

# Accessing Out-of-Network Subspecialty Cancer Care in Marketplace Plans

Key Findings From a  
Scan of Four States



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#### **About The Leukemia & Lymphoma Society:**

*The Leukemia & Lymphoma Society is a global leader in the fight against cancer. The LLS mission: cure leukemia, lymphoma, multiple myeloma, and improve the quality of life of patients and their families. LLS funds lifesaving blood cancer research around the world, provides free information and support services, and is the voice for all blood cancer patients seeking access to quality, affordable, coordinated care.*

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#### **About Manatt Health:**

*This analysis and report was prepared by Alex Morin, Joel Ario and Bardia Nabet of Manatt Health. Manatt Health is an interdisciplinary policy and business advisory division of Manatt, Phelps & Phillips, LLP, one of the nation's premier law and consulting firms. Manatt Health helps clients develop and implement strategies to address their greatest challenges, improve performance, and position themselves for long-term sustainability and growth. For more information, visit [www.manatt.com/health](http://www.manatt.com/health).*

# Executive Summary & Introduction

Blood cancer takes a demanding physical, mental and emotional toll on the 1.3 million patients living with this disease in the U.S. Many blood cancer patients also face the daunting task of managing their own care – obtaining the right treatment, at the right time, from the right provider, at the right cost. That process is not always simple, and patients with blood cancer face numerous obstacles when navigating their care.

For example, some forms of blood cancer are rare and require the most advanced treatments, which may only be available at a limited number of facilities such as large academic medical centers and National Cancer Institute (NCI)-designated cancer centers. These challenges can be exacerbated by provider networks – the list of providers and hospitals that a patient’s insurer has contracted with to provide care. When these networks are limited, patients may face barriers that prevent them from accessing appropriate care due to high out-of-pocket costs associated with out-of-network care. Researchers and advocates have documented the increased existence of and enrollment in narrow-network insurance plans, particularly within the individual market. While the Affordable Care Act (ACA) provided protection for patients from catastrophic cost sharing for in-network services, limits on cost sharing do not automatically apply to out-of-network cost sharing.

In many cases, patients may be able to receive medically necessary out-of-network care with in-network levels of cost-sharing. However, doing so often requires patients to navigate their plans’ coverage determination and appeals processes, which can be complex and time intensive.

This report reviews policy challenges that may hamper patients’ ability to navigate and obtain proper treatment for their cancer. We focused our review on four states and their policy and regulatory frameworks governing marketplace plans, conducting interviews to ascertain the perspectives of state regulators, insurers, and cancer care providers. The lens for the report is that of a patient navigating the cancer care journey and the coverage-associated rules put in place by plans and states.

Key findings include:

- The journey of patients from diagnosis to treatment can involve many complicated steps, especially when care is needed outside of their insurer’s network.
- There is significant variation among state regulatory frameworks governing plan network development, network maintenance, appeals and grievance rights and processes, and other cancer care-related consumer protections.
- States and insurers have guardrails in place to allow patients to seek medically appropriate treatment when the available in-network providers and services are insufficient. This is done primarily through appeals and grievance processes. While state regulators and plans do not report major problems with respect to patients utilizing these tools, the process is often complicated and difficult to navigate for patients.
- Cancer providers are adept at navigating out-of-network coverage determination processes on behalf of their patients, usually at a cost to the providers’ respective systems.
- According to payers and state regulators, patients often do not appeal plan decisions, due partly to complex appeals and grievances process or simply a lack of awareness. Some states have implemented incremental consumer protections to augment network adequacy and appeals/grievances processes.

**Fortunately**, there are specific policies that states and health plans can implement to improve network adequacy and access to medically necessary care for treatment of cancer and other health conditions. These policies include:

- Adopting robust network adequacy standards and/or refining current network adequacy standards to include certain service-level requirements that allow for greater specificity.
- Creating and enforcing proactive network maintenance mechanisms to identify potential problems.
- Increasing transparency and streamlining appeals and grievances processes.
- Increasing state resources for regulatory bodies.
- Providing enhanced and easy to understand educational information and support services to providers and consumers regarding appeal mechanisms.
- Pursuing policies to protect particularly vulnerable populations.
- Developing and enforcing cancer care-specific network adequacy standards.

## Background on the Regulatory Landscape & Its Impact on Cancer Care Access

The Affordable Care Act (ACA) created rating standards and other consumer protections aimed at ensuring access to comprehensive, affordable health insurance coverage. Under the ACA, qualified health plans (QHPs) offered on or off an ACA marketplace must maintain provider networks that offer a sufficient numbers and types of providers in order to ensure that all services are accessible to enrollees without unreasonable delay; this is a standard known as network adequacy. However, neither the ACA nor federal regulations specify the precise standards for network adequacy. Rather, patients' access to QHP coverage for their cancer care (like coverage of any provider or service) is a function of (1) network adequacy requirements set by state regulators, (2) insurer development of provider networks that underpin insurance products and (3) providers that contract with plans to provide services at set in-network rates. As a result, provider networks are influenced by sometimes-competing motivations and priorities among regulators, insurers, and providers in the following ways:

**State regulators** generally have broad authority to design regulatory frameworks for network adequacy requirements for QHPs and other commercial health insurance plans. State regulators may be influenced by the preferences of elected officials and the perspectives of insurers. Many regulators seek to

### Regulatory Landscape

balance promoting competition among plans in the state with consumer protections that prevent significant negative outcomes with respect to consumers seeking to access their insurance benefits.

**Insurers**, particularly for-profit insurers, are highly conscious of net revenue and also conscious of maintaining a satisfied consumer base. Without a satisfied consumer base, plans would not be purchased in the first place and, in cases of extreme dissatisfaction, could lead to negative publicity. They also seek to develop contracts with higher-performing providers that presumably will provide higher-quality and lower total cost care. Insurers operate within a specific regulatory framework at the state level, but they often develop their own methods to allow consumers to access care.

