

# Oregon's HISPC Implementation Project Summary and Impact Analysis Report

Prime Contract No. 290-05-0015  
Subcontract No. 7-321-0209825

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November 30, 2007



**OFFICE FOR  
OREGON HEALTH  
POLICY & RESEARCH**

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## **Executive Summary**

The electronic exchange of health information holds the potential to revolutionize health care in many ways including through improved quality and cost efficiencies, enhanced patient/consumer engagement and greater continuity of care. Public trust in health information exchange (HIE) efforts is critical to participation and realization of such benefits. Consumers and providers must have confidence in the privacy and security protections in place to protect personal health information.

Much of the privacy and security work to date in Oregon has been accomplished by multi-stakeholder groups primarily organized by the hospitals/health systems and the providers through the medical association. Representatives of the State, health plans and others have been active participants over the past 6 years since they assembled to solve issues surrounding the implementation of HIPAA. During the 2003 Oregon Legislative Session, prominent privacy and security attorneys and other experts in the state, drawing mainly from the above-mentioned groups, examined the relevant state laws and then made recommended statutory changes to ensure that Oregon law conformed to HIPAA.

The Office for Oregon Health Policy and Research (OHPR) was awarded a contract by RTI, Inc. to participate in the Health Information Security and Privacy Collaboration (HISPC). This Project is part of a national effort managed by the US Department of Health's Office of the National Coordinator for Health Information Technology (ONC), the Agency for Healthcare Research and Quality (AHRQ) and the National Governor's Association. In Oregon, Governor Ted Kulongoski appointed a HISPC Steering Committee with a breadth of expertise and a deep commitment to accomplishing the work of the project. During the first phase of Oregon's HISPC involvement, the Steering Committee served as the decision-making body responsible for the direction of the project, reviewing workgroup products and assuring that all stakeholders' interests were considered.

The Oregon HISPC team engaged a variety of stakeholders to identify and find solutions to the most significant privacy and security issues facing Oregonians with regard to the implementation of the electronic exchange of health information. Broad community input was sought to identify the challenges involved in protecting the privacy and security of health information while enabling electronic HIE and to ensure acceptance of solutions. Stakeholders from health care, consumer and privacy organizations participated throughout the project.

Oregon's early phase HISPC work opened the lines of communications between stakeholders and enabled a greater understanding of the complexity of the privacy and security issues. While the HIE/HIT landscape in Oregon remains in transition, the HISPC project has been pivotal in raising the privacy and security issues to the forefront of discussions.

Oregon's HISPC work also identified a need for greater communication with consumers about the current privacy and security issues facing their health information and how electronic exchange holds the potential to mitigate those risks. Of course it is also necessary to address the privacy and security concerns of an electronic environment – and our main implementation project has been conceived to accomplish both of these objectives.

There have been a number of major outcomes from our HISPC work. First, during the 2007 Oregon Legislative Session, legislation calling for portable, accessible, electronic health records was passed. The Oregon Health Fund Board is tasked with bringing this to fruition. In order to assist with this endeavor, the Governor is transitioning the HISPC Steering Committee to a Health Information Infrastructure Advisory Committee (HIIAC). The HIIAC will advise the OHFB on HIE issues, including privacy and security.

Oregon has collaborated with a number of other states and has gained immensely from contacts and work with other HISPC states and we are looking forward to our continued work with the multi-state collaborative focusing on consumer education and engagement.

This report provides an update on Oregon's HISPC implementation plan to improve health information exchange in Oregon and the vision for future work on HIE privacy and security issues.

## **Introduction and Overview**

### **a. Current HIT/HIE Landscape**

The HIT/HIE landscape in Oregon remains in transition. Various initiatives are coordinating with the state government to define boundaries for entities involved in HIT/HIE and to decide on a system of governance. Recent activities include the following:

- Medicaid Transformation Grant awarded to the Oregon Division of Medical Assistance Programs (DMAP) for the Health Record Bank of Oregon which proposes the provision of a health record account for Medicaid beneficiaries.
- Electronic Health Record Implementation Initiative – completion of the 3 year federally-funded CMS DOQ-IT project by Oregon’s Quality Improvement Organization – Accumentra Health which assisted 50 clinics in Oregon with EHR implementation.

