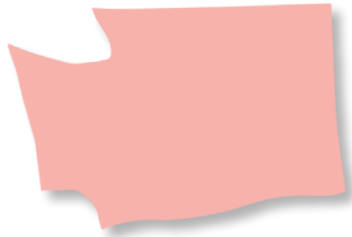


CONFIDENTIAL + COVERED



Protecting Patients' Privacy in Health Insurance Billing & Claims: **A Washington Profile**

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Contents

Introduction.....	1
Background: Confidentiality & Insurance in Washington.....	2
Federal Notice Requirements for “Denials”.....	4
The Washington Regulation: “Right to Limit Disclosure of Health Information”.....	5
Elements of the Washington Regulation.....	5
Major Themes.....	7
Positive Features of the Washington Landscape.....	7
Challenges for Implementation.....	8
Recent Implementation Efforts.....	9
Implementation Challenges.....	9
Minors, Adults, & Alternative Confidentiality Approaches.....	11
Path Forward & Next Steps.....	12
Conclusion.....	12
Appendix A.....	13
Appendix B.....	14
Acknowledgements.....	15

Introduction

Confidential & Covered is a three-year research project led by the National Family Planning & Reproductive Health Association (NFPRHA) and funded by the US Department of Health & Human Services' Office of Population Affairs as part of its Affordable Care Act Collaborative. The project is designed to identify policies and practices to mitigate revenue loss at Title X-funded health centers due to the provision of confidential health services. The purpose is to improve service sites' sustainability while preserving one of Title X's core principles, namely the provision of confidential services for patients served by this essential program. *Confidential & Covered* partnered with the Center for Adolescent Health & the Law (CAHL), the George Washington University's Milken Institute School of Public Health, and the University of California, San Francisco's Bixby Center for Global Reproductive Health to conduct research on insurance use and confidentiality throughout the payment process—in other words, payment that does not breach privacy.

Protecting confidentiality is complex and has presented particular challenges in the health insurance arena. The insurance landscape is replete with opportunities for disclosure of private information, some of which are the result of explicit legal requirements or insurance carriers' policies and practices, such as the sending of explanations of benefits (EOBs) when insurance claims are filed and acted upon. These disclosures may result in patients' information reaching a family member, often the policyholder for the health insurance, even when the patient wants the information to remain private. In some cases, the information could pertain to family planning or other sensitive health services or the patient would be in jeopardy due to the disclosure. In this context, the *Confidential & Covered* project is working to identify ways to protect confidentiality without forfeiting the opportunity to secure health insurance payments for patients insured as dependents on a family member's policy.

In the first year of the project (2014-2015) the *Confidential & Covered* policy team at NFPRHA and CAHL undertook extensive research and detailed analysis of federal and state laws and policies relevant for publicly funded family planning that provide confidentiality protection or, on the other hand, that can lead to the disclosure of confidential information via billing and health insurance claims. The team published a white paper¹ and policy guide² based on that research and analysis. In the second year of the project (2015-2016) the team visited states that have laws in place designed to enable individuals to use their health insurance coverage without foregoing confidentiality protection or triggering privacy breaches. The three states visited in 2015 were California, Colorado, and Washington.

This report provides a profile of the current policy environment (as of January 2016) for confidentiality and insurance in Washington based on interviews in person and by telephone with key informants conducted between October 2015 and December 2015, as well as a review of Washington state laws. The informants included diverse stakeholders such as family planning providers, adolescent and young adult health experts, school-based health providers, policy advocates, public health officials, health insurance carriers, and health insurance regulators.³

The profile offers background on the legal and policy framework for confidentiality and insurance in Washington, explains a state regulation adopted in 2001 to provide improved privacy protection, highlights major themes that characterized the evolution of Washington policy, details recent implementation efforts for the regulation, explores future policy challenges and discusses next steps needed to further confidentiality protection for patients while enabling providers to receive revenues from health insurance payments. The report represents a composite picture drawn from the varied comments of the informants interviewed.

1 Abigail English, Robin Summers, Julie Lewis, and Clare Coleman, Confidentiality, Third-Party Billing, & the Health Insurance Claims Process: Implications for Title X (Washington, DC: National Family Planning & Reproductive Health Association, 2015). http://www.confidentialandcovered.com/file/ConfidentialandCovered_WhitePaper.pdf.

2 Julie Lewis, Robin Summers, Abigail English, and Clare Coleman, Proactive Policies to Protect Patients in the Health Insurance Claims Process (Washington, DC: National Family Planning & Reproductive Health Association, 2015). http://www.confidentialandcovered.com/file/ConfidentialandCovered_PolicyGuide.pdf.

3 A list of individuals interviewed is included in Appendix A.

Background: Confidentiality & Insurance in Washington

Since the Affordable Care Act (ACA) was enacted in 2010, Washington has experienced an increase in the number of individuals with health insurance, which has been largely driven by successful enrollment in marketplace plans through the state's exchange, the Washington Health Plan Finder; expansion of Medicaid, known as Apple Health; and the ACA provision allowing young adults to remain on a parent's health insurance up to age 26.⁴ Many of the newly insured individuals who gained health insurance coverage as a result of the ACA as well as those with coverage under employer-based plans are covered as dependents on a family member's plan. These include young adults and adolescents, as well as spouses and domestic partners, some of whom are affected by intimate partner violence. When health insurance coverage is used to pay for dependents' care, these individuals may have their privacy infringed. This occurs due to legal and policy requirements for disclosure of information in the health insurance billing and claims process, or as a result of health plan contracts and practices, and in spite of existing legal protections for the confidentiality of health information. Washington is noteworthy among states in that it not only has strong privacy protections in its statutes and regulations, it also has included in those protections explicit provisions that impose confidentiality obligations on health insurers and carriers.