**Providers** often seek to be a participating provider in an insurer's network in order to attract patients. However, providers also seek to maximize payment rates from the insurer. Providers typically need rates that pay for the costs associated with their delivery of care.

## Patient & Provider Experience Factors

To thoroughly understand how narrow networks impact patients seeking cancer care, it is critical to understand the multiple factors that contribute to the patient and provider experience – including the significant cost of cancer care. A 2018 analysis supported by The Leukemia & Lymphoma Society (LLS) found that in the first year following diagnosis, the average cost of treating a patient’s blood cancer is nearly \$157,000 and that in the following years, treatment costs remain high for many patients.<sup>1</sup> Treatments may range from chemotherapy, immunotherapy, and radiation therapy to bone marrow and stem cell transplantation, and many treatments increase in their complexity with each new year. Consumers are protected from catastrophic cost sharing for in-network services under the ACA, but limits on cost sharing do not automatically apply to out-of-network cost sharing.

Provider consolidation is another factor. Over the past few decades, the regional availability of cancer care has consolidated resulting in a smaller number of providers via the formation of “mega health systems” and affiliated networks that contract with payers together. For example, the Community Oncology Alliance reports that, between 2010 and 2020, 435 community oncology clinics and/or practices closed, 203 were acquired by hospitals, 203 underwent corporate mergers, and 348 reported that they are struggling financially— additionally, there was a 9.7% increase in the number of consolidations in the hospital setting between 2018 and 2020.<sup>2</sup>

Relatedly, there are 71 NCI-designated cancer centers, located across 36 states and the District of Columbia, that are funded by NCI and recognized for their scientific and research leadership.<sup>3</sup> These centers are likely to attract patients who have a rare diagnosis and those that require more complex and costly care. Notably, a 2018 National Comprehensive Cancer Network (NCCN) and Avalere Health study found, among 29 NCI-designated cancer centers, most (93%) were out-of-network for some or all of the QHPs in their state. These centers are increasingly consolidating next generation therapies and may serve as the sole provider for some medically necessary cancer care, raising potential concerns around access for patients.

## Narrowing Networks

Researchers and advocates have documented the increase in narrow-network insurance plans and their purchase by consumers, particularly within the individual market.<sup>4</sup> Health plans started offering coverage in 2014 under the new ACA rules and subsidies. Among 2015 federal marketplace plans, nearly 15% had no in-network physicians within 50 miles for at least one specialty.<sup>5</sup> Relatedly, a 2017 academic study found that narrower provider networks have a higher likelihood of systematically excluding oncologists affiliated with NCI-designated or NCCN cancer centers.<sup>6</sup> Therefore, patients in narrow-network plans may not only have less access to blood cancer providers, but also may never even have the option of seeking them out as they are unable to gain access to the appropriate treatment centers.

Federal rules leave states considerable flexibility to interpret whether a health plan’s network is compliant with the ACA’s network adequacy rules, including the ACA’s standard that a sufficient number and types of providers are available to deliver benefits without “unreasonable delay.”<sup>7</sup> Federal and state rules also require health insurers to make provider directories available so that the network is transparent as consumers shop for plans.<sup>8</sup> States regulate the adequacy of insurer networks through quantitative (i.e., specific) and subjective (i.e., flexible) standards. Subjective standards allow insurers greater flexibility to identify reasonable delays and provider-enrollee ratios.<sup>9</sup> For decades, the National Association of Insurance Commissioners (NAIC) maintained a model law for states to use as a foundation for regulating network adequacy through quantitative standards. In 2015, NAIC updated its model law to provide states with guidance and options for determining the appropriate regulatory structure to meet their consumers’ needs. Mid-year changes to provider networks (i.e., providers cease operations, etc.) can create ongoing challenges to keep networks up to date and enforce standards.

However, over time, trends indicate that issuers have begun to rely on narrow networks as a means of controlling costs. Insurers have competed primarily on the basis of premiums in the individual

market, driven in part by the knowledge that consumers mostly choose coverage based on the cost of a plan's monthly premium.<sup>10</sup> Moreover, the structure of the ACA's advance premium tax credit rewards insurers with the lowest premiums: premium tax credit amounts are established by the second-lowest-cost "Silver" tier plan, and accordingly, insurers with the lowest-cost or second-lowest-cost premiums are much more likely to attract tax-credit-eligible enrollees. In order to control costs, plans in the individual market have tended to move towards offerings that are narrower.<sup>11</sup> Meanwhile, employers are moving more slowly towards narrow networks: according to a Kaiser Family Foundation (KFF) report, 7% of small companies with less than 200 employees offered a narrow-network plan in 2018, while 5% of larger firms with more than 200 employees offered a narrow-network plan.<sup>12</sup>

Parallel to issues of network design are the general difficulties accessing major cancer centers, described above. Prior research has indicated both benefits and challenges in seeking care at cancer centers. While these institutions may have access to novel investigational agents, technology biobanks and other treatment pathways, access to these facilities is limited to specific regions and areas, complicating both immediate and longer-term survivorship care, which can lead to higher overall costs over time.<sup>13</sup>

These factors can lead consumers to choose narrower-network products that may not have access to these specialized centers. For example, cancer patients in mid-treatment will likely seek out provider networks with oncologists but the unsuspecting consumer may not evaluate a narrow network for all specialty types.<sup>14</sup> Therefore, once a diagnosis is given, a patient will have few options for gaining access to treatment in a facility they believe is best for their needs.

