My name is Wren Ronan; I am the Injection drug user Health Specialist and Hepatitis C research Coordinator at Outside In, a Federally Qualified health clinic and nonprofit working with the most marginalized communities in Portland Oregon. Over the last year, I have had to watch people that I care about and work closely with slowly deteriorate and eventually pass away from a curable disease. I additionally have had to tell many young people that they are positive for a disease that they will not be able to receive treatment for because of OHA regulations regarding sobriety criteria for their illness. These regulations are not evidence based and are not medically relevant to the medications that are considered the gold standard in care, direct acting antivirals. We have moved passed the days of Interferon where only the most ill people should or could receive treatment. A simple eight-week treatment in most cases will cure almost 100% of cases no matter the fibrosis level, no matter the genotype. These drugs are able to prevent liver scarring, cancer and the morality of countless individuals who simply are struggling.

HCV is claiming more lives than any other infectious disease in the United States, more than HIV, tuberculosis and pneumococcal disease combined. Primarily new cases are found in communities of people who inject drugs; the people that OHA refuses to treat. Our screening measures, interventions and treatment plans in the state of Oregon are killing people. The state of Oregon is in fact killing more people than any other state in this country because of our in ability identify and track the problem.

There is an opportunity to slash health inequality and to put the mission of this committee to work. The intentions of these Health Quality Metrics are "making quality care accessible, eliminating health disparities, and controlling costs for the populations that they serve." I believe changing the data collection and CCO incentives could lead to increased screening, intervention and treatment of this curable disease. Appropriate attention and allocations of funds can slow and even halt the growth of this epidemic. It requires action and attention at the state level to remedy this ever-growing issue. There is now substantial amount of data supporting the fact that drug users, including those experiencing houslessness, have the ability to adhere to treatment plans and establish SVR-12, which is when an individual has cleared the virus and continued to practice safer injection strategies to prevent reinfection. We should be encouraging our medical establishment to address the major public health crises not ignore it, especially in the case of drug-users, which is and will continue to be the community most affected. How is the state to map a path forward without the 95,000 people living with HCV, many of whom will potentially experience irreversible health complication without treatment?

These treatments are feasible for all living within our community. The long-term health outcomes for thousands of people will improve. The long-term fiscal benefits for early intervention, treatment and slowing the spread of the virus are straightforward. This committee can make a difference for the future of Oregon.

Written testimony of Mark O. Loveless, MD, MHA, FACP Clinical Associate Professor, OHSU/PSU School of Public Health Steering Committee Member, Oregon Hepatitis Action Plan

Health Plan Quality Metrics Committee March 8, 2018

I strongly support the inclusion of a Hepatitis C screening quality metric as a critical component in the efforts to eliminate HCV infection in Oregon.

Hepatitis C is currently the most deadly curable infectious disease in Oregon. It accounts for more deaths per year than all other reportable infectious disease combined. There are medications available that will cure over 95% of those HCV infected patients who will take one pill, once a day for 12 weeks. And yet, Oregon ranks near the bottom of the states in medical outcomes related to Hepatitis C. This disease is an indicator of persistent health care disparities that the OHA has made a commitment to address. HCV is also a co-morbidity of the opioid epidemic.

You can't change what you don't measure.

This is a fundamental truth of any serious quality improvement process. In addition, what a system measures is also a clear, unambiguous indicator of what that system believes is important.

Hepatitis C is very important and there are only three metrics that are essential in assessing quality of care for persons with Hepatitis C. They are:

- 1. The proportion of persons identified as having elevated risk for HCV who have received a screening serologic test and know the result.
- 2. The proportion of HCV infected person who are receiving ongoing medical care.
- 3. The proportion of HCV positive persons who are treated for HCV and cured.

The metric that is most important is #1. It identifies the baseline denominator for the next two measures while providing the ongoing data that documents the epidemiologic assessment this disease of public health significance.

This is why a screening metric for HCV infection is so fundamentally important; it is literally the least we should do.

Mark Arel 3/3/13



March 8, 2018

Oregon Health Plan Quality Metrics Committee Wilsonville, Oregon

Dear Committee Members:

We write to ask you to approve the inclusion of three survey data collection instruments on your menu of measures to ensure that health plans, particularly Medicaid, can monitor plan quality and implement value-based purchasing for one of Oregon's most vulnerable populations.

The Maternal and Child Health Bureau defines Children and Youth with Special Health Professor and Chair Care Needs (CYSHCN) as those "who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition, and who also require health and related services of a type or amount beyond that required by children generally."¹ The most recent state estimates, from 2016, show that nearly 1 in 5 Oregon children under 18 years of age has a special health care need.² Of those, more than one-third have public insurance.³ Additionally, children with medical complexity, or CYSHCN with especially high needs, represented 6% of the pediatric population yet accounted for 34% of health care spending for children insured by Medicaid in 2011.⁴ In Oregon counties, the percent of children with complex chronic conditions insured by Medicaid ranges from a low of 5% to a high 11%.⁵ Medicaid is an essential resource for families of these children, and if Oregon health plans use data to identify high cost or high utilization members, children and youth with special health care needs will be among those identified.