In Washington, as in every state, the federal privacy regulations under the Health Insurance Portability and Accountability Act—the HIPAA Privacy Rule—require health care providers and health insurers to protect patients' privacy. Of particular importance, the rule includes two special protections that restrict disclosure of protected health information (PHI) and provide for confidential communications. The first allows patients to request restrictions on the disclosure of their PHI.⁵ Health care providers and health plans are not generally required to comply with such requests unless they agree to do so, but they must agree if the care has been fully paid for by the patient or someone other than the health plan. The second special protection allows patients to request that they “receive communications of protected health information ... by alternative means or at alternative locations.”⁶ Health care providers must accommodate reasonable requests and may not require patients to claim they would be endangered by disclosure; health plans must accommodate reasonable requests when there is a claim of endangerment. It is noteworthy that with respect to requests for confidential communications the HIPAA rule for health care providers differs from the requirement for health plans: plans are only required to comply with requests if endangerment is claimed.

Washington has strong state laws protecting patients' privacy and the confidentiality of their health information. These laws include the Washington Health Care Information Act, which contains detailed provisions governing access to and disclosure of medical records and health care information.⁷ Along with various general requirements, specific requirements govern confidentiality of information related to mental health services, reportable and sexually transmitted diseases, and HIV.⁸

“One significant Washington statute also explicitly requires that “[h]ealth carriers and insurers shall adopt policies and procedures that conform administrative, business, and operational practices to protect an enrollee’s right to privacy or right to confidential health care services granted under state or federal laws.””

4 The U.S. Department of Health & Human Services' Assistant Secretary for Planning Evaluation tracks and disseminates insurance enrollment information. Up to date enrollment numbers can be found at <https://aspe.hhs.gov/affordable-care-act-research>.

5 45 C.F.R. § 164.522(a)(1).

6 45 C.F.R. §§ 164.502(h); 164.522(b)(1).

7 Wash. Rev. Code Ann. §§ 70.02.005 - 70.02.905.

8 E.g., Wash. Rev. Code Ann. §§ 70.02.220 - 70.02.260, 70.02.300 - 70.02.320.

One significant Washington statute also explicitly requires that “[h]ealth carriers and insurers shall adopt policies and procedures that conform administrative, business, and operational practices to protect an enrollee’s right to privacy or right to confidential health care services granted under state or federal laws.”⁹ In addition, the Washington Office of the Insurance Commissioner has issued health privacy regulations.¹⁰ The rules require carriers to follow detailed privacy practices; they also specify the circumstances in which disclosure of health information does and does not require a patient’s authorization as well as when a patient may request restrictions on disclosure. An important regulation applicable to health insurers and carriers provides that a “licensee shall not disclose nonpublic personal health information about a consumer or customer unless an authorization is obtained from the consumer or customer whose nonpublic personal health information is sought to be disclosed,” subject to exceptions specified in Washington law or the HIPAA Privacy Rule.¹¹

Along with the laws that protect privacy and the confidentiality of health information for all age groups, Washington state laws allow minors to consent for their own health care in several circumstances. Some of these minor consent laws are contained in statutes, while others are found in court decisions. Washington statutes expressly allow emancipated minors to consent for their health care.¹² Also by statute, minors age 14 or older may consent for diagnosis or treatment of sexually transmitted diseases, including HIV;¹³ minors age 13 or older may consent for outpatient treatment for chemical dependency¹⁴ and outpatient mental health treatment.¹⁵ Although there is not an explicit Washington *statute* authorizing minors to consent for family planning, abortion, or pregnancy-related care, their right to do so was established by the Washington Supreme Court more than 40 years ago in a *court decision* determining that a minor’s privacy right is essentially the same as that of an adult and that a minor’s decision to have an abortion may not be subjected to a parental veto;¹⁶ this case also has been consistently relied on to support minors’ rights to consent for contraception and other pregnancy-related care. Minors also may obtain family planning services without parental consent in Title X-funded sites¹⁷ or when the minor is a Medicaid beneficiary,¹⁸ and ought to be able to do so in other health care settings based on the constitutional right of privacy.¹⁹ Washington statutes provide that when a minor is authorized to consent for health care under federal or state law, only the minor may exercise the rights of a patient under Washington’s Health Care Information Act.²⁰ This means that minors should have control of their health information to the same extent as adult patients. The fact that minors legally should be allowed to consent for family planning services does not mean that they are allowed to do so as a matter of practice in all settings; also, having a right to consent for family planning services does not necessarily guarantee that confidentiality will be fully protected in relation to these services.

⁹ Wash. Rev. Code Ann. § 48.43.505.

