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## New Medicaid Enrollees In Oregon Report Health Care Successes And Challenges

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### Abstract

Medicaid expansions will soon cover millions of new enrollees, but insurance alone may not ensure that they receive high-quality care. This study examines health care interactions and the health perceptions of an Oregon cohort three years after they gained Medicaid coverage. During in-depth qualitative interviews, 120 enrollees reported a wide range of interactions with the health care system. Forty percent of the new enrollees sought care infrequently because they were confused about coverage, faced access barriers, had bad interactions with providers, or felt that care was unnecessary. For the 60 percent who had multiple health care interactions, continuity and ease of the provider-patient relationship were critical to improved health. Some newly insured Medicaid enrollees recounted rapid improvements in health. However, most reported that gains came after months or years of working closely and systematically with a provider. Our findings suggest that improving communication with beneficiaries and increasing the availability of coordinated care across settings could reduce the barriers that new enrollees are likely to face.

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The Affordable Care Act is estimated to expand Medicaid coverage to an additional twelve million low-income adults in 2014.<sup>1</sup> With the expansion now under way, providers and health system leaders need information about how it will affect health care use and outcomes and how best to prepare to care for new enrollees. Results from recent studies suggest that insurance alone may not be sufficient to ensure that enrollees receive care that addresses their health needs.

Research on people who are currently insured has identified many steps between coverage and improved health, including timely, sustained, and coordinated interaction with health care providers.<sup>2,3</sup> Medicaid is sometimes criticized for giving its enrollees inadequate access to providers.<sup>4,5</sup> However, some evidence suggests that Medicaid provides access that is similar to or better than the access afforded by many private insurance policies purchased by low-income adults.<sup>6,7</sup>

As newly insured low-income populations engage with the health care system, it is vital to know whether there are systemic barriers to effective treatment that could be reduced to improve their outcomes. For this study we conducted 120 qualitative interviews among Oregon residents who had recently gained Medicaid coverage. Our purpose was to better understand how newly insured patients did—and did not—interact with the health care system. What did the newly insured do with their coverage, and how did it affect their health

and well-being? Understanding how enrollees' interactions shaped their health outcomes can provide policy makers with important information to improve the way Medicaid works for the coming wave of new enrollees.

## Study Data And Methods

### STUDY CONTEXT

In 2008 Oregon used a lottery to expand its Medicaid program for low-income adults, Oregon Health Plan Standard (OHP). The Oregon Health Insurance Experiment (OHIE) collected administrative, survey, and health screening data from those who signed up for the lottery.<sup>8-11</sup>

As a separate study, we conducted a series of qualitative interviews with a set of Oregonians from the newly insured group. These interviews do not use methodology based on the lottery to gauge the causal effect of insurance, and we do not provide causal estimates of the effect of insuring the uninsured. Rather, the intent of the interviews was to understand the factors associated with new enrollees' successful use of care, an understanding that can guide policy makers seeking to make Medicaid more effective in promoting access to care.

### SAMPLE SELECTION AND RECRUITMENT

Of the people who participated in our health screenings, 1,903 were selected by the lottery and enrolled in Medicaid. From this newly insured group, we drew a representative random sample of 173 to recruit for interviews. We excluded people who lived outside the Portland metropolitan area and those who did not have a phone number.

We recruited interviewees by letter and phone, and 121 (70 percent) agreed to participate. One interview was removed from the data set because the participant was intoxicated, leaving 120 interviews included in the analysis.

The interviews took place during March–September 2011 and were conducted in English or Spanish. The demographic characteristics of the interviewees (Exhibit 1) did not differ greatly from the population gaining Medicaid from which this sample was drawn.<sup>12</sup> However, previous work<sup>8</sup> suggests that the study population overall was slightly older and in somewhat worse health than low-income populations in the United States in general.

### INTERVIEWS

Our interviews were designed to explore in detail the health care experiences of people who had newly obtained Medicaid coverage; to examine how they made decisions about health care once they acquired coverage; and to allow participants to describe in their own words what effect, if any, Medicaid had on their lives.

Trained interviewers employed several tools to elicit each participant's history of health, care experiences, and relevant life events from their coverage in 2008 to the time of the interview. Interviewers prepared by reviewing a report of the participant's existing data, including insurance history, self-reported physical and mental health, use of health care, and financial information related to medical costs and debt.

