.

Your Professional Opinions About the Oregon Genetic Privacy Laws (OGPL)

How would you rate the following statements?

Advisory Committee on Genetic Privacy and Research (ACGPR) Health

23. The OGPL provides necessary protections for the public.

- Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree

24. The OGPL is easy to understand.

- Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree

25. Genetic information should be given more privacy than other types of medical information.

- Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree

26. Genetic information should be given more protections than other types of medical information.

- Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree

27. Individuals should have more control of what happens to their genetic information than other types of medical information.

- Strongly agree Agree Neither agree nor disagree Disagree Strongly disagree

THIS IS THE LAST PAGE!

YOU ARE ALMOST FINISHED! Three more questions to go.

* AN ASTERISKS INDICATES THAT YOU MUST ANSWER THE QUESTION BEFORE MOVING ON TO THE NEXT QUESTION.

THE ASTERISKED QUESTIONS IN THIS SURVEY ARE ESSENTIAL for us to determine if the Oregon Genetic Privacy Laws (OGPL) are understood and the goals of the Oregon Legislature regarding genetic privacy are being accomplished.

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* 28. If you use genetic information to conduct research and your work has been affected by the OGPL, please explain how. (If not, just write "N/A".)

29. Please share any other comments or observations related to the OGPL:

30. If you are willing to meet with representatives from the Advisory Committee on Genetic Privacy and Research to discuss this topic further, please provide your contact information below.

If you would like to take this survey anonymously (and therefore did not enter your contact information above) but would also like to discuss the Oregon Genetic Privacy Laws further, please contact Summer Lee Cox at summer.l.cox@state.or.us or 971.673.0273.

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Thank you for your time. Your input is valuable to us.

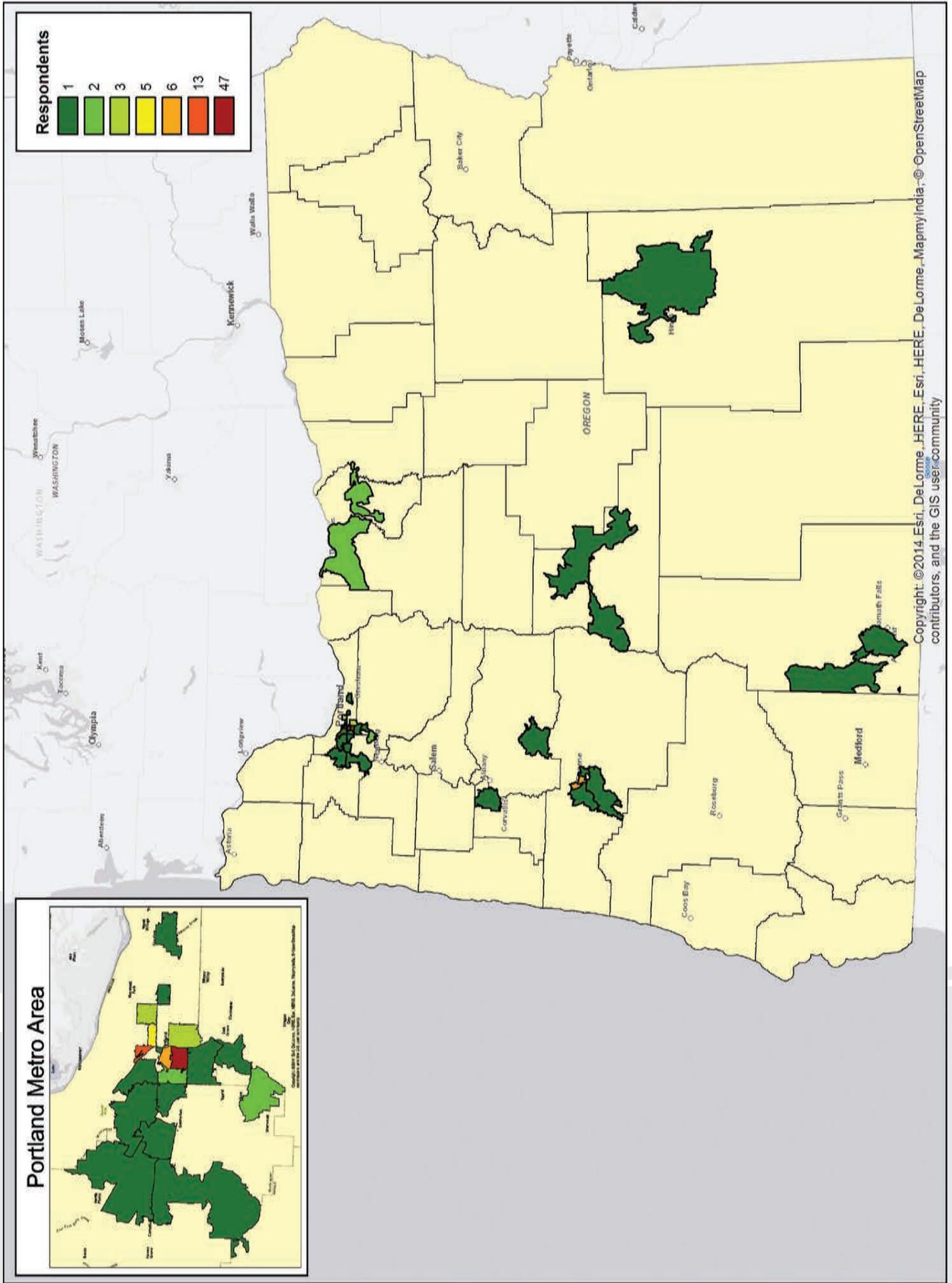
Remember that this is based on a convenience sample, so please forward this survey to your contacts within and outside of your institution. The survey link is <https://www.surveymonkey.com/s/OGPL>. It will be helpful to get responses from a broad base of individuals, across Oregon.