Children are not small adults. CYSHCN experience a broad range of fundamentally different diagnoses, in contrast to adults, whose chronic diseases tend to cluster in a smaller number of specific diagnoses (e.g., cancer, diabetes, and heart disease/stroke).⁶ Further, the systems that support pediatric patients, and their families, must be coordinated and family-centered to support the unique care that these children requires. Consequently, measures of adult chronic disease cannot be applied to the pediatric population. Thus, we request that your committee add the following to its menu of metric options:

- 1. CAHPS Children with Chronic Conditions (CCC) Supplement⁷ CYSHCN can be identified from the screener included in this instrument, which Oregon currently collects. From this survey instrument, we particularly support the
 - a. Coordination of Care, NQF Measure 0719 (Oregon collects).

⁵ Oregon Health Authority. (2017). Review of specific data used to operationalize global indicator of health complexity based on flags of medical and social complexity. Presentation at the Stakeholder meeting to inform the Oregon Health Authority-Health Analytics efforts to identify children with indications of health complexity using system-level data, Portland, OR.

⁶ Bachman, S.S., Comeau, M., & Long, T.F. (2017). Statement of the problem: Health reform, value-based purchasing, alternative payment strategies, and children and youth with special health care needs. Pediatrics, 139(s2), S89-S98.

⁷ https://www.ahrq.gov/cahps/surveys-guidance/item-sets/children-chronic/index.html

OHSU Doembecher Children's Hospital

School of Medicine **Department of Pediatrics**

tel 503-494-4265 fax 503-494-7447

Dana A. Braner MD, FAAP, FCCM Credit Unions for Kids Chair Department of Pediatrics Physician-in-Chief Doernbecher Children's Hospital branerd@ohsu.edu www.ohsu.edu

Mail code: CDRCP3 CDRC Administration 707 S.W. Gaines Street Portland, OR 97239



DOERNBECHER CHILDREN'S Hospital

¹ McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P.W., et al. (1998). A new definition of children with special health care needs. Pediatrics, 102(1), 137-140.

² 18.5% or 158,652 children. http://childhealthdata.org/browse/survey/results?g=4562&r=39

³ http://childhealthdata.org/browse/survey/results?q=4828&r=39

⁴ Berry, J.G., Hall, M., Neff, J., Goodman, D., Cohen, E., Agrawal, R., Kuo, D., & Feudtner, C. (2014). Children with medical complexity and Medicaid: Spending and cost savings. Health Affairs, 33(12, 2199-2206.

- b. Access to specialized services (i) needed treatment or counseling, (ii) special equipment, and (iii) therapy (Oregon collects).⁸
- Pediatric Integrated Care Survey (PICS)⁹ This validated instrument presents a number of measurement options that, importantly, characterize the integration of care across providers that is essential for this pediatric population.
- Family Experiences with Coordination of Care (FECC) Survey¹⁰ This validated instrument contains eight National Quality Forum (NQF) endorsed measures.
- 4. NQF Measure 1340, Children with Special Health Care Needs Who Receive Services Needed for Transition to Adult Health Care¹¹ – CYSHCN who transition to adult health care without specific transition services are more likely to have poor outcomes compared to their peers, including higher hospitalization rates.¹² Currently, fewer than 16% of Oregon CYSHCN ages 12 through 17 years receive services necessary to transition to adult health care.¹³

Children and youth with special health care needs grow into adults with special health care needs, and our state needs to know that its systems are working for them and their families.

We thank you for your consideration of our requests and your efforts to improve the quality of health care for Oregon's children.

Sincerely,

Dana A. Braner, MD, FAAP, FCCM Chair, Department of Pediatrics OHSU School of Medicine

Professor of Pediatrics Division of General Pediatrics OHSU School of Medicine

Benjamin D. Hoffman, MD, FAAP Professor of Pediatrics Division of General Pediatrics OHSU School of Medicine

Director, Oregon Center for Children and Youth with Special Health Care Needs

Medical Director, Tom Sargent Safety Center, Doernbecher Children's Hospital

⁹ Ziniel, S.I., Rosenberg, H.N., Bach, A.M., Singer, S.J., & Antonelli, R.C. (2016). Validation of a parent-reported experience measure of integrated care. *Pediatrics, 138*(6), http://pediatrics.aappublications.org/content/pediatrics/early/2016/11/28/peds.2016-0676.full.pdf.