In addition to a private sector HIE effort in the Portland metro area, there are other community-based efforts moving forward with AHRQ funding. There is a heightened awareness of patient control issues in terms of privacy and security. The HISPC Steering Committee is being transitioned to a state designated body, the Health Information Infrastructure Advisory Committee (HIIAC), with appointments to the HIIAC to be made by the Governor in December, 2007. It is expected that this committee will tackle issues currently dividing stakeholders within the state, such as the level of focus on privacy and security issues above and beyond HIPAA. Pursuant to legislation passed during the 2007 Legislative Session, the Oregon Health Fund Board (OHFB) was recently appointed by the Governor. It is expected that the OHFB will seek input from the HIIAC regarding the incorporation of health IT into a new healthcare environment in Oregon. The OHFB has been tasked with developing a plan to rebuild Oregon’s health care system so it is accessible, affordable and effective. HIE/HIT will play an important role in reform measures and privacy and security issues will garner more attention as the Oregon Health Fund Board moves forward.

The HISPC project advanced a greater focus on understanding the complexity of issues inherent to the privacy and security of electronic medical records and allowed stakeholders to take a more realistic view of the issues that needed to be discussed before exchanging data.

The project enabled and supported work across states in formulating and implementing privacy and security solutions. In particular, it has facilitated work with Washington State due to similar concerns and potential models for state health information exchange systems that incorporate consumer involvement. There was also great benefit gained from working with other states in the region such as Alaska and California.

The 2007 Oregon Health Policy Commission Report devoted a section to HIE and privacy/security in particular, which spurred a set of recommendations. Although the Metro

Portland HIE was started before HISPC, the HISPC did inform the initiative about privacy and security issues.

#### **b. HIT/HIE Privacy and Security Landscape prior to HISPC**

In 2004, the Oregon Health Policy Commission formed a subcommittee on Electronic Health Records (EHR) and Data Connectivity to develop recommendations for 1) fostering the adoption of EHR in Oregon's health care delivery systems and 2) developing the infrastructure for the secure exchange of electronic health data between systems. The subcommittee report, completed in March 2005 recommended the State's role in fostering the use of interoperable electronic health records. The Joint Legislative Committee on Information Management and Technology has been closely following the work of the subcommittee and is supportive of EHR adoption and interoperability efforts, though proposed legislation to create a task force was not successful. As a result of the committee's work, the Oregon Office of Health Policy and Research has committed resources for creation of a position for health information technology coordination.

The Oregon Healthcare Quality Corporation (Quality Corp) and the Oregon Business Council (OBC) have worked together in pursuit of a secure health information exchange. The OBC leadership group is comprised of the CEOs of some of the largest health systems, health plans, employers, and physician groups in the state. These leaders funded Quality Corp to delineate first-step options for health data exchange in the Portland Metro area. This planning effort resulted in completion of a mobilization plan for a provider-centric exchange which contains technical, financial, governance, and privacy and security policies, for a RHIO.

The Oregon and Southwest Washington Healthcare Privacy and Security Forum was created in May of 2000 to address Oregon's version of HIPAA compliance. The Forum has been instrumental in shaping Oregon statute around privacy and security, especially during the 2003 Legislative Session. A comprehensive legal and statutory review was done at that time to conform state statute to federal law. The Forum developed standard forms, contracts, policies, standardized legal forms, and created educational materials to assist in understanding HIPAA. It has also been active in collaborating with Washington, Idaho, Montana, and Alaska in developing privacy standards. A number of successful initiatives and work products have been produced, including an Oregon authorization form to use and/or disclose protected health information, standard companion documents for electronic transmission of data and privacy and security policies.

Other important privacy and security groundwork has been performed by the Oregon Association of Hospitals and Health Systems (OAHHS), which has two groups: the HIPAA security and HIPAA privacy task forces. The Oregon Medical Association has also pioneered groundwork as part of the Oregon Medical Electronic Network (OMEN) project. This effort set up a statewide network that operated from 1993-2003 and included 12 health plans

(including the state Medicaid program), several health systems, and independent physician associations in order to share eligibility data.

The Chronic Disease Data Clearinghouse project of the Quality Corp, the Oregon Diabetes Coalition, and the Asthma Network also addressed policy issues for data exchange. This proof-of-concept pilot demonstrated that 12 health plans working together were able to establish and maintain data sharing agreements. One of the products is a combined report that physicians will use to manage care for patients with diabetes and asthma.