After obtaining informed consent from the interviewees, interviewers created a timeline on which participants indicated their health care history over the past two to three years. Visual aids and context can improve recall.<sup>13</sup> Thus, participants were asked to place "marker events"—important events such as a marriage in the family—on the timeline before adding health events. The timeline helped establish participants' health care history and tracked

which health events occurred during periods of coverage and which occurred while participants were uninsured.

During and after the creation of the timeline, interviewers asked participants to share their experiences with the health care system. The interviews were unstructured. However, interviewers were trained to ask about topics of interest such as care experiences, management of chronic conditions, and the ways in which participants' health affected their day-to-day lives.

Interviewers completed a post-interview summary, to highlight key events in each participant's experience and any details that might be lost in transcription, such as extreme emotion. Interviews took place at a clinic or in the participant's home, and they lasted an average of sixty minutes.

## ANALYSIS

The interviews were professionally transcribed and uploaded into the qualitative analysis software Atlas.ti, version 7. The initial list of codes for particular interview responses was developed from a pilot focus group. Using this coding dictionary, each transcript was coded thematically by multiple independent members of the research team, and a trained qualitative analyst adjudicated any differences between the members' codes.

In weekly meetings, coders discussed emerging themes and developed new codes to capture them. Participating in these meetings also ensured that coders had a common understanding of the coding dictionary and the definitions it contained.

## NARRATIVE SUMMARIES

After the data collection and coding were complete, the study team used the coded transcripts, timelines, and post-interview reports to assess participants' health and health care in the years leading up to and following their obtaining coverage through Medicaid. We grouped people by shared experiences and subgroup characteristics. The categories were designed to be mutually exclusive; they represent the final end point of this analysis.

## LIMITATIONS

Our research had some important limitations. Qualitative interviews offer the potential to contextualize findings from traditional surveys and to explore the mechanisms behind those findings. However, by their nature, they cannot be directly compared to each other. The involved role that the interviewer plays in an unstructured or semistructured interview by probing for details and asking follow-up questions can elicit responses that are rich in data, but the same role creates the potential for subjectivity because the interviewer-interviewee dyad shapes each interview. Nor does this approach allow us to make causal inferences about the effects of insuring the uninsured. Therefore, we see qualitative interviews as a methodological complement to existing quantitative analysis.<sup>8-11</sup>

There are also specific limitations to generalizing our study results to other populations or broader Medicaid expansions such as those under the Affordable Care Act. Oregon's health care delivery system is similar to that of other states, and our study population is similar in many ways to low-income adults who are newly eligible for Medicaid across the United States. Nonetheless, there are several important differences: The population of Oregon has a larger share of whites than do the populations of many other states. Oregon also has a high rate of participation in Medicaid managed care and requires some enrollees to pay a small monthly premium (up to \$20, depending on income), a form of cost sharing not used in all Medicaid programs.

Additionally, there is a great deal of variation in structure and utilization across state Medicaid programs.<sup>14</sup> States with larger expansions may experience additional problems with access related to providers' capacity to accept new patients. Furthermore, as of December 11, 2013, twenty-three states had indicated that they would not expand Medicaid under the Affordable Care Act at all.<sup>15</sup>

The effects seen in Oregon may also be idiosyncratic because of the lottery mechanism for expansion. Enrollment was voluntary, and individuals were not subject to a mandate. Oregon has also recently implemented innovations in its Medicaid program aimed at improving the coordination of care.

Finally, as discussed below, our findings might reflect issues related to the quality of care that participants received and their health literacy that are present in the health care system and consumer population at large, and that might not be specifically related to the Medicaid experience.<sup>16</sup> These factors, along with the inherently individual perspectives gleaned from in-depth interviews, suggest that our results should be more broadly generalized with caution.

## Study Results

Our analysis focused on how the newly insured interviewees responded to Medicaid coverage, how they used health care, and what impact that use had on their health experiences. The themes we observed fell into two overall groups: the experiences of people who used little or no health care, and the experiences of those who had multiple interactions with the health care system (Exhibit 2). We identified subgroups within both groups.