- ¹⁰ https://www.ahrg.gov/sites/default/files/wysiwyg/policymakers/chipra/factsheets/chipra_15-p002-ef.pdf
- 11 http://www.qualityforum.org/

 ¹² White, P., McManus, M., McAllister, J., & Cooley, C. (2012). A primary care quality improvement approach to health care transition. *Pediatric Annals*, 41(5), e1-e7. <u>http://www.gottransition.org/resourceGet.cfm?id=142</u> "NQF Measure Information" Inclusion of this measure also aligns with Healthy People 2020 goals: <u>https://www.healthypeople.gov/node/3501/objectives#4153</u>
¹³ http://childhealthdata.org/browse/survey/results?a=4557&r=39

⁸ http://www.oregon.gov/oha/HPA/ANALYTICS/CAHPS%20documents/Banner%20Books%20101.pdf

Oregon Hepatitis Access Collaborative

January 22, 2018

Pat Allen Director, Oregon Health Authority 500 Summer St. NE, E20 Salem, OR 97301-1097

Dear Mr. Allen,

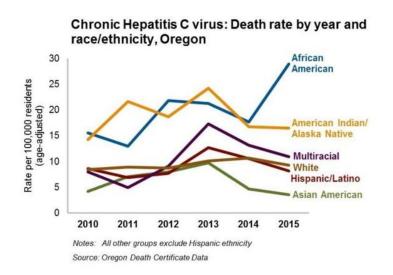
We are writing to inquire about the status of creating a new Coordinated Care Organization (CCO) quality measure for the testing and treatment of viral hepatitis C (HCV) among Medicaid recipients. Advocates including clinicians, patients and public health experts agree that the creation of an HCV quality measure is critical to our ability to accurately assess the scope of HCV, and provide treatment.

The case for creating an HCV quality measure is keeping with the intent of the 2017 Memorandum of Understanding between the Oregon Health Authority (OHA) and the Oregon Law Center (OLC) and the Center for Health law and Policy Innovation. Paragraphs 5 of the agreement address data collection and reporting between the OHA and OLC, paragraph 7 states:

"[OHA] will continue to take reasonable steps to ensure CCO's comply with the contractual and legal obligations to avoid impropriate barriers to treatment, including but not limited to, monitoring CCO denials of direct acting antiviral (DAA) treatment upon completion of the denial data collection system described in paragraph 5 above;"

According to the OHA data, Oregon has the has highest mortality rate in the nationally and the third highest prevalence of HCV of all 50 states. Ethnic disparities alone should qualify this as a statewide quality measure for all Medicaid and all CCO members. As illustrated in the graph below, despite having a majority White population (87%), HCV disproportionately impacts African American (2.1)% and Native/American Indian people (2.2)%.

And yet, despite OHA promises to address and reduce inequities and racial disparities among all OHP members, people of color are living with acute HCV infection at rates ranging from 1.7 times higher for African American and 1.8 for Native/American Indian people. In both of these communities, people with HCV are twice as likely to die from HCV infection compare to White people.



With the dramatic rise in opioid use comes an increase in HCV infections. This a fact and lesson we know very well. We have already seen this situation play out in Ohio, and other states struggling to battle addiction. We know the public health implications well, and the price of ignoring the crisis.

It is critical for public health to be measuring and reporting HCV data on a regular basis. The United States Centers for Disease Control and Prevention is estimating increases in new HCV infection in excess of 300%.

In 2015, the death rate from HCV (500) was almost equal to motor vehicles (254) and opioids (263) COMBINED. What is OHA doing to protect its citizens and making sure all those that need treatment are being diagnosed and referred to care?

The time to act is now, while we still have the chance.

Sincerely,

MULA

Lorren Sandt Executive Director Caring Ambassadors Program Lorren@caringambassadors.org

Mark Loveless, Clinical Associate Professor of Medicine, OHSU/PSU School of Public Health. BJ Cavnor, Executive Director, 1in 4 Chronic Health Jacki Gethner, Executive Director, Women of a Certain Age Steve Nemirow, Cured patient Advocate Rob Shinney, Cured Patient Advocate

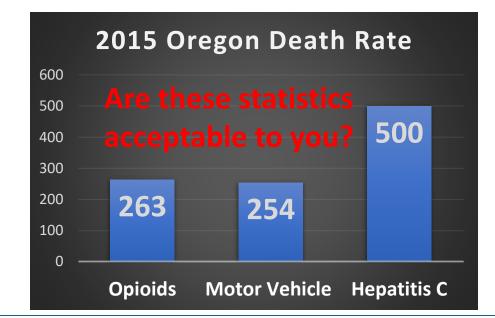


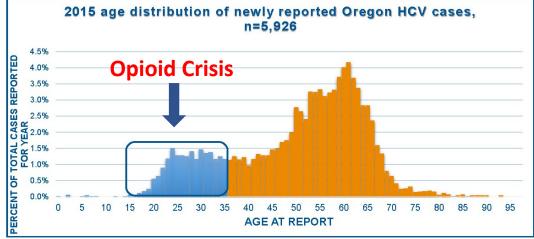
THE SYNDEMIC

Oregon Leaders,

Oregon has the <u>highest</u> Hepatitis C mortality rate and the 3rd highest Hepatitis C prevalence rate in the nation.