¹⁰ Wash. Admin. Code §§ 284-04-500 – 284-04-525

¹¹ Wash. Admin. Code § 284-04-505. The definition of a “licensee” includes “all licensed insurers, health care service contractors, HMO’s, and fraternal benefit societies, producers and other persons licensed or required to be licensed, or authorized or required to be authorized, or registered or required to be registered pursuant to the insurance law of this state.” Wash. Admin Code § 284-04-120(18).

¹² Wash. Rev. Code § 13.64.060.

¹³ Wash. Rev. Code §§ 70.24.110; 70.24.017(13).

¹⁴ Wash. Rev. Code § 70.96A.095.

¹⁵ Wash. Rev. Code § 71.34.530.

¹⁶ *State v. Koome*, 530 P.2d 260 (1975).

¹⁷ Abigail English, Center for Adolescent Health & the Law, and National Family Planning & Reproductive Health Association, *Adolescent Confidentiality Protections in Title X*, June 5, 2014.

<http://www.nationalfamilyplanning.org/document.doc?id=1559>.

¹⁸ 42 U.S.C. §§ 1396a(a)(7), 1396d(a)(4)(C). 42 C.F.R. § 441.20.

¹⁹ *Carey v. Population Services International*, 431 U.S. 678 (1977).

²⁰ Wash. Rev. Code § 70.02.130.

At the same time that Washington laws protect patients' privacy, they also contain provisions that require disclosure of certain information as part of the health insurance claims process. These laws are numerous and varied, with requirements that apply to a wide range of health insurance carriers and insurance communications. For example, insurance regulations specifically require insurers to notify a "claimant"²¹ whether a claim has been accepted or denied; denials must be given in writing and reference to the specific provision, condition, or exclusion that is the basis for the denial must be included.²² The regulations also require that a "reasonable explanation of the basis in the insurance policy" be provided when a claim is denied.²³

State regulations also allow, as one possible exception to the requirement that insurers and carriers obtain authorization for the disclosure of personal health information, disclosures "for the performance of insurance functions," for activities permitted under Washington statute on a need-to-know basis, and for activities permitted under the HIPAA Privacy Rule.²⁴ More recently, as part of Washington's response to the ACA, the Insurance Commissioner issued regulations setting forth the "Adverse Benefit Determination Process Requirements For Nongrandfathered Plans."²⁵ These regulations make clear that important communications regarding health insurance claims may be sent to a variety of recipients, including "a person covered as an enrollee, subscriber, policy holder, participant, or beneficiary of an individual or group health plan, and when designated, their representative."²⁶

Federal Notice Requirements for "Denials"

Federal law requires that insurers and health plans share information about denials of claims—often referred to as "adverse benefit determinations"—with policyholders, subscribers, and enrollees – as detailed in the Affordable Care Act (ACA), Employee Retirement Income Security Act (ERISA), and Medicaid Managed Care regulations.²⁷ These denial notices are commonly sent in a format that looks like an explanation of benefits (EOB). See *Confidentiality, Third-party Billing, and the Health Insurance Claims Process: Implications for Title X for a robust discussion of federal insurance law and its impact on privacy.*²⁸

21 Wash. Admin. Code § 284-30-320(2), (6), and (14).

22 Wash. Admin. Code § 284-30-380.

23 Wash. Admin. Code § 284-30-330(13).

24 Wash. Admin. Code § 284-04-505.

25 Wash. Admin. Code §§ 284-43-3000 – 284-43-3210.

26 Wash. Admin. Code § 284-43-3010.

27 45 C.F.R. § 147.136; 26 C.F.R. § 54.9815-2719; 29 C.F.R. § 2590.715-2719; 42 C.F.R. § 438.404.

28 Abigail English, Robin Summers, Julie Lewis, and Clare Coleman, *Confidentiality, Third-Party Billing, & the Health Insurance Claims Process: Implications for Title X* (Washington, DC: National Family Planning & Reproductive Health Association, 2015). http://www.confidentialandcovered.com/file/ConfidentialandCovered_WhitePaper.pdf.

The Washington Regulation: "Right to Limit Disclosure of Health Information"

The 2001 Washington regulation²⁹ that creates a right for patients to limit disclosure by insurers of their health information was closely modeled on a provision of the Health Information Privacy Model Act³⁰ issued by the National Association of Insurance Commissioners (NAIC) in 1998.³¹ The language of the Washington regulation is virtually identical to Section 14 of the NAIC Model Act. Both Section 14 of the Model Act and the Washington regulation contain protections for individuals who would be jeopardized by disclosure, for individuals receiving a range of sensitive health services, and for minors who may obtain health care without parental consent. Notably, the language in the Washington regulation is broader than the language in other states' laws in at least two ways: first, it encompasses not only requests for confidential communications (as in California) but also restrictions on disclosure of information; and second, it grants protection to minors as well as adults (in contrast to Colorado). The Washington regulation comprises a number of key elements.