### GROUP 1: MINIMAL INTERACTIONS WITH HEALTH CARE

Forty percent of the newly insured enrollees whom we interviewed did not use their coverage much, if at all. These individuals (called *low users*) sought care only occasionally, and when they did, it was primarily for acute needs. Low users gave one of the following four main reasons for not using their Medicaid benefits very often.

► **PERCEPTION OF GOOD HEALTH**—About one-third of the low users described making few, if any, attempts to access care because they perceived themselves to be healthy. Some of these participants—many of them males under age forty—mentioned few health concerns, and most of them probably were indeed relatively healthy.

Others, however, described themselves as healthy but also reported health concerns or diagnoses, which suggests that they could have benefited from health care services. These participants often expressed stoicism in the face of what they considered to be minor health problems.

Ellie (all names of interviewees are pseudonyms), a fifty-one-year-old woman, received OHP coverage in 2008 and then lost it in 2010 when she was unable to pay the premiums. Despite reporting a diagnosis of chronic obstructive pulmonary disease and having Medicaid, Ellie said she “wasn’t sick”: “I didn’t really use it [OHP]. I didn’t really get sick that much when I had that. I think I only used it like once. Oh yeah, I had to use it once when I got an abscessed tooth.... I remember it was like a little bit right after I got my insurance because I remember I kept saying, thank God I have insurance.”

Weeks after losing her insurance, Ellie spent four days in the hospital with kidney stones. She had two other ED visits and hospital stays later that year, which left her more than \$20,000 in debt.

Several low users also expressed the belief that more people would have access to health care if fewer people overused it. Lee, a twenty-eight-year-old man, described himself as being “pretty happy and surprised” when he learned that he had won Medicaid. Lee did not use his insurance for seventeen months, until he tore his anterior cruciate ligament—one of the four major ligaments in the knee—while playing softball.

At that point, he went to the ED and was referred to a physician who recommended knee surgery. However, Lee decided to treat his injury through physical therapy exercises at home instead. Lee claimed that he did not want to “waste” medical care and that he used it “only when I need it.” He did not classify his knee injury as a health problem, saying: “Well, [my health] is not so bad that I need [insurance]. . . . But it’s nice to have, of course, when I need [it] or have a problem.”

Such concerns were not restricted to the relatively healthy or the low users. In fact, 9 of the 120 interviewees discussed concerns about the responsible stewardship of public resources when making decisions about use of care.

► **CONFUSION ABOUT COVERAGE**—Thirty percent of the low users reported being confused about their coverage. Some avoided care because they were unsure what costs they might be responsible for, and they did not want to receive a bill that they would have trouble paying. Others assumed that what they needed would not be covered, so they did not get care. A few did not even know that they were covered by OHP.

One common story was that upon receiving their Medicaid card in the mail, many beneficiaries immediately tried to access dental services. OHP covers only emergency dental services, and dental office receptionists typically informed new enrollees that OHP was “emergency only” coverage. The enrollees often misinterpreted this dental care restriction to mean that the only place they could receive any health care was in the ED—contributing to common confusion about the care covered by OHP.

Jason, a forty-year-old man with a chronic knee problem, read in the paperwork that he received from OHP that it would only cover emergency—not regular—dental care. This information led him to “assume that it would be the same way” if he tried to get care for his knee. He decided not to try to use his coverage: “It was the basic health plan—basically useless because they won’t do anything I need unless I’m dying or [it’s a question of] picking me up off the street.”

► **DISSATISFACTION WITH CARE**—About one-fifth of the low users attempted to get care but had a poor experience that deterred them from further use of their coverage. They reported that physicians were dismissive of them or did not follow up as promised. Many of these interviewees did not bother to reapply for Medicaid at the six-month window for renewal.

John, a forty-five-year-old man, did reapply in spite of a bad experience. He had been uninsured for ten years prior to gaining OHP. Since he had a physically demanding job, he scheduled a physical right away. He described his visit as “rushed” and the communication with the doctor as poor, and he had no desire to return: “It was a nightmare when they were taking blood, and then they lost my blood and then they wanted me to come back in to take more blood and stab me some more times. . . . First time I’ve been there, last time I’ve been there. I’ve never been back, I’ve never used the Oregon Health Plan since, but I keep [enrolling so that] just in case something happens, I’ll have coverage.”