The Oregon Health Information Infrastructure (OHII) has provided groundwork through a strategic plan, developed through stakeholder meetings. This plan helped set the agenda to encourage adoption of EHR and systems for securely and efficiently getting information to where it is needed. OHII work has included: multiple statewide conferences, CIO/CMIO forums, a pilot project proposal, and an EHR inventory to establish a baseline of EHR adoption in the state.

Five groups are conducting community data exchange projects as part of the AHRQ initiative. These efforts include:

- Improving the Quality of Healthcare in Central Oregon- Bend, Oregon
- Bay Area Community Informatics Project- Coos Bay, Oregon
- Using IT to Improve Medication Safety for Rural Elders- Lincoln City, Oregon
- Medication Management: A Closed Computerized Loop- Grants Pass, Oregon
- Improving Safety and Quality with Integrated Technology- Portland, Oregon

### **c. Current Privacy and Security Landscape**

Much of the privacy and security work to date in Oregon has been accomplished by multi-stakeholder groups primarily organized by hospitals, health systems and medical associations. These organizations have not included consumer representation.

Representatives of the State, health plans and others have been active participants over the past 6 years since they assembled to solve issues surrounding the implementation of HIPAA. Another significant background issue is the way in which HIPAA was addressed by the 2003 Oregon Legislature. Prominent privacy and security attorneys and other experts in the state, drawing mainly from the above-mentioned groups, examined the relevant state laws and harmonized them with HIPAA.

There is now a heightened awareness of patient control issues in terms of privacy and security. However, there is little agreement among individuals regarding the comprehensibility of HIPAA—some believe HIPAA sufficiently covers the privacy and security issues of HIT/HIE, while others do not. The HISPC project has facilitated an educated discussion on HIPAA among the interested groups and also provided the impetus for legislative action. The project has helped the understanding of the complexity of privacy and

security issues and allowed stakeholders to form a more realistic view of the issues that need to be discussed before data is exchanged. The project has also encouraged some collaborative efforts across states boundaries with Alaska, California and Washington. Some of these efforts are dealing with similar issues concerning interpretation and application of HIPAA.

Oregon does not have a formal governance structure for privacy and security. The HISPC Steering Committee is currently in transition to the Health Information Infrastructure Advisory Committee (HIIAC) and this body will inform the Oregon Health Fund Board on HIE/HIT issues and decisions. The legislation establishing the Oregon Health Fund specifically charges the Board "... to deliver efficient, safe and quality health care and a voluntary program to provide every Oregonian with a personal electronic health record that is within the individual's control, use and access and that is portable." The legislation makes it clear that the Oregon Health Fund Board will need to address patient control issues, including those involving privacy and security.

## **I. Implementation Project Update**

### **a. Describe reasoning for choosing implementation project(s)**

Since the submission of Oregon's Final Implementation Plan Report in April, 2007, we have done some focused work in the area of consumer education and engagement. A review of our work from April 2006 through April 2007 inspired the project team to focus on a strategy for consumer education and engagement. Initially, we created a process to gain patient permission for participation in a HIE system. We created a booklet which explained HIE in plain language and interviewed patients with a high usage level of the health care system using this booklet as a basis for discussion. Our research identified a significant knowledge gap regarding the privacy and security of health information in both the current system and proposed exchanges. Our consumer interviews demonstrated that the concepts of privacy and security of health information are very complex and difficult to explain to an uninitiated audience. While the benefits of HIE are quickly understood, accurate privacy and security facts are not. Those we interviewed showed a thorough lack of familiarity with how their personal health information is treated today, despite the fact that our subjects were frequent health system users. The misperceptions about the current system affect individuals' beliefs and willingness to accept a new way of storing and using health information. As we considered how to move forward on obtaining permission from individuals to participate in a HIE system, we recognized the need to provide more information and education about the privacy and security of health information in order to obtain true informed consent.

With a goal to present a balanced discussion of the importance of health information portability and privacy and security such that participants can make a truly informed decision regarding information sharing and a hope of extending the HISPC experience

beyond the participants in the HISPC process, Oregon choose to produce a documentary film about the privacy and security issues inherent in HIE systems. Our work over the past five months has focused upon the production of the documentary film and a plan to disseminate the film upon completion.