We are interested in hearing from:

- Admitting/Patient Access staff,
- Corporate Compliance staff,
- Genetics health care providers,
- Other health care providers,
- Health Information Management/Medical Records/HIS staff,
- Hospital administrators,
- Hospital counsel,
- IRB staff/IRB members,
- Pathologists,
- Research administrators,
- Researchers,
- and others for whom the Oregon Genetic Privacy Laws have professional relevance.

Thanks for your help, have a nice day!

ACGPR Health System Survey Responses by Zip Code Tabulation Area, November 2014



A total of 125 individuals took the survey, reporting the following professional roles:

Professional role(s) of respondents		
Roles (not mutually exclusive)	Count	Percent
Admitting, patient access	9	7.2%
Corporate compliance	9	7.2%
Genetics health care provider	22	17.6%
Other health care provider (nongenetics)	7	5.6%
Health info management, medical records, history	6	4.8%
Hospital administrator	7	5.6%
Hospital counsel	1	0.8%
Institutional Review Board (IRB) staff, IRB member	8	6.4%
Pathologist	21	16.8%
Research administrator	8	6.4%
Researcher	37	29.6%
Other	7	5.6%
		100.0

Roles were grouped into “collapsed roles” to maintain an adequate cell size while examining findings by various professional roles:

Professional role categories	
Collapsed roles	Detailed roles
Genetics health care provider	Genetics health care provider
Other health care provider/pathologist (nongenetics)	Other health care provider (nongenetics), pathologist
Researcher	Researcher
Research administrator/IRB	Research admin, IRB staff, IRB member
Administrative/HIS/counsel	Admitting, patient access Corporate compliance Health information management Medical records, HIS Hospital/practice administrator Hospital counsel
Other/unknown	Other missing

Necessity of OGPL changes

Forty-three percent of respondents were unsure or did not know if the OGPL should be changed. This indicates that even among professional stakeholders for whom these laws are pertinent, the laws are difficult to understand.

Necessity of OGPL changes				
Do you think the OGPL needs to be changed?		Count	Percent	Valid percent
Valid	No, no changes needed	25	20.0	23.6
	Yes, some provisions should be changed	23	18.4	21.7
	The OGPL should be repealed in its entirety	12	9.6	11.3
	Unsure/don't know	46	36.8	43.4
	Total	106	84.8	100.0
Missing		19	15.2	-
Total		125	100.0	-

The valid responses indicated that:

- 43% were unsure or didn't know if the OGPL should be changed.
- 24% said the OGPL should not be changed.
- 22% said some provisions of the OGPL should be changed.

Excerpts from survey question #22.

Please explain your answer to the question above. [Do you think the OGPL needs to be changed?]

“I think that having this law helps further research and I think it is a good to have provisions in place to ensure that genetic privacy is maintained. However, I think that most of my patients that have come in and that I have explained this law to have no idea that it exists. This bothers me because I know these patients have been in the care of other Oregon providers. I would like to know what kind of testing

has been done since this law went into effect. I think it would help educate the patients as well. Maybe also using language that is more easily understood by the general public. Some people shut down once they hear “genetic” and give you the deer in the headlights look.”

“Federal law has changed since OGPL passed. From a professional and personal point of view, it would be nice if there was more awareness regarding these laws. I don't think the population at large understands what this is. They either just sign or don't sign without really understanding.”