Elements of the Washington Regulation

Protected Individuals	Adults and minors who are the subject of health information that might be communicated by health insurers & carriers
Rights & Obligations of Individuals	<ul style="list-style-type: none"> Request limitation on disclosure of information about them, including "health information" and "personal health information concerning health services related to reproductive health, sexually transmitted diseases, chemical dependency and mental health" Receive health care services or file a claim without the authorization of the policyholder or other covered person
Obligations of Health Insurers/Carriers	<ul style="list-style-type: none"> Honor request from an individual to limit disclosure of any information, including health information, about the individual if the individual states that disclosure to other specified individuals could jeopardize the safety of the individual Limit disclosure consistent with the individual's request (e.g., request not to release information to a spouse to prevent domestic violence) Honor written request from an individual to refrain from disclosure of personal health information concerning health services related to reproductive health, sexually transmitted diseases, chemical dependency, and mental health
Obligations of Health Insurers/Carriers to Minors	<ul style="list-style-type: none"> Recognize right of minors who may obtain health care without the consent of a parent under state or federal law to exercise rights under the regulation to request limitations on disclosure Refrain from disclosing nonpublic personal health information related to any health care service to which a minor has lawfully consented without the express authorization of the minor
Type of Communications to Be Limited	<ul style="list-style-type: none"> Mailing of appointment notices Calling the home to confirm an appointment Mailing a bill or explanation of benefits to a policyholder or certificateholder
Required Contents of Request to Limit Disclosure	<ul style="list-style-type: none"> Name and address of individual Type of information that should not be disclosed Type of reproductive health services subject to nondisclosure Identity or types of persons from whom information should be withheld Information about how payment will be made for any cost sharing Phone number or address where individual may be reached

²⁹ Wash. Admin. Code § 284-04-510. The full text of the regulation is included in Appendix B.

³⁰ National Association of Insurance Commissioners, Health Information Privacy Model Act (1998). <http://www.naic.org/store/free/MDL55.pdf>.

³¹ In requiring health carriers and insurers to adopt policies and procedures to protect enrollee's privacy and the confidentiality of their health information the Washington Legislature had specifically indicated that the Insurance Commissioner might consider NAIC standards in crafting regulations to implement the requirement. Wash. Rev. Code Ann. § 48.43.505.

First, the regulation provides that insurers must limit disclosure of an individual's health information if the individual clearly states in writing that disclosure could jeopardize the individual's safety.³² The regulation requires that disclosure be limited *in ways that the individual requests* and it includes, by way of example, that the individual might request information not be disclosed to a spouse to prevent domestic violence. However, the "domestic violence" example is just that—an example, not a limitation on the type of restriction an individual might request.

Second, insurers must honor written requests by individuals not to disclose their health information pertaining to reproductive health, sexually transmitted diseases (STDs), chemical dependency, and mental health.³³ Of particular note, the regulation's protection extends to the mailing of bills or explanations of benefits (EOBs) to policyholders. It also specifies that carriers or insurers may not require a policyholder's consent for an individual to receive health services or file a claim.

Third, the regulation makes clear that minors who may obtain health care under state or federal law without parental consent are able to exercise the right to limit disclosure under the regulation and that insurers must recognize this right on the part of minors.³⁴ This aspect of the regulation is closely related to the broad minor consent laws that have been in place in Washington for several decades. The regulation requires insurers to refrain from disclosing information related to the services for which a minor has consented – including via the mailing of bills or EOBs – without first obtaining their authorization. Notably, the protection for minors does not require them to make a written request, but rather requires insurers to refrain from disclosing the information whether or not such a request is made.

“Notably, the protection for minors does not require them to make a written request, but rather requires insurers to refrain from disclosing the information whether or not such a request is made.”

Finally, the regulation specifies the information that must be included when a request for nondisclosure is made, either based on endangerment or in connection with the enumerated sensitive services.³⁵ Among other items, the request should specify the type of information that should not be disclosed, the type of persons from whom information should be withheld, and how payment will be made for any cost sharing.³⁶

Significantly, the Washington regulation explicitly states that its provisions apply “[n]otwithstanding any insurance law requiring the disclosure of information.”³⁷ Thus, it suggests that the confidentiality protections it creates should take precedence over other state laws requiring insurers to disclose information. However, no accountability mechanism or specific method for resolving conflicts between this regulation and other insurance laws is articulated in the regulation.

³² Wash. Admin. Code § 284-04-510(1).

³³ Wash. Admin. Code § 284-04-510(2).

³⁴ Wash. Admin. Code § 284-04-510(3)(a).

³⁵ Wash. Admin. Code § 284-04-510(4).

³⁶ Wash. Admin. Code § 284-04-510(4)(b), (d), and (e).

³⁷ Wash. Admin. Code § 284-04-510(2).

Major Themes

In adopting the 2001 regulation designed to protect patients' privacy by specifying restrictions on disclosure of personal health information in the health insurance arena,³⁸ Washington stands out as a very early adopter, leading other states by more than a decade in putting such a law in place. The Washington regulation even preceded the promulgation at the federal level of the final version of the HIPAA Privacy Rule in 2002.

The regulation contains a set of important protections specific to information about sensitive services, minors who may consent for their own care, and individuals whose safety would be jeopardized by disclosure.

Positive Features of the Washington Landscape

Washington Health Privacy and Insurance Laws

Washington laws distinguish themselves in the degree of detailed—and in some cases unique—protections they provide for the health privacy of individuals and in the explicit ways they link those protections with requirements related to insurance disclosures. Specifically, Washington laws explicitly require health carriers and insurers to adopt policies and practices that conform to state and federal health privacy and confidentiality laws. They also prohibit disclosure by carriers and insurers of individuals' personal health information without authorization, with only limited exceptions. Provisions such as these provide the context in which the regulation on "Right to Limit Disclosure of Health Information" was adopted.