One method of supporting this unsuspecting consumer is to seek a second opinion, which may be beneficial in multiple scenarios: when the diagnosis or treatment is unclear, when the patient is a child, when the patient wants peace of mind, or when a patient is diagnosed with cancer.<sup>15</sup> Second

opinions may even have an impact on the diagnosis and care that patients receive—for example, a 2018 study found that a second review by a multidisciplinary tumor board at an NCI-designated cancer center changed the diagnosis for 43% of patients in the study.<sup>16</sup> However, there is wide variability in state laws and regulations that provide protections for second opinions, and few states do so for cancer services or anything beyond surgical procedures.<sup>17</sup>

An emerging, less-discussed issue for patients navigating narrow networks is the denial and appeal process by which patients may receive an exception and be able to access medically necessary out-of-network care. The federal government, through the departments of Health and Human Services, Labor, and Treasury, has outlined requirements for health plans to provide appeal processes and to provide explanations of benefits and other documents to educate consumers about their appeal rights.<sup>18</sup> To abide by these regulations, states and insurers have tools and processes in place for consumers to file complaints and for insurers to grant exceptions in cases where narrow networks lead to lack of available providers for certain diagnoses and treatments.

However, when faced with these processes, consumers may not choose to appeal insurer decisions. An analysis from the KFF utilized data from 122 major medical issuers to show that ACA marketplace plans denied more than 40 million claims, or 17% of all claims.<sup>19</sup> Of these denials, the vast majority (72%) were denied for reasons other than the service being an excluded from their coverage (18%), requiring a prior authorization or referral (9%), or based upon an evaluation of medical necessity (1%).<sup>20</sup> Consumers may seek external review of their claim if it was denied based on medical necessity or related clinical reasons. Consumers may also appeal decisions to the insurer and appealed fewer than 64,000, or less than 0.2%, of all denials. Moreover, when consumers appeal claims denials to their insurers, insurers uphold their original decision 60% of the time.<sup>21</sup> Narrow networks, combined with complicated exceptions processes, may represent significant barriers to accessing appropriate blood cancer treatments.



## Key Findings from State-level Analysis

This report investigates the myriad dynamics outlined in the previous section, seeking to more fully understand in particular how states create a positive environment where plans, providers, and consumers interact. The lens for the report is that of a patient navigating the cancer care journey and the coverage-associated rules put in place by plans and states.

The findings in this report are based on an analysis of four state policy and regulatory frameworks governing marketplace plans, as well as interviews representing the perspectives of states, insurers, and cancer care providers. All the information shared in this report is publicly available, and the completed interviews were utilized to provide additional context. Manatt's analysis focused on five key areas:

1. **Network adequacy standards for cancer care.** How are network adequacy standards developed and enforced?
2. **Scale of impact of narrow networks on blood cancer treatments.** To what extent are patients seeking out-of-network cancer care, and how is information tracked and reported?
3. **Patient experience.** How complex is the patient journey when out-of-network care is needed?
4. **Appeals and exceptions processes.** What are the mechanisms available to consumers to appeal negative decisions by insurers with respect to seeking out-of-network cancer care?
5. **Additional cancer care-related consumer protections.** Outside of network adequacy-related policy and regulation, are there other consumer protections included in state law that promote or inhibit access to out-of-network cancer care?

Each of these areas was analyzed from the three primary perspectives of state regulators, insurers, and providers. The analysis revealed a complex set of dynamics, summarized by the following five key findings:

1. The patient journey from diagnosis to treatment can involve many complicated steps, especially when care is needed outside of their insurer's network.
2. There is variation among state regulatory frameworks governing plan network development, network maintenance, appeals and grievance rights and processes, and other cancer care-related consumer protections.
3. States and insurers have guardrails in place to allow patients to seek medically appropriate treatment when the available in-network providers and services are insufficient. This is done primarily through appeals and grievance processes. While state regulators and plans do not report major problems with respect to patients utilizing these tools, the process is often complicated and difficult to navigate for patients.
4. Cancer providers are adept at navigating out-of-network coverage determination processes on behalf of their patients, usually at a cost to the providers' respective systems.
5. According to payers and state regulators, patients often do not appeal plan decisions due to, in part, the complex appeals and grievances process or just a lack of awareness. Some states have implemented incremental consumer protections to augment network adequacy and appeals/grievances processes.

According to payers and state regulators, patients often do not appeal plan decisions due to, in part, the complex appeals and grievances process or just a lack of awareness. Some states have implemented incremental consumer protections to augment network adequacy and appeals/grievances processes. These findings suggest that patients have mechanisms that facilitate access medically necessary out-of-network cancer care; however, the patient journey to reaching a positive coverage determination can be complex and time intensive, and thus a deterrent, which may lead to delaying or not received care at all.



## Meet Jessica

Like many Americans, the COVID-19 pandemic had an immediate and significant impact on Jessica Botts, a 38-year-old administrative assistant living in Reno, Nevada. Weeks into the public health emergency, as the country was reeling from its initial effects, Jessica suddenly lost her job. In addition to navigating the challenges of a global pandemic and the loss of her only source of income, Jessica faced significant health challenges. In December of 2019 she was diagnosed with myelofibrosis, a rare blood disorder.

Jessica learned that her diagnosis was too complex to be treated by her oncologist in Reno. In fact, there were no medical facilities in Nevada that could provide the care she needed. The only potential cure for myelofibrosis is allogeneic stem cell transplantation, using the stem cells of a donor, and only specialized facilities are able to perform this procedure. Jessica was referred to a transplant specialist that would accept out of state care at Stanford Medical Center in California — over 250 miles away and across state lines.

Thankfully, Jessica was able to stay on her company's health insurance plan through COBRA. While her plan had low deductibles, affordable out-of-pocket costs, and other critical protections she would need, the premiums were extremely high. Without a steady stream of income and knowing she would not be able to return to work post-transplant, she began researching insurance options on the Nevada state health insurance exchange.