► **ACCESS BARRIERS**—Fifteen percent of the low users experienced access barriers. These interviewees reported not being able to find a doctor who accepted the plan, cited long waits for appointments, or said that they had difficulty finding transportation to doctors who would see them. A few said that stressful life circumstances prevented them from using the insurance, and untreated mental health issues might have prevented some people from doing so.

Lisa, forty-six, wanted to use her coverage to get care for her diabetes, but she had trouble finding a doctor close by: “I had a terrible time finding doctors that would take OHP that I could get to.... I never actually got in to see anybody. The only person that would take... OHP was [name deleted], and at the time, I couldn’t get there. And another guy in [name deleted] that I could have got [to] couldn’t see me until, like, four months down the road, and by then, I didn’t have OHP anymore. I was really excited I got picked, but then I couldn’t afford the premiums and then it was over.”

Most low users did not describe significant acute illnesses that were going untreated. However, some reported chronic physical and mental health conditions that were not being managed. The majority of low users who had difficulty using OHP did not maintain their coverage. Instead, they concluded that the program was not worth the financial burden of premiums or the hassle of renewal.

## GROUP 2: REGULAR OR FREQUENT INTERACTIONS WITH HEALTH CARE

The remaining 60 percent of respondents (called *regular users*) used their insurance more than a time or two but reported varying degrees of success.

► **REGULAR PREVENTIVE CARE AND MINOR NEEDS**—About one-tenth of the regular users took advantage of access to preventive care and also received treatment for occasional illnesses or injuries. These users were generally aware of recommended preventive care and valued the investment in their future health that such care provided.

For instance, Simone, a thirty-year-old working mother of four, reported no major health concerns except for mild depression. She said that she felt a need to be healthy in order to be a good mother, and therefore she saw an OB-GYN regularly: “I do see my gynecologist once a year because I think that’s really important. There’s history of genetic problems, and I don’t want to fall through the cracks, so to speak.”

► **IMMEDIATE HEALTH IMPROVEMENT**—Another tenth of the regular users described an immediate transformation in their health after they received insurance. These people all had serious health problems that could be improved quickly, such as by getting back on a previously effective medication or having an operation that had been postponed because of lack of coverage. The members of this group saw their new insurance coverage as directly related to an improvement in their quality of life.

Gloria, a forty-three-year-old woman, had such trouble sleeping that she could not maintain her normal activities. She was severely depressed and at times contemplated suicide. After obtaining OHP coverage, she saw a doctor who diagnosed her with sleep apnea and prescribed a continuous positive airway pressure (CPAP) machine. After her sleep improved, Gloria said that she decided to take better care of herself and to improve her diet. She lost fifty pounds, had annual medical exams, and got her diabetes and blood pressure under control.

Gloria reported that she was no longer depressed. She felt that “everything is so much better now,” and she thought that she “would have died without insurance.” She said: “[I couldn’t



do] anything, just walking around the block. My kids would have things after school, and I wasn't able to walk to the school. Things of that nature, being at the park, just taking a walk with them, I just couldn't do it and I wanted to do it. And even cleaning my home, I just couldn't do it. And now with the CPAP machine—I was like buzzing.”

Jessica, a thirty-year-old woman, had a history of serious depression, which had been controlled by medication for more than ten years. When she went without medication during a period of un-insurance, her depression affected everything from her close relationships to her motivation to do household tasks. After obtaining coverage, Jessica was able to get the medication she needed, and she made a full recovery. Without medication, she said, her situation could have been very different: “I could be dead.”

► **MIXED SUCCESS**—Forty-four percent of regular users continued to experience challenges. Some interviewees were able to get partial treatment— such as prescriptions for chronic conditions—but had serious needs remaining. Some reported feeling misunderstood by physicians or being unable to build a relationship with a primary care provider. Others struggled with very poor health that continued to deteriorate even with regular treatment.

For example, Vera, a fifty-six-year-old woman, reported experiencing debilitating headaches daily, and she also suffered from asthma, lupus, rheumatoid arthritis, and diverticulosis. She had poor reactions to medications, especially those prescribed for pain.