A secondary implementation project has been work on transitioning the HISPC Steering Committee to a Health Information Infrastructure Advisory Committee (HIIAC). Senate Bill 329, passed during Oregon's 2007 Legislative Session, envisions portable, personal health records as a means to improving quality of care and reduction of costs in the health care system. A broader, higher-level body is necessary to incorporate all the prevailing HIT/HIE issues facing the state to meet the goal established by SB 329.

#### **b. Progress made on the implementation plan to date**

In addition to the implementation projects listed above, Oregon's implementation plan included nine additional areas of focus upon which work continues.

##### 1. Consumer Privacy and Security Protection

The Markle Foundation's *Connecting for Health* principles were adopted by the Oregon HISPC Steering Committee as guiding principles for consumer protection. These principles were codified in SB 329 which calls for a program to provide every Oregonian with a personal electronic health record that is within the individual's control, use and access and that is portable. Additionally, Oregon has recently been awarded a Medicaid Transformation Grant and the *Connecting for Health* principles will also underlie the implementation of the work done pursuant to that grant.

##### 2. Provider Identification

The Oregon Medical Association (OMA) is continuing its work on development of a basic authentication depository for provider authentication. Phase I is set to be operational in February, 2008. Community meetings will be held in January, 2008. OMA is using DHS and OHSU as its major data sources and has health plans and providers committed to participate.

Phase II is planned to begin in early 2009 and will involve digital certificates for additional authentication. The State of Oregon will issue the certificates for a minimal fee to providers.

##### 3. Patient Identification

Much discussion has taken place in Oregon regarding patient identification options. Despite the private sector consortium which continues to research and analyze patient identification systems and statewide conferences devoted to this

issue. a state-wide approach to this issue has not been fully addressed at the present time.

#### 4. Specially Protected Information

The issues arising from the treatment of specially protected information in an electronic exchange environment will be addressed by the work of the Health Information Infrastructure Advisory Committee (HIIAC). Additionally, through its work with the multi-state collaborative project, Oregon will have an opportunity to develop education and engagement strategies and tools to help consumers navigate the different laws regarding specially protected information from state to state. There has been some discussion regarding the arbitrary nature of specially protected information in that it only refers to certain types of information. It is recognized that this doesn't take into account individual preferences with regard to information-sharing. What one person may think warrants special protection is different from another person. A more universal policy has been the topic of some HISPC discussions.

#### 5. Medical Identity Theft

Senate Bill 583, passed during the 2007 Legislative Session, contains requirements for notification in the case of a breach of security involving a consumer's personal information. The legislation specifies the rights of the consumer in the case of a breach. The legislation also mandates that organizations that possess consumers' personal data implement a security program for that data and specifies the requirements for the security program. While this does not pertain specifically to medical information, it does include medical information. In effect, HIPPA compliance is now state law with respect to these issues.

The HIIAC will monitor the current laws and rules and recommend changes as it deems necessary.

#### 6. Technical Assistance

We will continue to evaluate, update and disseminate the Best Practice documents that were created during the HISPC process. The Oregon and SW Washington Privacy and Security Forum is planning a spring, 2008 industry-wide event to develop technical, business and privacy and security standards. These standards will be the foundation for larger scale HIE.

#### 7. Non-covered Entities

The HIIAC will address the privacy and security issues that arise in an electronic exchange environment from entities not subject to HIPAA.

## 8. Secondary Use

The HIIAC will identify and define types of secondary use and develop model practices, policies and procedures for each type in order to ensure patient privacy is protected. Recently created definitions and nomenclature for secondary use developed by the American Medical Informatics Association will be helpful in the discussions.

## 9. Enforcement

The HIIAC will review enforcement mechanisms currently available and assess the need for further enforcement tools. Additionally, Oregon has proposed the creation a Patients' Rights Guide as part of its work with the multi-state collaborative project. This guide will let consumers know what rights and remedies are afforded them in the case of a breach of their privacy with respect to health information.

### **c. Issues encountered during the implementation and lessons learned**

Our work thus far has not raised any new issues but it has served to confirm that trust and funding remain the two greatest barriers to progress. As we planned the documentary film, we were solicited and received feedback on our outline and plans from stakeholders. We have strived to make this film a balanced view of the privacy and security issues involved in health information exchange and believe our stakeholders will benefit from seeing the subject matter portrayed in a balanced manner. The lesson learned is that building trust is a long-term endeavor that needs to be approached with honesty, transparency and commitment from all parties.