Jessica spent hours calling every insurance carrier on the exchange, only to come up empty-handed. Not one policy could guarantee her specialist in California would be covered. Despite the marketplace plans being more affordable, she made the choice to stay on her COBRA coverage and dip into savings to afford the high premiums.

Jessica successfully received her stem cell transplant in September of 2020. Though her recovery is going smoothly, she is at high-risk of getting COVID-19 and is postponing returning to work until she can be vaccinated. She continues to pay the high costs of her COBRA premiums out of her dwindling savings to ensure she can still access the specialists who are equipped to manage her post-transplant care and give her the greatest chance of living a healthy life.

*The above story is Jessica's first-hand experience and shared with her permission.*



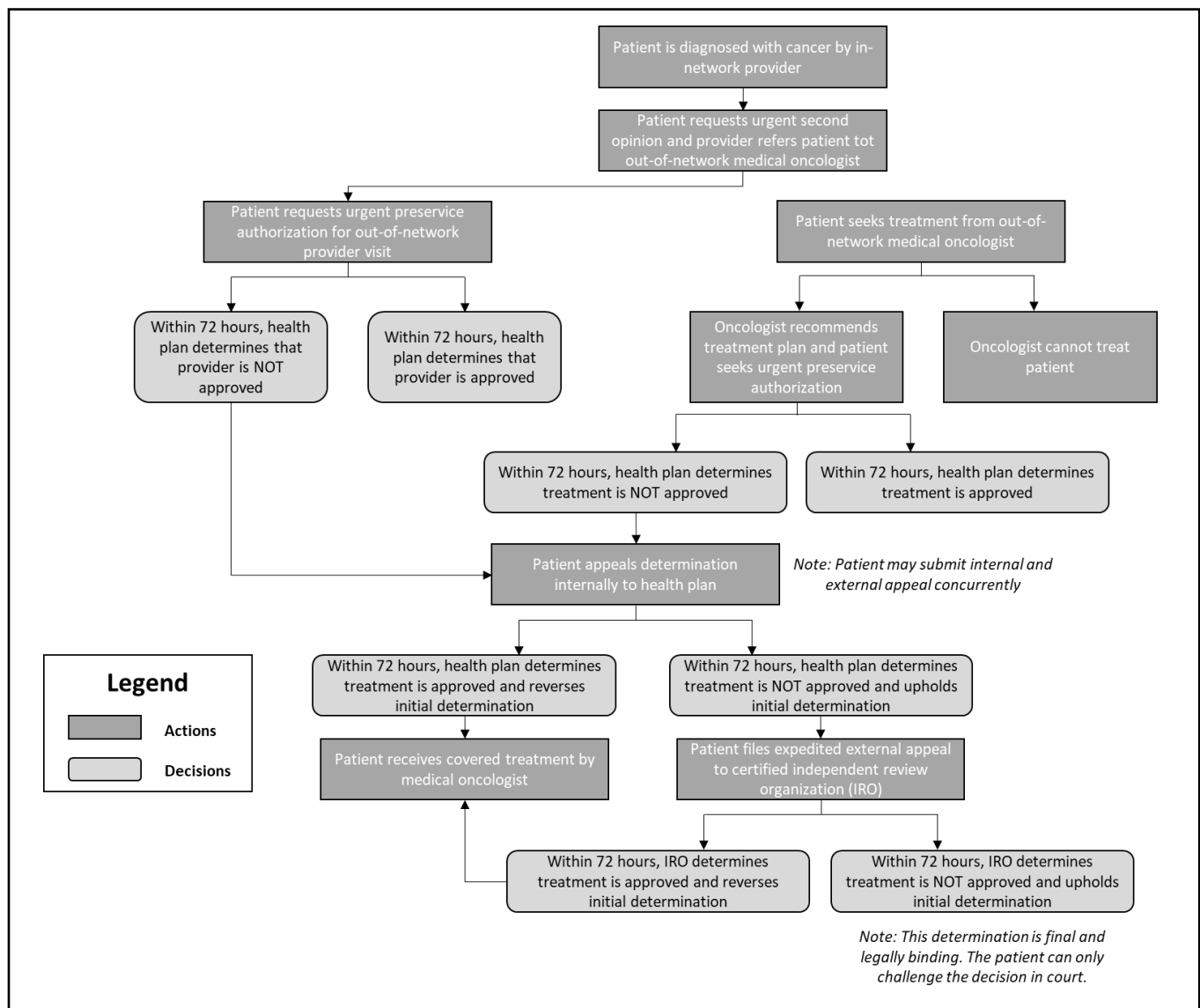
**Finding #1:** *The totality of the patient journey from diagnosis to a positive coverage determination for medically necessary out-of-network treatment can involve many complicated steps.*

The key finding of this report’s analysis is the complexity of the patient journey from a cancer diagnosis to a determination that out-of-network cancer care is medically necessary and will be covered at in-network rates. This process is further illustrated in Figure 1 for a sample patient in **Washington** who is diagnosed with cancer. When out-of-network care is necessary, the patient may face multiple barriers, roadblocks, and slowdowns—potentially waiting for days to weeks—navigating the

process before being able to access the necessary care. Although states have worked to ensure processes are expedited in certain circumstances, a patient with a recent cancer diagnosis, particularly if a member of a vulnerable population, may be unable to devote the time and energy to achieve coverage for the optimal treatment outcome, let alone make the initial step to begin this process.

Despite insurer and plan mechanisms to provide education and support to patients navigating the journey, it remains complex. When adding in the stress of a cancer diagnosis, potential human errors in completing paperwork, and other factors, these protections and supports may not be utilized or utilized effectively on a reasonable timeline.