Because she had serious memory problems and feared overdosing by mistake, Vera was on a pain contract that required her primary care provider to approve any pain medication prescription. She was frustrated that because of the pain contract, other providers sometimes viewed her as trying to obtain drugs, and she was not satisfied with the care at her primary care clinic because it used a system of revolving resident physicians.

Although Vera regularly used health care, she did not find that most of it met her needs. She had recently required emergency surgery to treat hemorrhaging from diverticulosis, and she believed that this condition would have been caught much earlier if she had had a regular doctor.

Vera's experience was marked with dissatisfaction and ongoing health problems. Nonetheless, she said that coverage had improved some aspects of her health and that she continued to get care: “My rheumatoid arthritis doctor, [name deleted]—she is the best. I love her to death. She helps with my arthritis.”

► **SUCCESS OVER TIME**—Finally, 39 percent of regular users reported that their health had improved with insurance, but that it had taken time. They experienced incremental benefits once they found and built a relationship with the right doctor.

Often these users' problems were addressed in order of severity or impairment. Lifestyle changes, such as modifications to diet and exercise, were not discussed until their acute symptoms had improved. Many of the positive changes that they reported were relatively recent.

One such user, Forrest, a thirty-three-year-old man, had suffered debilitating back pain from a car accident: He had walked with a cane and felt that he would never recover from the injury. It took almost two years after he received OHP coverage before his pain was under control and his physical condition improved enough so that he could walk without a cane.

Since then, Forrest found employment, lost eighty pounds, and gave up fast food. He said: “And how has [insurance] affected my life? It's made it so that I can recover to where I'm at

now. I was walking with a cane [until 2010]. No one would hire me walking with a cane.... Being able to walk all day long at work—I'm a gas [station] attendant and that's all I do, so basically, that exercise from work made it so that I can lose all the weight that I have."

► **STABLE COVERAGE IN GROUP 2**—Of the regular users who reported that their health had improved as a result of care obtained after they gained coverage (the users in the subgroups with immediate health improvement and success over time), 83 percent maintained stable insurance coverage. Of the regular users in the subgroup reporting mixed success, only 30 percent maintained coverage.

The interviews suggested that the length of time people were insured might have been an important difference between those who reported mixed success and those who had success over time. However, discerning this relationship was complicated by the fact that many who were dissatisfied with care decided not to reenroll.

## Discussion

These qualitative interviews illuminate the types of experiences of those newly covered by Medicaid: Many people who felt healthier described subsequent improvements beyond their health, such as in their ability to parent, plan for the future, or participate in the workforce. The interviews also provide insights into what worked well and what did not for the newly insured. Thus, our results can give policy makers information about making insurance more effective in promoting access to care and improving health.

Both health needs and initial experiences with the health care system affected how people used their Medicaid coverage. The different groups we identified faced different barriers to navigating the health care system.

For the relatively healthy enrollees, the most frequently identified barriers to care were not the usual suspects—difficulty in finding a provider or getting a timely appointment. Instead, the barriers reflected the enrollees' inexperience with coverage and with available recommended health care, such as routine screenings.

Many people were unsure what they would be financially liable for if they tried to use care, and many believed that health care was to be used only in dire circumstances. This is consistent with previous research suggesting that people are confused about benefits: Privately insured people had a basic understanding of what their insurance would pay for, but they underestimated the coverage of some services, such as mental health, and overestimated the coverage of others, including long-term care.<sup>17</sup> New Medicaid enrollees in 2014 may have had less exposure to coverage than is usual, which suggests the importance of educating them about their coverage and costs.

In addition, many younger and healthier people in our study were unaware of the potential health benefits of routine screenings. This was particularly the case for men, since women had often been exposed to the benefits of screenings through family planning services. The interviews support previous evidence that younger men are less likely than others to establish a relationship with a primary care provider or use nonurgent care.<sup>18</sup> Designing program materials and structuring interactions with enrollees that are sensitive to enrollees' concerns about the appropriate use of care and responsible stewardship of resources can help avoid suppressing the use of beneficial services.