Role of Insurance Commissioner

The Washington Office of the Insurance Commissioner played a central role in the development and implementation of the state's insurance confidentiality regulation. While the HIPAA Privacy Rule was evolving at the federal level, Washington was a leader among states, adopting a comprehensive regulatory approach to protecting patients' health information, including in the insurance arena. Recently, a coalition of health care providers and advocates turned to the Insurance Commissioner's office, which has been receptive to considering strategies to implement or improve the regulation.

Confidentiality Approaches

Several of the largest health care providers and at least one of the large health insurance carriers in Washington have made significant efforts to protect the confidentiality of health information and patient privacy, particularly for adolescents and young adults. Although these efforts do not appear to be directly linked to the insurance privacy regulation, they seem to operate in tandem with it and to be consistent with efforts to ensure that confidentiality breaches via insurance claims are not allowed to jeopardize access to health care in general or sensitive health services in particular for adolescents, young adults, and other individuals insured as dependents.

³⁸ Wash. Admin. Code § 284-04-510. The full text of the regulation is included in Appendix B.

Challenges for Implementation

Clarity and Enforcement

The Washington regulation, as written, offers the promise of significant protections for the health information of both minors and adults seeking sensitive services or who would be endangered by disclosure, imposing obligations on insurers to provide those protections. However, the regulation lacks clarity. First, it does not include a clear enforcement mechanism, which has hindered its implementation and led to no enforcement taking place. Second, it does not specify a consistent method for protecting individuals' privacy. It is this clarity that is being sought by the coalition that recently formed to promote effective privacy protections for individuals using their health insurance.

Concerns about Minors

Washington has longstanding laws that allow minors to consent for their own health care in numerous situations. These laws occupy a central place in the state's insurance confidentiality regulation; they also represent a source of both concern and confusion. On the one hand, many of the groups that have been advocating for improved implementation of that regulation are anxious to make sure that the state's minor consent laws remain in place, unaffected by any future regulatory or legislative action. On the other hand, some insurers are not familiar with these laws and are uncertain about how to implement the insurance confidentiality regulation in a manner consistent with the minor consent laws.

Barriers

The main barrier repeatedly cited by Washington informants was the issue of deductibles and cost sharing. Insurance carriers want to be able to communicate with policyholders and financially responsible parties about their financial status under the policy. Policyholders are increasingly concerned about tracking their financial liabilities and obligations, as deductibles and other forms of cost sharing continue to increase. While health care providers who serve adolescents, young adults, and individuals who might be endangered by disclosures understand the need for transparency, they continue to hesitate to bill insurance lest confidentiality be breached via EOBs and other communications from insurers. Patients are largely unaware of the regulation's protections and their right to request restrictions on disclosure by their health insurers.

Insurance Market Characteristics

The Washington health insurance arena is characterized by several important elements. One of the largest insurers is Group Health, an integrated system that functions as both an insurance carrier and health care provider. Washington is home to several very large corporations—such as Microsoft, Boeing, and Amazon—whose health insurance plans are “self-insured” or “ERISA” plans, which are regulated by the federal Department of Labor and are not subject to state regulation by the Washington OIC. Washington also expanded Medicaid under the ACA, implemented a family planning waiver that makes family planning services available to even higher income levels than the Medicaid expansion, and has a relatively generous Medicaid program. These factors form part of the overall context in which the current regulation will be implemented or amended.

Recent Implementation Efforts

Although the Washington regulation has been part of the state's law for 15 years, and is fairly directive, interviews with several informants made clear both that many health care professionals were not familiar with its terms and that implementation of the regulation has been limited. A few years ago, concerns began surfacing about the loss of confidentiality associated with the filing and processing of health insurance claims. As a result, concerned health care provider and consumer advocacy groups came together to assess the nature of the problem and discuss potential remedies.

Some of the impetus for this advocacy effort came from school-based health centers (SBHCs), which were trying to boost revenues from Medicaid and commercial insurance for services provided to insured students. In doing so, SBHCs encountered the reality that although SBHCs customarily provided services on a confidential basis, that confidentiality could be, and sometimes was, breached by insurers' sending of EOBs and other communications to the parents who were the policyholders.

The loose coalition of providers and consumer advocacy groups that formed to address the issue of confidentiality breaches associated with health insurance claims included, in addition to SBHCs, women's health, children's mental health, domestic violence, and sexual assault groups as well as family planning providers. In 2013 they raised their concerns with the Office of the Insurance Commissioner (OIC). Meetings between the OIC and the providers and advocates took place, with insurance carriers at the table.

A varied picture of what was happening and what needed to happen emerged from the meetings and interactions among providers, consumer advocates, insurance carriers, and the OIC. Overall the goal of the providers and advocates was what one informant described as wanting to capture the regulation's protective intent.

Youth advocates and women's health care advocates were aware that young people were not accessing the care they needed, at least in part due to the risk of confidentiality breaches, but they had varied ideas about how to remedy this. One main goal was to improve the clarity of the regulation and create a uniform and meaningful enforcement mechanism.