Figure 1: Illustrative **Washington** State Patient Journey for Access to Urgent Treatment



**Finding #2:** *There is wide variation among state regulatory frameworks governing plan network development, network maintenance, appeals and grievance rights and processes, and other cancer care-related consumer protections.*

States generally rely on network adequacy standards that link to measures such as appointment wait times, provider-to-enrollee ratio minimums, and travel time and distance standards to ensure access to care. The table on page 12 summarizes the types of requirements the states we analyzed include in their framework.

However, in some states, these approaches have been in place since before the ACA, or were updated shortly thereafter, and may require further refinement given the potential issues consumers face today. For example, **New York's** standards for provider-enrollee ratios simply require a limited number of providers per county, without establishing clinically based ratios.<sup>22-23</sup>

Some states are seeking to evolve their regulatory approaches to network adequacy, and the way they engage with plans in their states may be instructive nationally. In **New Hampshire**, the state established a new system to retrospectively evaluate the adequacy of provider networks that includes standards at the *service level*, rather than just at the specialty level as is seen in most states.<sup>24</sup> **New Hampshire** is the first state in the country to use all-payer claims data to support a network adequacy approach that allows for greater transparency and accountability in its review of health insurers' provider networks.<sup>25</sup> The state uses actual claims experience to review carrier networks and mandate providers for services rather than particular specialists. The state classifies services into three categories (core, common and specialized) for the purposes of network adequacy reviews. All other covered services must also be available from providers within New England.<sup>26</sup> Cancer-related services are listed across all three categories of services. For example, mammograms are listed as core, chemotherapy is listed as common, and certain biopsies and radiation therapy are listed as specialized.

In **Washington**, the state adopted a more prospective system to work with insurers to maintain networks across a given plan year, which facilitates frequent dialogue between the state and plans to

ensure network adequacy gaps that emerge over time are addressed in closer to "real time." Insurers must report to the insurance commissioner any changes affecting the ability of their network providers and facilities to furnish covered services to enrollees. Triggering events requiring written notice to the commissioner within 15 days include:

- Reduction of 10% or more in the number of specialty providers, mental health providers or facilities participating in the network
- Termination or reduction of a specific type of specialty provider where there are fewer than two of the specialists in a service area
- An increase or reduction of 25% or more in the number of enrollees in the service area since the annual approval date
- The termination or expiration of a contract with a hospital or any associated hospital-based medical group within a service area
- A 15% reduction in the number of providers or facilities for a specific chronic condition or disease who are participating in the network where the chronic condition or disease affects more than 5% of the issuer's enrollees in the service area<sup>27</sup>

Written notice to the commissioner must include the insurer's preliminary determination about whether the identified changes in the network require an alternative access delivery request.

The above are two examples of states that are seeking to evolve their regulatory frameworks in different ways to mitigate the potential negative consequences of broad network adequacy measures and network maintenance requirements with respect to more-specialized care.

**Finding #3:** *Both states and insurers have guardrails in place to empower consumers to seek medically appropriate treatment when available in-network providers and services are insufficient (primarily through appeals and grievances). State regulators and plans do not report major issues with respect to cancer care access.*

Each state we examined has mechanisms in place that enable consumers to appeal decisions by insurers to deny out-of-network coverage. These mechanisms are often at the plan level (“internal appeal”) or at the state level (“external” or “third-party” appeal). Plans and states differ in how these mechanisms are structured and in the processes through which consumers must go to engage. Some consumers may not feel empowered or have access to the information they need in order to seek out second opinions or additional treatment options for their cancer care. If they did seek these services and were denied, they may be unaware or distrustful of the potential “safety valve” for triggering an appeal or complaint.

Use of internal appeals/grievances processes is variable. Plans provide treating physicians and members with information about their rights to appeal coverage decisions or file grievances subsequent to a denial of coverage for a service or for coverage at an out-of-network provider or facility. A **New Hampshire** insurer noted that utilization management typically handles appeals before they become broader complaints. Utilization management is an added step in the patient journey to access care. Utilization management reviews are tools that plans use to determine the medical necessity of particular treatments or services, and often are a first step prior to a decision regarding coverage, regardless of whether providers or facilities are in-network or out-of-network. However, state requirements vary as to whether or not medical reviews must be performed by reviewers with relevant expertise or training for the cases they are reviewing.

Details of each state’s requirements regarding appeals are included in the Appendix, but generally states require plans to maintain internal appeals processes and to provide state-level “external appeal” or review mechanisms where an independent body can review a plan’s decision. Requirements are often also in place that force plans and external review bodies to make decisions in a timely manner, once the appropriate information is received and confirmed to be complete.

However, external appeal review bodies do not often have a publicly accessible system containing appeal decisions. Where they exist, these databases can help consumers (and consumer advocates) determine whether others have faced similar issues and empower consumers to similarly appeal

decisions. States vary in the degree that data about appeals is tracked and reported. This data provides information that may be valuable to consumers in selecting plans, particularly as an indicator for how “restrictive” a network may be. **New York** is highly transparent in its appeals and grievances policies. Moreover, the Department of Financial Services (DFS) stands out with its commitment to publishing a yearly “Consumer Guide to Health Insurers” to inform consumers of their insurance options.<sup>28</sup> This guide summarizes the complaints handled by DFS and the Department of Health that involve issues related to coverage, network adequacy and other key issues. For example, data on health maintenance organizations (HMOs) in the 2019 guide noted that DFS received 1,184 complaints and resolved 654 of those complaints in favor of the consumer. Moreover, the guide highlights internal and external appeals, information that is often difficult to locate for other states, in an accessible format that consumers can use to select the best plan for their needs. Finally, DFS also provides an online searchable database where summaries of external appeal decisions are available.