“I think some of the provisions have harmed research without additional benefit or protection to patient. Other elements (insurance, nondiscrimination) sound extremely important, though I don't work with those elements so should not comment on details and practicalities”

“I think that patients should have limited ability to opt out of coded/anonymous research that may occur at the institution from which they receive care. The ability to use coded/anonymous clinical samples for research purposes is critical to our continued investigation and understanding of disease processes. By allowing patients to “opt out” of such a process, we are limiting the ability to make discoveries and advance medicine.”

“The requirement to notify patients about, and to opt out of anonymous genetic research provides no value to our patients other than to confuse and frighten them. The use of leftover patient samples and PHI for research should be simpler and easier. The risk to patients is negligible and the paperwork and documentation is a serious burden.”

“GINA covers the bases, OGPL is unnecessary and represents an administrative burden on health care providers in the state of Oregon that adds no value and makes genetic research no easier.”

“I don’t understand how the OGPL applies to my day-to-day practice. For example, when tissue is requested by clinicians for send out tests that are “genetic” does the OGPL need to be evoked? Who’s responsibility is it ... the lab/pathologist or the clinician requesting the test? Also, regarding tumor banking. When I hand over tissue to the researcher is it my responsibility to ensure that the procedures and policies

under the OGPL have been followed?”

“HIPAA covers patient confidentiality.”

“I am not sure I understand the law well enough to know if it should be changed or modified.”

“I don’t know the details well enough to have a strong opinion. I have never personally had an issue with any part of the law.”

Perception of OGPL protections

A majority of respondents reported that the OGPL provides necessary protections for the public.

Necessity of OGPL changes				
The OGPL provides necessary protections for the public.		Count	Percent	Valid percent
Valid	Strongly agree	14	11.2	13.5
	Agree	46	36.8	44.2
	Neither agree nor disagree	28	22.4	26.9
	Disagree	11	8.8	10.6
	Strongly disagree	5	4.0	4.8
	Total	104	83.2	100.0
Missing		21	16.8	-
Total		125	100.0	-

- 57.7% strongly agreed or agreed that the OGPL provides necessary protections for the public.
- 26.9% were neither agreed nor disagreed.
- 15.4% strongly disagreed or disagreed.

Comprehension of the OGPL

There is a fairly even distribution of people that strongly agree/agree (31.7%), neither agree nor disagree (33.7%), or strongly disagree/disagree (34.6%) that the OGPL is easy to understand.

Comprehension of the OGPL				
The OGPL is easy to understand.		Count	Percent	Valid percent
Valid	Strongly agree	3	2.4	2.9
	Agree	30	24.0	28.8
	Neither agree nor disagree	35	28.0	33.7
	Disagree	28	22.4	26.9
	Strongly disagree	8	6.4	7.7
	Total	104	83.2	100.0
	Missing	21	16.8	-
Total		125	100.0	-

Should genetic information be given more protections than other types of medical information?

Protection of genetic information				
Genetic information should be given more protections than other types of medical information.		Count	Percent	Valid percent
Valid	Strongly agree	14	11.2	13.5
	Agree	22	17.6	21.2
	Neither agree nor disagree	37	29.6	35.6
	Disagree	25	20.0	24.0
	Strongly disagree	6	4.8	5.8
	Total	104	83.2	100.0
	Missing	21	16.8	-
Total		125	100.0	-

There is a fairly even distribution of people that strongly agree/agree (34.7%), neither agree nor disagree (35.6%), or strongly disagree/disagree (29.8%) that genetic information should be given more protections than other types of medical information.

Should genetic information be given more privacy than other types of medical information?

Protection of genetic information				
Genetic information should be given more privacy than other types of medical information.		Count	Percent	Valid percent
Valid	Strongly agree	14	11.2	13.5
	Agree	23	18.4	22.1
	Neither agree nor disagree	34	27.2	32.7
	Disagree	27	21.6	26.0
	Strongly disagree	6	4.8	5.8
	Total	104	83.2	100.0
Missing		21	16.8	
Total		125	100.0	

There is a fairly even distribution of people that strongly agree/agree (35.6%), neither agree nor disagree (32.7%), or strongly disagree/disagree (31.8%) that genetic information should be given more privacy than other types of medical information.

Should individuals have more control of what happens to their genetic information than other types of medical information?