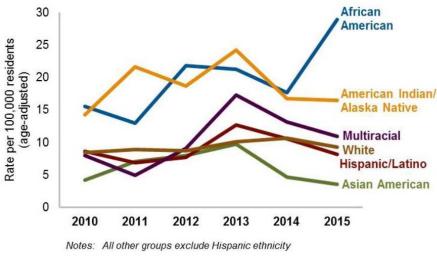
What are you doing about the syndemic?





"Hepatitis C is a deadly, common, and often invisible result of America's opioid crisis," said Jonathan Mermin, M.D., M.P.H., director of CDC's National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention. "By testing people who inject drugs for hepatitis C infection, treating those who test positive, and preventing new transmissions, we can mitigate some of the effects of the nation's devastating opioid crisis and save lives."

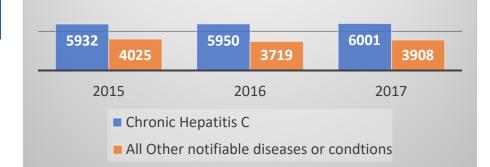
Chronic Hepatitis C virus: Death rate by year and race/ethnicity, Oregon



Source: Oregon Death Certificate Data

With these disparities, where is our Quality Measure?

Reported Cases of Selected Notifiable Diseases or Conditions in Oregon



Public Health Division



Hepatitis C Infections in Oregon

IVIAY 2017

What is Hepatitis C?

Hepatitis C is a liver disease caused by infection with hepatitis C virus (HCV). HCV is usually spread when blood from a person infected with HCV enters the body of someone who is not infected. Hepatitis C infection can range from a brief illness lasting a few weeks to a serious and lifelong (chronic) illness. Approximately 75% to 85% of people infected with HCV develop a chronic infection. Most people do not experience symptoms when they are first infected with HCV and many people have few symptoms for the first 10 to 15 years after infection. However, this does not mean that HCV is not damaging the liver and it is impossible to predict the rate of liver damage early in HCV infection. Heavy alcohol use can speed the progression of HCV disease. Other infections known to speed HCV disease progression include co-infection with hepatitis B virus (HBV) and co-infection with human immunodeficiency virus (HIV).

Over time, untreated chronic HCV infection can result in cirrhosis, end stage liver disease, and liver cancer. Approximately 20% to 30% of people with untreated chronic HCV will develop cirrhosis over 20-30 years. Cirrhosis is a disease in which liver cells are damaged and replaced by scar tissue. Among people with cirrhosis caused by chronic HCV infection, 1% to 4% develop end-stage liver disease or liver cancer each year.

HCV infection can be cured. New, highly effective HCV treatments can cure more than 90% of people living with chronic HCV infection and successful HCV treatment can slow or stop liver disease progression.

Facts at a Glance

- HCV reporting began in Oregon in 2005 and by 2015 there were 59,645 people reported with HCV.
- Between 2011 and 2015, an average of 5,213 people were reported with chronic HCV each year.
- HCV affects all Oregon counties.
- Persons under 30 years of age account for half of all acute (new) HCV infections in Oregon.
- Oregon's rates of people with chronic HCV and HCV related deaths are among the highest in the United States.
- Among chronic HCV cases in Oregon, 2/3 are 45-64 years of age.
- The majority of chronic HCV infections, liver cancer cases, HCV related hospitalizations and HCV related deaths occur among persons 45-64 years of age.
- American Indians /Alaska Natives and Blacks in Oregon experience significant HCV related health disparities.

How is hepatitis C transmitted?

Before 1992, when widespread screening of the blood supply for HCV began in the United States, the infection was spread through blood transfusions, blood products, organ transplants, other health care exposures, intranasal illicit drug use and shared equipment, including needles used to inject drugs. Today, most people become infected with the HCV by sharing equipment, including needles, to inject drugs. While health care related exposures still occur, they are rare. Hepatitis C can also be transmitted through shared personal items that may have come in contact with HCV infected blood such as razors or tooth brushes, from a pregnant mother with HCV to her infant, or by having sex with a person who is infected with HCV, although sexual transmission is rare. Sexual transmission of HCV most often involves men who have sex with men.

Hepatitis C <u>cannot</u> be transmitted through sharing eating utensils, breastfeeding, hugging, kissing, holding hands, coughing, or sneezing. It is also <u>not</u> spread through food or water or transmitted by insect bites.

Currently, there is <u>no vaccine</u> to prevent HCV transmission and there is <u>no post-exposure prophylaxis (PEP)</u> to prevent infection after exposure to HCV. The best way to prevent HCV infections is to avoid or reduce behaviors that put you at risk for HCV infection, such as injection drug use or sharing injection related equipment including syringes. Access to sterile needles and new injection equipment, medication assisted treatment (MAT) and recovery services are evidence-based public health strategies to decrease transmission of HCV in the community.