Health insurers and carriers appeared to be responding to the regulation in different ways, with some believing that they were already doing an excellent job of protecting confidentiality and others uncertain about what specifically was required of them. Insurance carrier approaches included: focusing on use of an internet portal to manage communications; suppressing EOBs for at least some services; mailing EOBs addressed to the patient who received services, via email or in confidential envelopes; and shutting down communications, either immediately or within a few days, when a request to limit disclosure was made based on safety concerns. Carriers with dedicated privacy officers focusing on the issue were perceived as doing the best job, but overall a consistent approach seemed to be lacking.

The OIC was sympathetic to the concerns of the providers, the consumer advocates, and the insurance carriers. The OIC also was receptive to suggestions for best ways to clarify the regulation or improve its implementation. The interactions among providers, advocates, insurance carriers, and the OIC led to better understanding of the very real challenges that made implementation difficult.

Implementation Challenges

A broad range of implementation challenges were identified by Washington informants. These included a lack of awareness of the regulation among providers and patients and an associated lack of confidence in its effectiveness; some confusion about how insurers should interpret and implement the protections for minors; the absence of a specific enforcement mechanism; and concerns about transparency in relation to deductibles and cost sharing.

During the 15 years that the Washington regulation has been part of state law, few health care providers were actually aware of it and there was a general sense that few patients had made use of it. Although requests to limit disclosure based on safety concerns were at least occasionally received by insurance

carriers, no consistent mechanism was in place for informing patients and health care providers about the availability of the regulation's protections or the appropriate means for making use of them. Also, there was a perception that minors and young adults have little understanding of insurance in general, so that expecting them to understand the specific ways in which confidentiality can be breached and what they can do to prevent such breaches is a tall order for these age groups.

Several informants indicated that even if providers and patients were aware of the regulation and how to use it, many would be reluctant to rely on it unless they could be assured it was working effectively. Their lack of confidence seemed like it would pose an implementation challenge for the regulation in its current form and one that would have to be overcome for any future iteration of the regulation, requiring extensive training for providers and education of patients. Informants indicated that all of the patient groups entitled to protection—those whose safety would be jeopardized by disclosure, those using sensitive services, and minors who are authorized to consent for their own care—would need assurance of the regulation's effectiveness.

The regulation places an affirmative obligation on carriers and insurers to protect minors by refraining from disclosing information about services for which they can give their own consent without first obtaining their authorization to do so. However, the minor consent laws are contained in both statutes and court decisions and vary by age for different services. Insurance carriers were unfamiliar with these minor consent laws and the variations among them and, therefore, were uncertain about how to implement the protections required by the regulation for minors, particularly because the obligation was on the insurers rather than the minors themselves to trigger the protections. The OIC also viewed this as a challenge in improving clarity of the regulation and identifying an enforcement mechanism.

Many of the providers and advocates wanted greater clarity and enforcement to increase the effectiveness of the regulation. However, the OIC was limited in its ability to enforce it in current circumstances. First, none of the existing enforcement mechanisms available to the OIC in general—fines, compliance plans, refunds to policyholders—were either available or appropriate for at least two reasons: the unfairness of penalizing carriers and insurers when there was insufficient guidance and they did not know what to expect; and the absence of any significant number of complaints about violations received by the OIC from patients whose confidentiality had been compromised. The OIC is put in the difficult position: understanding there could be a problem but lacking examples of the regulation not being followed upon which to base enforcement actions. Also, without an investigative mechanism—such as something like a “secret shopper” test—there would be no comprehensive way of determining how insurers and carriers are handling requests to limit disclosures, if and when they receive them.

Ultimately, one of the major implementation challenges is represented by the need for transparency with respect to deductibles and cost sharing. Most informants acknowledged that policyholders have a legitimate need to know about any monetary figure that is being applied to their deductibles and the amount of cost sharing for which they are responsible. This is increasingly important to many policyholders as their financial obligations for copayments, coinsurance, and deductibles continue to grow. Parents may have particular concerns in this regard when they are both the policyholders of the health plans covering their adolescent or young adult children and the guarantors for the care those children receive from various providers.

The concern about confidentiality breaches related to EOBs and disclosure of information about deductibles and other cost sharing was also expressed as a major consideration on the part of many health care providers in Title X and other settings. This conflict can play out in a variety of specific ways: for example, if a patient agrees to an arrangement with a provider to make payments toward copayments or cost sharing that is owed, and then fails to make those payments, the bill could be sent to collections and a notice might go back to the policyholder from this insurer.

Insurers and carriers are keenly aware of the need for transparency. At the same time, they are uncertain about how to reconcile the legal obligation to keep policyholders informed about important financial information related to the status of their policies with the legal obligation to protect the confidentiality of patients' personal health information. They know they have to provide notices of any “denials” or “adverse benefit determinations” while they also have to comply with state and federal confidentiality laws.

Minors, Adults, & Alternative Confidentiality Approaches

Longstanding practice among health care providers in Washington state—including family planning sites, adolescent health providers, and school-based health centers—has been to protect the privacy of adolescents, young adults, and all patients seeking sensitive services. The ability to do so for minors has been grounded in the minor consent laws and, in the case of family planning providers, in Title X regulations and Medicaid. Several informants noted a widespread desire to ensure that any strategy to address the issue of confidentiality in insurance not undermine or limit existing minor consent laws. Family planning advocates, in particular, expressed a desire to protect the right minors currently have to consent for family planning services without an age limitation.