Individual control of genetic information					
Individuals should have more control of what happens to their genetic information than other types of medical information.		Count	Percent	Valid percent	
Valid	Strongly agree	11	8.8	10.6	
	Agree	21	16.8	20.2	
	Neither agree nor disagree	38	30.4	36.5	
	Disagree	28	22.4	26.9	
	Strongly disagree	6	4.8	5.8	
	Total	104	83.2	100.0	
	Missing		21	16.8	
	Total		125	100.0	

There is a fairly even distribution of people that strongly agree/agree (30.8%), neither agree nor disagree (36.5%), or strongly disagree/disagree (32.7%) that individuals should have more control of what happens to their genetic information than other types of medical information.

How research in Oregon has been affected by the OGPL

Survey Question #28:

If you use genetic information to conduct research and your work has been affected by the OGPL, please explain how. (If not, just write “N/A.”) - Open-ended response, all responses included below, in entirety:

“As an IRB member, I have to evaluate genetic research requests to ensure they comply with OGPL. As a researcher, I must ensure my research complies with OGPL (when applicable), and I also have to work around other entities’ interpretation of the OGPL.”

“Genetic information is one of the most important keys to understanding most disease processes and responses to treatment. To put undue limits or constraints on the ability to collect samples for the purpose of genetic testing, including undefined future genetic testing, greatly diminishes the likelihood of making key discoveries for the betterment of human health. I don’t think so many limits should be placed on coded or anonymous samples. And I think some of the limits on specific cellular components should be eased, especially when the likelihood of being able to identify an individual based on the material is low to non-existent.”

“It takes more time to figure out what tissue samples can be used for research (need to check for opt out).”

“Have explicitly consented patients to research where they indicate a willingness to share their genetic information (therefore no need to check opt-out). Have also used anonymous or coded samples in research in which we have checked the opt-out status. The first time I had to do this it was quite the hunt to track down the appropriate person to do this. Each department I called didn’t know who to talk to, or sometimes what I was talking about. I am now connected with the appropriate person.”

“I am confused with cancer genetic information from genetic information for congenital disorders. I do not know if cancer genetic information should be treated as congenital disorders.”

“I am required to get consent from patients on any genetic testing done for my research studies. Almost all of my studies have a genetic optional or not optional portion. If patients do not agree to the genetic testing sometimes they cannot participate in my study.”

“I conduct genetic epidemiology, and complying with OGPL does not hinder my work. It provides reasonable protections.”

“I don’t know; I comply with the requirements of IRB but I cannot tell which of these requirements are subsumed under OGPL, or how this differs dramatically from any common sense-based approach.”

“I have been forced to ask clinic personnel to spend their time looking at patient charts to make sure that a patient from whom I will collect surgical tissue (which would otherwise be destroyed) has not opted out of genetic testing. I do not receive any identifying information about the patients, and the results of these genetic tests could never be linked to the tissue donor. I don't see how this protects the patient.”

“I have had to get IRB to use deidentified genetic information.”

“I use genetic info but so far OGPL has not affected my work.”

“It has not been impacted.”

“My lab uses archived tissue samples for a number of genetic studies. OGPL adds a layer of complexity and liability that requires cross-referencing all potential cohorts against opt-out database before testing. This takes time and creates opportunity for error. It is NOT NECESSARY. HIPPA protects patient privacy because only coded de-identified tissue samples are allowed for study. In rare instances when research requires patient or patient family contact this is done through the IRB and patient consent.”

“On occasion, we have to check genetic opt out to determine if we can use patient data for research.”

“Our IRB's interpretation of the OGPL at first required checking opt out even for research at eliminated 10% of subjects from some studies. I believe the IRB's interpretation has been updated.”

“Operating as an honest broker, distribution of clinical residual specimens for researchers requires my group to review patients genetic opt-out decisions on a daily basis.”

“The amount of IRB-required paperwork to do research that includes any aspect of “genetic” testing, the definition of which is extremely broad and includes almost everything, has become a severe burden for researchers. The ability to use leftover patient samples for research is critical to most advances in the medical field. The necessity to check every consent form and also to check with the opt-out office is very time-consuming and slows down the process. Pathologists are asked to support many research studies and these requirements make it very difficult to do so in a timely manner.”

“The OGPL causes confusion, and can be time-consuming if patients ask questions about it. I see that patient have opted out, who I suspect believe they're signing because they believe they should or believe the health care provider/institution wants them to.”

“The only affect it has had on our dept. is to separate/keep track of subjects out who prefer not to have their samples stored in a genetic repository.”