Who should be tested for Hepatitis C?

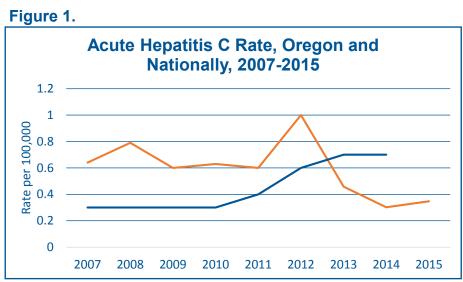
The CDC and the United States Preventive Task Force (USPTF) recommend HCV testing based on a person's age, past or ongoing risk behavior, or exposures or conditions associated with increased risk or HCV infection.

- Age All persons born between 1945 and 1965 should be screened for HCV once without determining risk. This group may also be referred to as the "Birth Cohort" or "Baby Boomers."
- **Risk behavior or exposure** Other persons should be screened for past or on-going risk behaviors or exposures associated with an increased risk of HCV infection. Persons with past behaviors or exposures should be tested once and persons with current or on-going risk behaviors or exposures should be tested for HCV infection regularly.
 - Risk behaviors include
 - History of injection drug use, including people who have injected once
 - Intranasal illicit drug use.
 - Risk exposures include
 - Long term blood dialysis
 - Needle exposure in unregulated settings such as informal body piercings or tattoos
 - Healthcare, emergency medical, and public safety workers after needle sticks, sharps, or mucosal exposures to HCV-infected blood
 - History of incarceration
 - Children born to women living with HCV infection
 - Prior recipients of blood transfusions or organ transplants, including persons who:
 - Received blood from a donor and was notified that the donor tested positive for HCV infection
 - Were recipients of a blood transfusion, blood components, or organ transplant before July 1992
 - Received clotting factor concentrates produced before 1987
- **Conditions** Persons with conditions associated with increased HCV infection risk, including people
 - Living with HIV
 - Who are sexually active and starting pre-exposure prophylaxis (PreP) for HIV
 - With unexplained chronic liver disease or chronic hepatitis including elevated liver enzymes

What is the burden of Hepatitis C in Oregon?

Acute Hepatitis C Infection

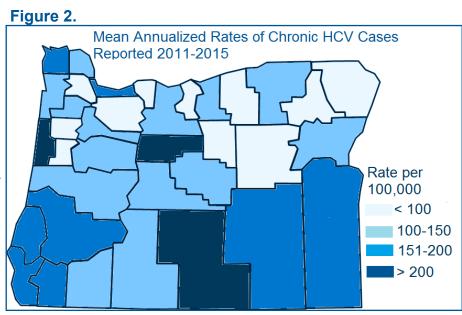
Hepatitis C is the most commonly reported blood-borne disease in the US and in Oregon. The annual number of acute (recent) HCV infections in Oregon has remained stable with an average of 21 cases per year from 2011 to 2015. After accounting for asymptomatic cases and under reporting, these 21 cases likely represent about 277 annual acute infections because most acute infections are not reported. Oregon's annual acute HCV rate was higher than the national acute HCV rate from 2007 until 2012, when the national rate increased significant-



ly due to the growing number of acute HCV infections related to the national opioid crisis. From 2011 to 2015, 66% of acute HCV cases reported injection drug use, and this percentage was similar for males and females. Lastly, persons 15-34 years of age accounted for 61% of Oregon's acute HCV cases from 2011-2015.

Laboratory Reports of Hepatitis C Infection

Chronic HCV infection became reportable in Oregon in 2005 and since that time, 59,645 cases of chronic HCV have been reported in Oregon, including an average of 5,125 cases each year from 2009 and 2015. Figure 2 shows the mean annualized rates of chronic HCV cases by county from 2011 to 2015. Some of our state's highest chronic HCV rates are in rural areas. A recent CDCsupported study¹ calculated standardized state-level estimates of HCV prevalence to describe and compare the extent of the HCV epidemic between the states for the first time. The researchers estimated that in 2010 90,500 people in Oregon had antibod-



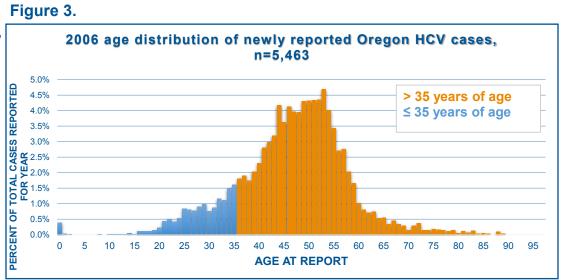
ies to HCV (meaning they have been exposed to HCV at some point in their lives). This figure corresponds to a chronic HCV prevalence rate of 3,050 cases per 100,000 population, or 3.05% of the population of the state. This prevalence was third highest in the US, after Oklahoma and the District of Columbia.