**Finding #4:** *Cancer care providers have become adept at navigating out-of-network coverage determination processes on behalf of patients.*

Large academic medical centers (AMCs) and NCI-designated cancer centers have become adept at navigating insurance coverage issues for out-of-network referred patients. They report success in working with plans directly to achieve positive decisions for certain treatments (single case agreements, etc.), alleviating the need to access the appeals/grievance process at the plan or state level. This success comes at a cost to the system and is contingent on a referral (self-referral or by a provider) to the center. What is unknown is the number of patients who do not seek treatment out-of-network who may, if they had been referred, qualify for an exception for medically necessary care.

Additionally, AMCs note that navigating coverage and access issues with plans is not a one-time task for each patient. Particularly, for younger populations where the blood cancers are some of the most common types of cancer, patients and providers may have to navigate the transition from “child” to “adult” while maintaining the patient’s

ongoing care, which can also create challenges with networks and in-network facilitates. Preferred “adult” providers may be out of network, or plans may seek to transfer these patients to lower cost sites of care due to their new adult status and this can result in an interruption in treatment. These interruptions to the care plan and navigation for patients results in additional stress for patients and coordination efforts for providers that are providing ongoing care for patients.

Providers perceive an adverse selection issue with cancer centers being removed or kept out of networks. AMCs and cancer centers have experience being in-network with a single insurer in both marketplace and Medicaid managed care plans. In these cases, insurers saw an increase in adverse patient selection – meaning patients with cancer, who need higher-cost treatments, chose these plans – due to these providers and promptly dropped the AMCs from their networks in subsequent plan years. In some cases, cancer centers may contract with an insurer for a specific out-of-network rate, on a case-by-case basis, but not be featured in their exchange plan or provider directory.

**Finding #5:** *Some states have implemented incremental consumer protections related to network adequacy and appeals/grievances processes.*

Outside of network adequacy requirements and direct appeal/grievance processes, some states examined have developed additional consumer protections through legislative and/or regulatory changes. Among states examined, **New York** is notable for its focus on consumer protection, particularly for patients requiring ongoing specialty care. DFS highlights these protections clearly on its consumer-facing website.<sup>29</sup> For example, DFS reinforces that consumers may get a referral to or authorization for an out-of-network provider when their health plan does not have an in-network provider with the appropriate training and experience to meet the consumer’s particular health care needs (at a cost no higher than for an in-network provider).<sup>30</sup> In fact, cancer patients are also entitled to an out-of-network second opinion.<sup>31</sup> To further avoid interruptions in care, consumers have

the right to request a standing referral to a specialist or specialty care center if they require ongoing specialty treatment.<sup>32-33</sup> Finally, due to their ongoing health care needs, consumers with blood cancer may prefer and have their needs better met by receiving care solely through their specialty care provider. In those cases, because they have a life-threatening disease and ongoing specialty care needs, they may request that a specialist coordinate their care instead of their primary care provider (PCP).

For children with special needs who may not already qualify, **Pennsylvania** provides access to Medical Assistance (Medicaid) through the PH category 95 program (PH-95).<sup>34</sup> PH-95 is a last resort for children under the age of 18 with special needs, and income eligibility is based on the child’s income, as opposed to the parents’ income.<sup>35</sup> Importantly, children are eligible if they have a physical condition that results in marked and severe functional limitations that last, or are expected to last, at least 12 months or are expected to result in death.<sup>36</sup> Other criteria include:

- The child’s meeting the Social Security Administration’s (SSA) disability standards (requires proof from SSA or the Department of Human Services Medical Review Team)
- Reports of clinical and laboratory findings that support the diagnosis and show the physical or mental changes that have occurred
- A medical assessment describing the child’s ability to do activities such as sitting, standing, moving about, lifting, carrying, handling objects, hearing and speaking
- Declaration and documentation of all earned and unearned income for the parents and the child

**New York** has a similar “Medicaid Excess Income” program by which individuals under the age of 21 are eligible for Medicaid coverage even if their monthly income is over the Medicaid level.<sup>37</sup> For families, these programs offer an additional lifeline for coverage, while for providers they allow an additional reimbursement mechanism to cover the potentially costly care.

## Summary of State Network Adequacy and Maintenance Approaches<sup>38</sup>

State	Provider Access	Appointment Wait Times	Provider-Enrollee Ratios	Travel Time and Distance	Provider Directories	Balance Billing	Appeals/Denials Processes	NAIC Model Policy
<b>New Hampshire</b> (federally facilitated marketplace)	<u>Yes</u> , for primary care and specialists, leverages all-payer claims database	<u>Yes</u> , exact wait times listed	<u>None</u>	<u>Yes</u> , on ZIP code level based on most recent U.S. Census Bureau data for all providers	<u>Yes</u> , must update at least monthly	<u>Yes</u> , prohibits for certain types of care	<u>Yes</u> , internal and external appeals	<u>Follows</u> NAIC model with modified time and distance
<b>New York</b> (state-based marketplace)	<u>Yes</u> , for primary care and specialists	<u>Yes</u> , no exact times listed but must be considered	<u>Yes</u> , recommended on county level for all providers	<u>Yes</u> , recommended on county level for all providers	<u>Yes</u> , must update within 15 days of addition/termination	<u>Yes</u> , defines and establishes dispute resolution process	<u>Yes</u> , utilization review, preauthorization internal and external appeals	<u>Does not</u> exactly follow NAIC model
<b>Pennsylvania</b> (moving from federally facilitated to state-based marketplace)	<u>Yes</u> , for primary care and specialists	<u>None</u>	<u>None</u>	<u>Yes</u> , on county level based on most recent census data for all providers	<u>Yes</u> , must update at least annually	<u>No</u> , introduced balance billing law but has not passed it	<u>Yes</u> , multiple internal appeals and external appeal (preempted by ACA appeal process)	<u>Does not</u> follow NAIC model
<b>Washington</b> (state-based marketplace)	<u>Yes</u> , for primary care and specialists, with explicit mention of cancer care	<u>Yes</u> , exact wait times listed	<u>Yes</u> , based on average ratio for state in prior plan year for all providers	<u>Yes</u> , based on population distribution for all providers	<u>Yes</u> , must update at least monthly	<u>Yes</u> , defines and establishes dispute resolution process	<u>Yes</u> , utilization review, preauthorization internal and external appeals	<u>Follows</u> NAIC model