The differences in the ways the regulation treats adults and minors gave rise both to a desire to clarify it and to a concern that none of its protections be lost in doing so. The regulation in its current form allows anyone to request a limit on disclosure based on safety concerns; additionally, for individuals seeking sensitive services (which include those services minors are allowed to consent for), adults are entitled to restrict disclosure if they request it, but minors are entitled to automatic restriction, even though that is not current practice. Devising the best way to preserve at least this level of protection while clarifying the regulation so that it can be more easily understood by insurers and carriers, used by patients, and enforced by the OIC is an ongoing effort in Washington. One thorny issue to overcome is that some of the protections for minors are contained in court decisions rather than statute, while according to some informants interviewed the OIC seems to be more comfortable linking protections to statute than to case law.

The ongoing effort to address the insurance confidentiality issues is taking place against the backdrop of a health delivery environment in Washington that has been quite protective of confidentiality, particularly for sensitive services when they are sought by minors or young adults. These protections have taken varied forms, including customization of electronic health records and web portals, referral of patients to alternate sites, and enrolling patients in payment systems that support confidential service delivery.

For example, one large provider has designed its web portal so that all communications are driven through it and specific information is accessible only to adolescent patients themselves beginning at age 13. Another provider of care for adolescents and young adults has customized its electronic health record so that if a patient requests privacy, the record is coded as confidential in a way that is communicated to both the billing and information management departments to prevent breaches in those domains. These approaches represent good faith efforts to be creative and persistent in protecting confidentiality, but informants indicated that many challenges remain in how to operationalize them consistently.

For some minors and young adults with heightened confidentiality concerns and an absolute unwillingness to have information disclosed to their parents, providers have tried various strategies, such as assisting them in enrolling in Take Charge³⁹, Washington's family planning waiver, or establishing a payment arrangement, sometimes on a sliding fee scale, that lets them receive bills confidentially via e-mail or at an alternative address and pay out of pocket. Alternatively, if the sites where they seek services are unable to protect confidentiality or provide services without billing insurance, they sometimes refer those patients to another site that can. Some providers have continued to "write off" or absorb the costs of providing confidential care. Many of these strategies have been employed in the absence of effective implementation of the right to restrict disclosure regulation, but they have the disadvantages of placing a financial burden on the providers, while allowing carriers and insurers not to pay for the covered services for which they are receiving premiums.

Path Forward & Next Steps

As advocates and health care providers in Washington continue to work with carriers and the OIC to define a path forward, several aspects of the current situation stand out as significant. One important element is the widespread sense that a regulatory approach is preferable to a legislative strategy because of the likely lack of legislative receptiveness and the risk of undermining or limiting existing protections. Parents' rights legislation has recently been proposed and failed, leading many to believe there could be a risk

³⁹ Individuals under 18 and under are allowed to enroll in Take Charge for confidentiality reasons. Wash. Admin. Code § 182-532-790.

to a legislative proposal that could be perceived as expanding minor access to care. In this context the willingness of the Insurance Commissioner to take on the effort of updating the regulation is both fortunate and key.

The OIC has encouraged the group of health care providers and advocates to provide a clear idea of what an updated regulation might look like. One suggestion from the group is for the OIC to require carriers to take a standardized approach when individuals request restrictions on disclosure of their information or suppression of their EOBs. Part of the process of updating the regulation could be to expand its scope to include 18-25 year olds who are now so frequently insured on a parent's plan; the OIC has authority to do this without legislation pursuant to state legislation implementing the ACA. An additional consideration is that the current regulation is not reflective of the internet age; any updated version needs to account for electronic health records, web portals, and other means of electronic communication. Another highly desirable feature of an updated regulation from the perspective of providers and advocates would be extending the right to affirmative protection beyond minors to other groups so that the burden is on carriers and insurers rather than on patients.

A possible approach for OIC going forward would be to establish a clear hierarchy of information and expectations with respect to the content of communications, limiting the content of EOBs to essential information and specifying any exceptions to when EOBs must be sent. The OIC could be directive, identifying instructions that insurers and carriers have to give and tools for youth to understand and utilize rights, but would need to do so in a way that would not be challenged legislatively and would not engender excessive pushback from insurers and carriers, who are concerned about the cost and complexity of retooling their systems and about maintaining transparency for policyholders.

Two ultimate questions need to be addressed and resolved for an updated regulation to be crafted and implemented. One question is whether there is any way to craft an updated state regulation that would overcome providers' reluctance to bill insurance for patients with strong confidentiality concerns. The other is whether there is a way to reconcile the protection of confidentiality with the disclosure of essential information about claims denial and financial liability. If these questions can be resolved and an updated regulation crafted, an intensive dissemination effort would be required to reach the multiple entities and stakeholders affected by the regulation and to make its implementation effective. The OIC has a variety of options available for dissemination of information about the new rule via the media, the OIC website, and websites of other agencies and organizations.

Conclusion

The Washington regulation that creates a "right to limit disclosure of health information" represents a multi-faceted effort to protect the privacy of three key groups: individuals who might be jeopardized by disclosure of their information; those who are seeking a range of sensitive services; and minors who are authorized to consent for their own care. The regulation tracks the language of a key section of NAIC's Health Information Privacy Model Act, but Washington was the first and so far the only state to craft a regulation along these specific lines.