^{1.} Rosenberg ES, Hall EW, Sullivan PS, Sanchez TH, Workowski KA, Ward JW, et al. Estimation of State-Level Prevalence of Hepatitis C Virus Infection, US States and District of Columbia, 2010. Clin Infect Dis. 2017.

Laboratory Reports of Hepatitis C Infections in Oregon

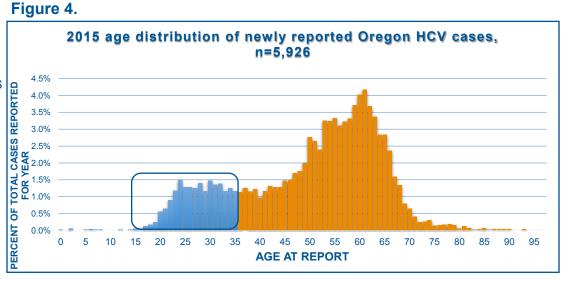
Since many people with HCV infections may experience few to no significant symptoms for years, "newly reported" HCV cases are rarely "newly infected." In Oregon, people born between 1945 and 1965 represent the majority of persons newly reported with chronic HCV infection. We have had an increase, however, in the proportion of newly reported cases in

young adults over the past decade. Figure 3 shows the ages of Oregon's newly reported HCV cases in 2006. The blue bars indicate cases in persons 35 years of age and younger, while the orange bars represent persons over the age of 35 years. In 2006, persons 35 years and younger accounted for 7.5% of reported cases that year.



In contrast, Figure 4 shows the state's newly reported HCV case age distribution for 2015, when 11.9% of cases were part of this younger age group, an increase of 60%. This increase in cases under 35 years of age in 2015 reflects HCV infection likely acquired more recently through risk behaviors or exposures such as shared injection equipment, including nee-

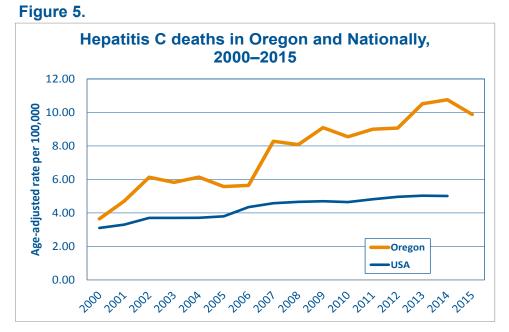
dles, unregulated or unsterile tattoos or piercings, high-risk sex, or blood exposures during incarceration. The emergence of this younger group suggests a failure to address the HCV prevention needs of persons with risk behaviors or exposures associated with increased HCV infection risk. The lack of comprehensive substance abuse prevention; recovery and



community services that use harm reduction strategies; providers trained to provide medication assisted treatment (MAT); methamphetamine treatment programs; and barriers to accessing clean injection equipment, including sterile syringes, hinder effective community responses to prevent new infections in urban, suburban and rural areas.

Hepatitis C Deaths in Oregon

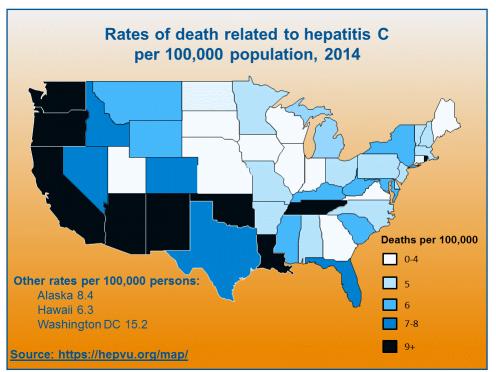
Since 2000, Oregon's HCV-related mortality rates have nearly tripled and have also consistently been higher than the national average; in 2014, Oregon's age-adjusted rate was 10.8 per 100,000 population, twice the US rate of 5.01 per 100,000 (Figure 5).



The CDC recently launched an interac- Figure 6. tive web site in collaboration with Emory University, called HepVu*, that allows the user to view state-specific HCV prevalence and mortality rates.

In 2014, Oregon had an unadjusted HCV mortality rate of 15 per 100,00 population, the highest in the nation that year¹⁻² (Figure 6).

The CDC/Emory University state-specific HCV website can be found at <u>www.HepVu.org.</u>



- Source: National Vital Statistics System (NVSS), and U.S. Census data intercensal data (1999-2012) and 2010 data. Any records that in-1. cluded the ICD-10 code for acute viral Hepatitis C (B17.1) or chronic viral Hepatitis C (B18.2) as the underlying or multiple cause of death were used to identify deaths related to Hepatitis C.
- 2. The higher mortality rate reported on the HepVu website is due to use of unadjusted rates, while Oregon's own estimates have been adjusted for age.