## Opportunities to Enhance Regulatory Frameworks & Improve the Consumer Experience

The states profiled in this report reveal lessons for policymakers and legislators. Based on our review, there appear to be examples of state action to support consumers in navigating the insurance landscape and accessing medically necessary coverage, as described below:

1. **Adopt robust network adequacy standards and/or refine reactive network adequacy standards to include certain service-level requirements that allow for greater specificity.** As demonstrated in **New Hampshire**, while it is more complex to administer, for certain services it may be appropriate to track network adequacy at the service level, given the specialization that may be required for a particular course of treatment.<sup>39</sup>
2. **Create and enforce proactive network maintenance mechanisms to identify potential problems.** For example, analogous to **Washington's** proactive network model, state regulators can require plans to notify the state when there are changes in their provider networks and have varying thresholds for degree of action.<sup>40</sup> This increases the regular communication between plans and the state and proactively mitigates network adequacy issues that could negatively impact consumer access to timely care.
3. **Increase transparency and streamline appeals processes.** Similar to **New York**, states could more proactively track appeals and their determinations as a data point for consumers to evaluate as they make purchase decisions.<sup>41</sup> While not the only metric, it does provide a view into how often out-of-network care is sought and what those determinations were. It also provides states clearer, more objective data on where there may be service-level gaps across the state that need to be addressed. States should also ensure simplified appeals to an external independent review organization for health plan denials of out-of-network coverage. To further leverage this review, states may consider creating a publicly searchable database of external appeal decisions to assist consumers in making their appeals.
4. **Increase state resources for regulatory bodies.** A limiting factor for state regulators is budget. State

regulatory bodies with increased resources are able to better engage with plans and consumers, and can develop tools to support consumers in navigating the marketplace.

5. **Provide enhanced educational information and support services to providers and consumers regarding appeal mechanisms.** Anecdotally, the level of education and awareness for both consumers and referring providers about appeals and grievance rights is variable. States could develop more stringent requirements for plans to educate consumers on their appeal rights, especially plan denial notices and explanations of benefits, and on other protections. States could require supplemental education targeted to patients with certain diagnoses that are rare, life-threatening, are often misdiagnosed, or require complex treatment protocols. States could develop their own consumer-friendly educational materials to provide information about plans prior to purchase on the exchange. States may also consider funding consumer assistance programs that give consumers direct assistance navigating the appeals process and access to care.
6. **Pursue policies to protect particular vulnerable populations.** There may be opportunities for states to address specific vulnerable populations through different mechanisms. States can implement protections to ensure access to medically necessary cancer care even when out-of-network, or when cost sharing or other factors may put it out of reach. This can be done through broad diagnosis eligibility factors or by age groups. This presents multiple pathways for states to ensure coverage outside of regulatory frameworks specific to network adequacy.
7. **Consider development of cancer care-specific network adequacy standards.** States could develop new network adequacy measures to expand required coverage of cancer-care (and other specialty-care) services, which would include one or more NCI-designated cancer centers, or collaboration with the medical profession using clinically based ratios needed to effectively service a given population. Such standards could then be adopted by state regulators and health plans.



## Conclusion

Patients in marketplace plans have mechanisms that facilitate access medically necessary out-of-network cancer care, but the patient journey to reaching a positive coverage determination can be complex and time intensive. These factors can ultimately be a deterrent for these patients, which may lead to suboptimal clinical outcomes for some patients. While these dynamics are complex, states have sought to minimize access-to-care issues, though with wide variation among frameworks for network development, network maintenance, appeals and grievances, and other consumer protections. Ultimately, states have several tools in their arsenal to support consumers in navigating the increasingly difficult insurance landscape during a challenging time in their patient journey.

Although this report has not profiled every state network adequacy framework, it does detail features that may be applicable and employed in multiple state contexts. Furthermore, states, insurers and health systems are rapidly adapting to the COVID-19 pandemic, and this report has not attempted to identify how network adequacy frameworks have been or should be adjusted to account for potential increased pressure from the pandemic. In the future, it is likely that states will be focused on pandemic response and have reprioritized budgets, limiting their ability to develop the proactive network adequacy standards, network maintenance and consumer protections that are suggested in this report.

## Appendix

**Methodology:** This report was completed through a mixture of primary and scholarly research and discussions with states, insurance carriers and providers across the country. The Leukemia & Lymphoma Society provided on-the-ground consumer advocacy perspective to the issues identified throughout this report. Contacts were selected based on research findings of states with potential “best practices” for network maintenance. For purposes of this report, none of the individuals contacted have been identified. We thank those individuals for their insights and contributions to this report.