While Washington law has offered strong confidentiality protections for 15 years, implementation has lagged. If fully implemented, the protections appear to offer the potential for making important progress in addressing a problem – the loss of privacy of individuals insured by dependents – that has been known for a long time but not yet satisfactorily resolved in any state. The Washington Insurance Commissioner has played a key role both in crafting the original regulation and in working with a group stakeholders to develop an approach for clarifying the regulation and enhancing its enforcement. The Washington experience – characterized by a protective regulation, a group of active and committed stakeholders, and a receptive insurance regulator – offers some important lessons for advocates in other states.

Appendix A: List of Key Informants

The *Confidential & Covered* project staff would like to thank the many key informants that contributed to this work. All comments are a composite of interviews conducted, and comments should not be construed to represent the views of the organizations listed below.

Organization	Name	Title
Columbia Legal Services, Children and Youth Legal Services	Casey Trupin	(Former) Directing Attorney
Columbia Legal Services, Children and Youth Project	Mary A. Van Cleve	Interim Directing Attorney
Group Health	Gina Sucato, MD, MPH	Director, Adolescent Center
Legal Voice	Janet Chung	Legal & Legislative Counsel
Massachusetts Health Connector (former Senior Health Policy Advisor, Washington State Office of the Commissioner)	Emily Brice, JD	Senior Policy Advisor
Planned Parenthood Votes Northwest & Hawaii	Jennifer M. Allen	Director of Public Policy
Planned Parenthood Votes Northwest & Hawaii	Lisa Humes-Schulz	Public Policy Specialist
University of Washington/ Seattle Children's Hospital	David J. Breland, MD, MPH	Associate Professor of Pediatrics Clinical Director, Division of Adolescent Medicine
University of Washington/ Seattle Children's Hospital	Taraneh Shafii, MD, MPH	Division of Adolescent Medicine, Department of Pediatrics University of Washington School of Medicine Director, Inpatient Adolescent Medicine Services, Seattle Children's Hospital Director of Teen Health Services, Harborview Medical Center
University of Washington/ Seattle Children's Hospital	Leslie R. Walker, MD	Chief, Division of Adolescent Medicine Professor and Vice Chair, Faculty Affairs Department of Pediatrics
Washington School-Based Health Alliance	Paul Barry	Policy Committee Member
Washington School-Based Health Alliance	Mike Wiser	Board Member
Washington State	Lonnie Johns-Brown	Legislative Director, Office of the Insurance Commissioner
Washington State Department of Health	Cindy Harris	Family Planning Program Manager
Washington State Department of Health	Dorothy McBride, FNP, WHNP	Family Planning Program Public Health Nurse Consultant

Appendix B: The Washington Regulation

Wash. Admin. Code § 284-04-510. Right to limit disclosure of health information.

- (1) Notwithstanding other provisions of this chapter, a licensee shall limit disclosure of any information, including health information, about an individual who is the subject of the information if the individual clearly states in writing that disclosure to specified individuals of all or part of that information could jeopardize the safety of the individual. Disclosure of information under this subsection shall be limited consistent with the individual's request, such as a request for the licensee to not release any information to a spouse to prevent domestic violence.
- (2) Notwithstanding any insurance law requiring the disclosure of information, a licensee shall not disclose nonpublic personal health information concerning health services related to reproductive health, sexually transmitted diseases, chemical dependency and mental health, including mailing appointment notices, calling the home to confirm appointments, or mailing a bill or explanation of benefits to a policyholder or certificateholder, if the individual who is the subject of the information makes a written request. In addition, a licensee shall not require an adult individual to obtain the policyholder's or other covered person's authorization to receive health care services or to submit a claim.
- (3)(a) A licensee shall recognize the right of any minor who may obtain health care without the consent of a parent or legal guardian pursuant to state or federal law, to exclusively exercise rights granted under this section regarding health information; and
- (b) Shall not disclose any nonpublic personal health information related to any health care service to which the minor has lawfully consented, including mailing appointment notices, calling the home to confirm appointments, or mailing a bill or explanation of benefits to a policyholder or other covered person, without the express authorization of the minor. In addition, a licensee shall not require the minor to obtain the policyholder's or other covered person's authorization to receive health care services or to submit a claim as to health care which the minor may obtain without parental consent under state or federal law.
- (4) When requesting nondisclosure, the individual shall include in the request:
- (a) Their name and address;
 - (b) Description of the type of information that should not be disclosed;
 - (c) In the case of reproductive health information, the type of services subject to nondisclosure;
 - (d) The identity or description of the types of persons from whom information should be withheld;
 - (e) Information as to how payment will be made for any benefit cost sharing;
 - (f) A phone number or e-mail address where the individual may be reached if additional information or clarification is necessary to satisfy the request.

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About *Confidential & Covered*

Confidential & Covered is a multi-year research project designed to understand the factors that may make it difficult for Title X-funded family planning providers to seek reimbursement due to patient privacy concerns. Learn more at www.confidentialandcovered.com.

About NFPRHA

NFPRHA represents the broad spectrum of family planning administrators and clinicians serving the nation's low-income and uninsured. NFPRHA serves its members by providing advocacy, education, and training to those in the family planning and reproductive health care fields. For over 40 years, NFPRHA members have shared a commitment to providing high-quality, federally funded family planning care - making them a critical component of the nation's public health safety net.