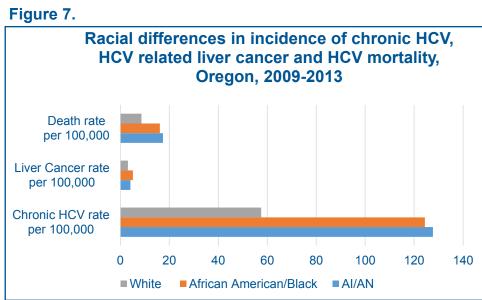
Racial and Ethnic Hepatitis C Disparities in Oregon

American Indians and Alaska Natives

In 2010, chronic liver disease (CLD) was the 5th leading cause of death among American Indians/Alaska Natives (AI/ANs) in the United States. In contrast CLD was the 12th leading cause of death in the US and 9th leading cause of death in Oregon overall in 2014. AI/ANs in Oregon experience some of the highest rates of HCV infection, liver cancer and deaths. In Oregon rates of acute HCV infection among AI/ANs were twice other racial or ethnic groups in 2011-2015 (0.92 per 100,000 vs 0.45 per 100,000). Chronic HCV infection among AI/ANs from in 2011-2015 was 1.8 times the rate of chronic HCV among Whites (147.7 cases per 100,000 vs 80 cases per 100,000). In addition to higher rates of acute and chronic HCV infections, AIANs in Oregon are twice as likely to die from HCV infection as Whites (17.4 per 100,000 vs 8.9 per 100,000).

African Americans and Blacks

While the rates of acute HCV infection in Oregon among African Americans and Blacks was not higher than Whites during 2011-2015, the chronic HCV rate was 1.7 times higher (133.8 per 100,000 vs 80.0 per 100,000). In 2009-2013, the rate of liver cancer associated with HCV was 1.6 times higher in Blacks and African Americans. In addition to higher chronic HCV infections and liver cancer, Blacks and African Americans are almost twice as likely to die from HCV infection as Whites (16.1 per 100,000 vs. 8.9 per 100,000). (Figure 7)



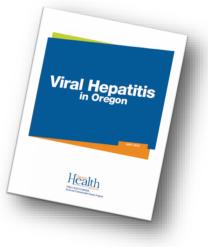
Public health Implications

There are major HCV health disparities between AI/AN and Black and African Americans compared to Whites in the United States and in Oregon that continue to persist. Addressing the effect HCV has on the lifelong health, including the avoidable gaps in health and health care outcomes these populations experience in Oregon, is a critical health equity issue. Working toward health equity means laboring for the highest possible standard of health for all people and giving attention to the needs of those at greatest risk of poor health and health outcomes.

Public health priorities and policies are informed by epidemiologic data and community priorities. Community members become more involved in the health issues when they have relevant local data. Providing accurate and consistent HCV epidemiologic data in partnership with community members to increase awareness and inform action is an important public health function. Another is to support communities to collect and analyze their own HCV data and design and implement their own evidence informed programs, interventions and strategies to raise awareness, promote prevention interventions, screen members in the birth cohort and those with risk and ensure equal access to care and curative treatments for community members who have HCV infection.

Oregon's Epidemiologic Profile Recommendations

Hepatitis C is one of the greatest public health threats in the last century. However, we have the tools to eliminate HCV. Evidencebased interventions to prevent new infections and highly effective curative treatments exist. Curing chronic HCV infection can slow or



stop liver disease progression. Taking action to prevent and cure HCV will be more cost-effective than continued inaction.

The public health recommendations outlined in Oregon's first state epidemiologic profile in 2015 are even more relevant today and include the need to prioritize and invest in the following:

Assessment

- Monitor trends in incidence, prevalence, liver cancer and mortality.
- Investigate epidemiologic trends, respond to outbreaks and study health disparities.

Policy Development

- Develop and implement evidence-based policies to prevent new HCV infections, identify people early and link people to care and treatment.
- Support comprehensive efforts to address opioid dependency and prevent people from transitioning to injection drug use.
- Conduct culturally appropriate awareness and testing campaigns that focus on populations with increased prevalence, immediate risk of advanced disease or ongoing transmission risks.
- Develop culturally appropriate health promotion interventions to reduce barriers to testing, care and treatment.

Assurance

- Enforce laws and regulations that mandate hepatitis surveillance, promote health care safety and expand access to hepatitis testing and preventive services.
- Support equitable syringe access and education about safe injection practices, and safe syringe disposal through local health departments, community-based agencies and pharmacies.
- Ensure priority access to drug and alcohol treatment programs for people with chronic viral hepatitis B and C.
- Integrate viral hepatitis prevention and screening with other public health services; collaborate with substance treatment and care providers to promote HBV vaccination, viral hepatitis testing and access to care; provide surveillance data to support registries to link persons with viral hepatitis to care.
- Evaluate surveillance, clinical and laboratory date to assess the accessibility, quality and outcomes of hepatitis preventive services and care.