Funding remains a barrier to progress in a number of areas. This is especially relevant in Oregon's rural communities. The lesson learned is that we will continue to make small strides in the areas, but without significant, dedicated funding, many of the larger, more comprehensive measures will need to take place further down the road.

### **d. Plans for continuing the project through the end of the year and, if applicable, after the end of the project.**

The documentary film is scheduled to be completed by the end of 2007. We will also have a dissemination plan for the film completed at that time as well. Part of our multi-state collaborative proposal is to Town Hall Meetings in 10 – 12 communities with nascent HIE projects in Oregon using the documentary film as a focus for discussion of HIE and in particular, privacy concerns of consumers. By adapting and refining the Town Hall format after each meeting, we will develop a "how to guide" for using the documentary film as a

consumer education and engagement tool. At the same time, we will be furthering Oregon's plan to educate and engage consumers in Oregon.

The HIIAC is expected to be in place by the end of 2007 and ready to embark on its charge beginning in 2008. The HIIAC's work in conjunction with the Oregon Health Trust Board holds the most promise for meaningful progress in the area of privacy and security for HIE.

### **III. Impact Analysis**

#### **a. Describe milestones that outline the major outcomes or conclusions of the project April 2006 through December 2007.**

There have been a number of milestones for Oregon over the past 18-months. First and foremost, HISPC created an understanding of the complexity of privacy and security issues in an electronic exchange environment. Each stakeholder views these issues differently and HISPC brought these parties to the table to begin to share their viewpoints and concerns. HIE holds such promise for improved care and reduced costs that it is tempting to jump to creation of a system without ensuring all aspects of privacy and security are covered. HISPC brought about a heightened awareness of patient control issues in terms of privacy and security and will allow Oregon to avoid mistakes other attempts at HIE have made around privacy and security issues.

The Oregon Health Policy Commission devoted a section of its 2007 report to the Governor to privacy and security issues arising from electronic information exchange. The Commission recommended state support for the implementation and dissemination of Oregon's HISPC recommendations including the funding of a Health Information Privacy Coordinator position.

Another milestone is the creation of the Health Information Infrastructure Advisory Committee (HIIAC). The HIIAC is a higher-level body than the HISPC Steering Committee and will guide the governance of health information exchange in Oregon. While the HIIAC will continue to focus on privacy and security issues, it will also broaden its reach to allow Oregon to fulfill its promise of a "voluntary program to provide every Oregonian with a personal electronic health record that is within the individual's control, use and access and that is portable." This very language is a milestone as well. SB 329, passed by the 2007 Oregon Legislature, charges the Oregon Health Trust Board to achieve this goal.

HISPC has offered an opportunity to forge a working relationship with other states. We have worked closely with our neighbors in Washington State and California and we are pleased that all three states are formulating similar designs moving forward.

HISPC also spurred the creation of Privacy and Security Best Practice compilations which will help to decrease the incorrect information and misinterpretations of current law.

**b. What has been the HISPC project impact on areas such as variation in privacy and security domains, leadership and governance, stakeholder knowledge and educational issues, funding/sustainability of HIE/HIT efforts, or other areas?**

HISPC identified the extent to which variation exists across organizations in Oregon in the understanding and adherence to appropriate privacy and security practices. Recommended practices are rapidly evolving as technological capabilities advance. In addition, organizations that are unprepared to adequately protect health information are becoming involved in electronic information exchange. The HISPC project has developed a list of recommended practices, but an ongoing effort to keep this information up-to-date and sustain its use is necessary to ensure widespread adoption of appropriate privacy and security practices. Also, education is required to assist in dispelling myths or incorrect legal interpretation of existing law that create barriers to health information exchange. The communication of standardized approaches needs to be accompanied with the rationale behind those standards, correct information regarding legal requirements and how misinformation and incomplete adoption of appropriate privacy and security standards hampers quality healthcare while also diminishing the trust of consumers. Through the dissemination of the compilation of Privacy and Security Best Practices we hope to reduce the variation which exists in the privacy and security domains.