For many of our interviewees with serious health needs, acquiring Medicaid was just the first step in a much longer journey toward health. Some people experienced immediate benefits through surgery or medication. However, the management of enrollees' complex



health conditions was often a complicated process that increased people's exposure—and, subsequently, vulnerability—to known problems with the health care system such as rushed appointments, lack of coordination, and poor follow-up. Indeed, problems in accessing high-quality care experienced by interviewees are likely not unique to Medicaid enrollees.<sup>19,20</sup>

Our interviewees valued respect, clear communication, continuity of care, and good follow-through—qualities that were directly linked to how they perceived their health outcomes. Interventions designed to foster good relationships between physicians and their patients, such as efforts to implement medical homes or to improve the coordination of care, could increase the impact of expansion on health.

It took time for people who were newly insured to establish a partnership with a provider and time for them—with the provider's help—to develop a plan for improving their health. Conditions causing the most immediate impairments were usually addressed first, with interviewees more likely to describe experiences with “well-ness” efforts—such as trying to lose weight, increase physical activity, or quit smoking—only after their more immediate care needs were met. Continuity of coverage and care was thus particularly important in addressing longer-term health needs.

## Conclusion

People have had very different health care experiences and health outcomes after gaining Medicaid coverage. Through in-depth interviews with a newly covered Medicaid population in Oregon, we found that approximately 40 percent of those who gained Medicaid coverage did not interact very much with the health care system: Their use of the system was hampered by confusion about coverage, access barriers, bad interactions with providers, or the sense that health care was unnecessary if they felt healthy (despite the availability of recommended preventive care).

For the 60 percent of our study population who had multiple interactions with the health system, continuity and ease of the provider-patient relationship were critical. These patients' experiences with health care were strongly influenced by how providers made them feel.

Many of our interviewees suffered from very poor health and difficult financial and social circumstances. Their interactions with multiple providers of varying quality led to mixed success in terms of self-reported health improvements. Many people told stories of significant and rapid improvements in health. However, gains more commonly came only after months or years of working closely with a provider to tackle one problem at a time.

Our findings suggest multiple opportunities to improve the way Medicaid works for the newly enrolled in conjunction with the Medicaid expansion now under way. New enrollees could benefit from better information that explains their coverage and how to access different types of care. Fostering better communication between providers and enrollees as well as better coordination of care and follow-up throughout the system could improve enrollees' health care experiences, health outcomes, and the value of the care delivered through Medicaid.

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**Exhibit 1**

## Demographic Characteristics Of 120 Newly Insured Oregonians, Interviewed March–September 2011

Characteristic	Number	Percent
<b>Sex</b>		
Male	55	46
Female	65	54
<b>Race and ethnicity</b>		
White, non-Hispanic	88	73
Black, non-Hispanic	13	11
Hispanic	3	3
Other, non-Hispanic	3	3
Multiple, non-Hispanic	13	11
<b>Percent of poverty</b>		
19–49	40	34
50–74	16	13
75–99	18	15
100–149	22	19
150 and above	23	19
<b>Education</b>		
Less than high school	16	13
High school diploma, no college	53	44
High school diploma, some college	37	31
At least a bachelor's degree	14	12
<b>Age (years)</b>		
20–29	23	19
30–39	32	27
40–49	30	25
50–65	35	29

**SOURCE** Authors' analysis of survey data.

**NOTES** Respondents' ages were updated at the time of the qualitative interview to reflect the passage of time from the original collection of data by the Oregon Health Insurance Experiment. Financial information needed to classify the federal poverty level was missing for one study participant. Percentages may not sum to 100 because of rounding.

**Exhibit 2**

## Use Of Coverage By 120 Newly Insured Oregonians, Interviewed March–September 2011

<b>Group 1: few interactions</b>		<b>Group 2: more regular interactions</b>	
<b>Subgroup</b>	<b>Percent</b>	<b>Subgroup</b>	<b>Percent</b>
1A. Perceived themselves to be in good health	34	2A. Used care for preventive care and minor needs	8
1B. Confused about coverage	30	2B. Used coverage with immediate benefit	10
1C. Dissatisfied with care received	21	2C. Used coverage for complex needs with mixed success	44
1D. Experienced access barriers	15	2D. Health improvements accrued over time	39

**SOURCE** Authors' analysis of qualitative interviews.

**NOTES** Group 1 interviewees ( $n = 48$ ) had few, if any, interactions with health care. Group 2 ( $n = 72$ ) had regular or frequent interactions with health care. Percentages may not sum to 100 because of rounding.