Oregon's Viral Hepatitis Action Plan

<section-header>

In 2016, following the completion of the state epidemiologic profile, the Viral Hepatitis Program convened a Viral Hepatitis Action

Plan group. The purpose of the group was to develop and begin to collectively implement a community centered and coordinated response to viral hepatitis in Oregon. The issues surrounding viral hepatitis in Oregon are complex and cross community, government, health system and health sectors. The Viral Hepatitis Action Plan group worked together over the course of the year to develop a living action plan. Over the coming years, members will work to align efforts and collaborate on shared priorities and strategies. The Viral Hepatitis Action Plan's aims, priorities, actions and strategy examples are below.

Aims

- Prevent new infections.
- Improve health outcomes.
- Reduce and eliminate community and population health disparities.
- Decrease future medical care costs.

Priorities and Actions

- Confront stigma directed at persons and populations affected by viral hepatitis.
- Educate communities and decision-makers about the urgency and need to address viral hepatitis prevention, treatment and health disparities.
- Address broader health issues faced by persons who use drugs to more effectively address viral hepatitis.
- Increase community based HCV screening and linkage to prevention, care and treatment efforts in affected populations.
- Improve access and reimbursement across all settings for screening, care, treatment and cure.
- Use data to focus prevention and evaluate interventions, and monitor viral hepatitis care continuums.

Strategies (examples)

- Implement communication and education campaigns.
- Initiate a cross-sector group to address health disparity, outcome and equity issues among persons who use drugs.
- Endorse and expand evidence-based and promising strategies and interventions for populations with viral hepatitis health disparities such as syringe access, syringe exchange and safer injection facilities.
- Expand coverage and reimbursement of curative HCV treatments across all payers and health systems.
- Increase stakeholder infrastructure and capacity to monitor, prevent and respond (including public health surveillance, primary care and public health workforce, community-based agencies and community members).
- Utilize data and evaluation information to direct and inform priorities and actions.

March 6, 2018

Office of Health Analytics Health Plan Quality Metrics Committee Oregon Health Authority

To Whom It May Concern:

I am offering this comment to inform your consideration of the Pediatric Integrated Care Survey (PICS) for the Health Plan Metrics in the health care delivery transformation for the State of Oregon. The PICS is included in *the Standards for Systems of Care for Children and Youth with Special Health Care Needs, Version 2.0*, (2017) (https://www.lpfch.org/sites/default/files/field/publications/standards v2 0.pdf), released by the Association of Maternal and Child Health Programs, in partnership with the National Academy for State Health Policy. The "Standards" document describes the core components of effective systems of care, enabling more accessible content for stakeholders at the level of states and delivery systems. The work was supported by the Lucile Packard Foundation for Children's Health. I want to point out that although I was the Principal Investigator for the creation of the PICS, I have no financial conflicts of interest.

Care integration is a family experience measure which makes it a true outcome for care delivery, and therefore a key domain of the Triple Aim (*Berwick DM, Nolan TW, Whittington J. The triple aim: care, health, and cost. Health Aff (Millwood). 2008;27(3):759–769*). The PICS is available, at no charge, in the public domain. It is a validated instrument. PICS was created in partnership with families—especially those who have children and youth with special health care needs (including chronic behavioral, developmental, and medical conditions). It can be used to assess the patient-/ family-reported experience of care integration for medical service delivery, but it was designed to be broader if desired (eg, assessing outcomes of care integration which include services offered by providers of behavioral health, education, community support services). The notion of the "care team" is broadly defined by families as across institutions and across the community, making PICS a powerful instrument to assess authentic integration of care across disciplines and settings. PICS is available in Spanish.

The Child CAHPS surveys are important measures of care experiences received by children, focusing on interactions with specific care providers but not necessarily how the providers integrate their efforts in addressing the holistic needs of the child and family. In contrast, the PICS assesses a family's experience of care integration across a team of providers, irrespective of institutional affiliation, the discipline of the provider, the type of intervention, or the location of care. (*Ziniel SI, Rosenberg HN, Bach AM, Singer, SJ, Antonelli, R. Validation of a Parent-Reported Experience Measure of Integrated Care. Pediatrics. 2016; 138(6).*

PICS is under consideration as an experience outcome measure in Massachusetts Medicaid's 1115 waiver, supporting our transformation to accountable care. Key questions from the PICS may be incorporated in patient- and family-reported outcomes, in conjunction with CAHPS.

There is an adult version of a patient-reported experience measure of care integration, called the Patient Perception of Integrated Care (PPIC). If Oregon wants an outcome experience measure of care integration that transcends age, the combination of PICS and PPIC should be considered.

Please let me know if you need anything else to inform your deliberations.

Richard Antonelli, MD

Medical Director of Integrated Care Medical Director of Physician Relations and Outreach Boston Children's Hospital/ Harvard Medical School