HISPC has been a catalyst for privacy and security leadership and governance in Oregon. For example, the Metro Portland HIE project predated HISPC, but the work emanating from the HISPC project informed the Metro HIE project with respect to privacy and security issues. The transition of the HISPC Steering Committee to a HIIAC was also precipitated by the HISPC project findings.

As was discussed in the prior section on milestones, HISPC had a major impact on stakeholder knowledge. The stakeholder group identified where education was needed and developed ways to address that need. HISPC allowed the stakeholders to approach the issues of trust inherent in HIE by bringing all parties to a "ground zero" before beginning the conversation about reaching consensus. Through the HIIAC, Oregon will continue the work we have begun in this area.

We continue to struggle with the funding for full-scale health information exchange. It is hoped that as the Oregon Health Fund Board progresses in its work, HIE will take a more prominent role with accompanying resources. Oregon will continue to encourage nascent exchanges to investigate new avenues to sustainability.

### **c. Any unanticipated outcomes?**

The relative lack of consumer involvement in the process was unanticipated. We had to make extra efforts to elicit consumer input such as the in-depth interviews and the documentary and town hall meetings.

## **IV. Future Vision**

### **a. Within the State**

#### **i. Any specific challenges to private and secure interoperable systems identified in Phase I still need resolution?**

All of the challenges identified in HISPC Part I still need more work to be considered 'resolved'. But HISPC has served to elevate the issue of privacy and to lay the groundwork for a profoundly more informed discussion. Some of the issues surrounding HIPAA became visible during this process. Because of HISPC, we are having the discussion and it is a different discussion that would have otherwise been.

The greatest challenges lie in the access to and control of personal health information and the governance of health information exchanges and/or RHIOs if they do come into existence. The control of the consumer with regard to the flow of their own information is the overriding issue and if not handled properly may result in mistrust of the health information systems and further privacy protective behavior.

#### **ii. What is the plan and/or commitment within the state to resolve these issues?**

In 2007, the Oregon legislature initiated significant health reform efforts within the state with the creation of the Oregon Health Fund Board (OHFB). Senate Bill 329 directs the Board to develop a comprehensive plan for the state with a delivery system that uses "information technology that is cost-neutral or has a positive return on investment to deliver efficient, safe and quality health care and a voluntary program to provide every Oregonian with a personal electronic health record that is within the individual's control, use and access and that is portable." This emphasis on individual control, use and portability is a direct result of the HISPC work in Oregon and is now a guiding principle for HIE in Oregon.

In addition, the Governor's office is further reinforcing the work of the HISPC Steering Committee by reforming the committee into an ongoing advisory body, the Health Information Infrastructure Advisory Committee (HIIAC), with members to be appointed by the Governor in December 2007. The HIIAC will

serve to advise the Governor's office and the larger health care reform efforts about the potential state role in the development of health information, including the development of consumer protections.

## **b. Multi-State Initiatives**

### **i. Interactions between states that have been of value**

One of the most valuable outcomes of the HISPC project has been the opportunity to interact with and learn from other states. This project has attracted some of the most experienced privacy, security and health information exchange personnel in the country. The bank of contacts and experiences we have accumulated will be crucial to efficiency moving forward. The exchanges and conversations during our face to face meetings have been very helpful on a number of fronts, especially with respect to consumer engagement and education.

### **ii. Intended/Future outcomes of Collaborative work**

As a participant in the Consumer Education and Engagement Collaborative, Oregon intends to refine its documentary film and a process for using the film as a basis for consumer engagement and education. We will create a replicable plan other states can incorporate into their consumer education plans. Additionally, we will work with Colorado, Kansas, Massachusetts, New York, Oregon, Washington and West Virginia to create a consumer education and engagement plan for other states to use. Our work will address language, literacy and diverse populations, and will include replicable templates as well as instructions on how to adapt the templates to meet the needs of individual states.

## **V. Conclusion**

The HISPC project has heightened the awareness of privacy and security issues inherent in electronic health information exchange and been a catalyst for addressing not only privacy and security issues, but many other issues in the HIT/HIE domain. Oregon looks forward to continued progress on privacy and security issues and more widespread adoption of electronic health records and the private and secure exchange of those records.

## **Acknowledgements**

The Office of Oregon Health Policy and Research would like to acknowledge the following members of the Oregon Health Information Security and Privacy Collaboration project team for their contributions to this report:

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