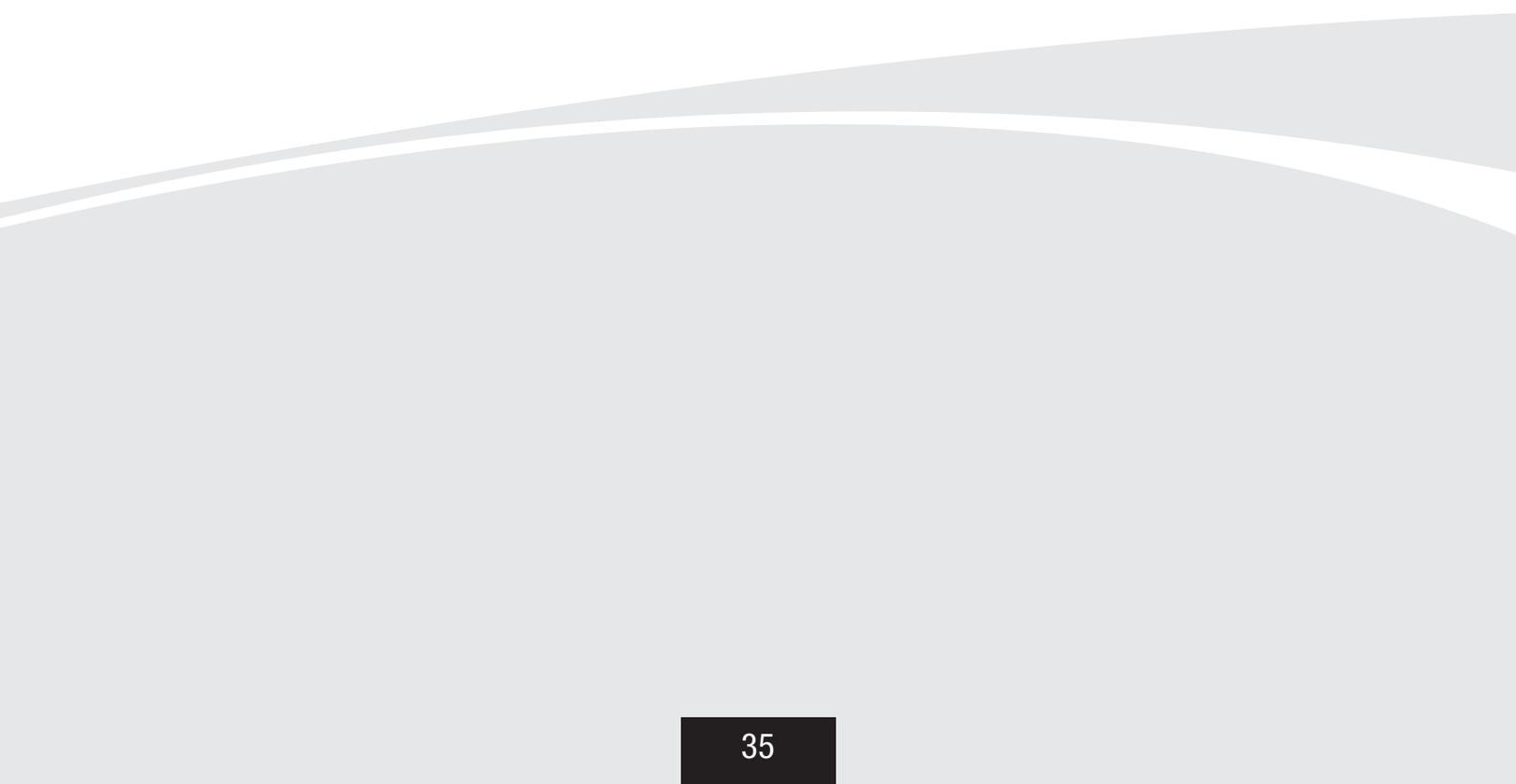
“There are additional burdens and hurdles for conducting research involving genetic information compared with research involving other types of medical information. This places a higher bar for genetic researchers, and creates an environment of fear and genetic exceptionalism.”

“We add that protection to our consent forms.”

“We have to eliminate all ‘opt-out’ patients from our research projects, which creates an additional (but necessary) administrative burden. Beyond that, OGPL has not really impacted our work.”

“We were asked to add to the informed consent that if a commercial product is developed in the future, the participants will not get any compensation. I think this is totally unnecessary and may turn off potential participants.”

“We would have been just as scrupulous about protecting privacy, however, participants and patient appear to be reassured by the protections provided by the legislation.”



2015 Biennial Report to the Oregon State Legislature
Advisory Committee on Genetic Privacy and Research (ACGPR)



PUBLIC HEALTH DIVISION
Center for Prevention & Health Promotion

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