New Hampshire Case Study	
General Information	<ul style="list-style-type: none"> <li>Federally facilitated marketplace managed by the Insurance Department.</li> <li>The marketplace was created in February 2013 under Governor Maggie Hassan as a partnership with the federal government.</li> <li>The state is responsible for plan management and consumer assistance while the federal government manages all other responsibilities.<sup>42</sup></li> <li>New Hampshire has three levels of insurance plans: Bronze level (40% coverage), Silver level (30% coverage) and Gold level (20% coverage)—with Bronze having lower premiums but higher out-of-pocket costs.<sup>43</sup></li> <li>Cost-sharing reduction benefits are available only on Silver plans, but all enrollees are eligible for premium subsidies on a sliding scale up to 400% FPL.<sup>44-45</sup></li> <li>In 2020, New Hampshire’s exchange is offering three plans.<sup>46</sup></li> </ul>

<b>Provider Access<sup>47</sup></b>	<ul style="list-style-type: none"> <li>The state classifies services into three categories (core, common and specialized) for the purposes of network adequacy reviews.</li> <li>Cancer-related services are listed across all three categories of services. For example, mammograms are listed as core, chemotherapy is listed as common, and certain biopsies and radiation therapy are listed as specialized.</li> </ul>																
<b>Appointment Wait Times<sup>48</sup></b>	<ul style="list-style-type: none"> <li>Standard waiting times for appointments shall be measured from the initial request for an appointment for behavioral health services, primary care providers, substance use disorder services.</li> </ul>																
<b>Provider-Enrollee Ratios<sup>49</sup></b>	<ul style="list-style-type: none"> <li>The evaluation of network adequacy shall be based on the most recent United States census data for populations under 65 years of age.</li> </ul>																
<b>Provider Directories<sup>50</sup></b>	<ul style="list-style-type: none"> <li>For each of its network plans, a health carrier shall electronically post and maintain a current and accurate searchable provider directory and update the provider directory for each network plan at least monthly.</li> </ul>																
<b>Travel Time and Distance Standards<sup>51</sup></b>	<ul style="list-style-type: none"> <li>New Hampshire is the first state in the country to use all-payer claims data to support a network adequacy approach that allows for greater transparency and accountability in its review of health insurers' provider networks.</li> </ul> <table border="1" data-bbox="657 905 1304 1140"> <thead> <tr> <th></th> <th>Urban</th> <th>Middle</th> <th>Rural</th> </tr> </thead> <tbody> <tr> <td>Core</td> <td>10 miles or 15 mins driving</td> <td>20 miles or 40 mins driving</td> <td>30 miles or 60 mins driving</td> </tr> <tr> <td>Common</td> <td>20 miles or 30 mins driving</td> <td>40 miles or 80 mins</td> <td>80 miles or 120 mins driving</td> </tr> <tr> <td>Specialized</td> <td>40 miles or 60 mins driving</td> <td>70 miles or 120 mins driving</td> <td>125 miles or 150 mins driving</td> </tr> </tbody> </table>		Urban	Middle	Rural	Core	10 miles or 15 mins driving	20 miles or 40 mins driving	30 miles or 60 mins driving	Common	20 miles or 30 mins driving	40 miles or 80 mins	80 miles or 120 mins driving	Specialized	40 miles or 60 mins driving	70 miles or 120 mins driving	125 miles or 150 mins driving
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<b>Balance Billing Protections<sup>52-53</sup></b>	<ul style="list-style-type: none"> <li>A health care provider performing anesthesiology, radiology, emergency medicine, or pathology services shall not balance bill the patient for fees or amounts other than copayments, deductibles, or coinsurance, if the service is performed in a hospital or ambulatory surgical center that is in-network under the patient's health insurance plan. This prohibition shall apply whether or not the health care provider is contracted with the patient's insurance carrier.</li> </ul>																
<b>Appeals and Denials Process<sup>54-55-56</sup></b>	<ul style="list-style-type: none"> <li>Health plans must have a utilization review process to identify whether the services are considered in- or out-of-network.</li> <li>A patient, patient's designee or patient's provider can appeal an adverse determination within 180 days from the date the claim was denied.</li> <li>The health plan or utilization review entity must make a determination within 30 days of the receipt of the necessary information to conduct the appeal. For health plans with two levels of appeals, the first level must be completed within 15 days, and the second level must be completed within 30 days of the initial filing.</li> <li>The health plan or utilization review entity will make an appeal determination that either upholds or reverses the adverse determination. The determination must include the reasons for the decision, notice of the insured's right to additional dispute</li> </ul>																

	<p>processes and a statement describing the patient’s ability to contact the insurance commissioner’s office for assistance.</p> <ul style="list-style-type: none"> <li>• Once the patient has exhausted all internal appeals, the patient has 180 days after they receive a final determination to file an external appeal.</li> <li>• The independent review organization (IRO) will review the final adverse determination and then will make a determination as to whether the out-of-network health service will be covered by the health plan, within 60 days of the receipt of the appeal request. The determination will be accompanied by a written statement that the out-of-network service will be covered or will uphold the denial of coverage.</li> <li>• The IRO’s decision is binding and enforceable by the Insurance Department. The decision is also binding on the patient, except that it does not prevent the patient from pursuing other remedies through the courts under federal or state law.</li> </ul>
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<b>New Mexico Case Study</b>	
<b>General Information</b>	<ul style="list-style-type: none"> <li>• Moving from a federally facilitated to a state-based marketplace and managed by the Department of Insurance.</li> <li>• Governor Susana Martinez established the exchange with the nonprofit Health Insurance Alliance actually developing the exchange in 2013.</li> <li>• New Mexico requires all of its participating insurers to offer plans at each of the metal levels.<sup>57</sup></li> <li>• In 2020, New Mexico has four insurers offering plans on its exchange.<sup>58</sup></li> </ul>
<b>Provider Access<sup>59</sup></b>	<ul style="list-style-type: none"> <li>• Each managed health care plan (MHCP) must demonstrate that a sufficient number of licensed medical specialists are available to covered persons for specialty care when referral to such care is determined to be medically necessary by the PCP or other treating health care professional in consultation with the MHCP.</li> </ul>
<b>Appointment Wait Times<sup>60</sup></b>	<ul style="list-style-type: none"> <li>• Urgent care shall be available within 48 hours of notification to the PCP or MHCP, or sooner as required by the medical exigencies of the case; for both emergent and urgent care, the MHCP shall ensure 7 day, 24 hour access to triage services, and that each PCP will have back-up coverage by another provider.</li> </ul>
<b>Provider-Enrollee Ratios<sup>61</sup></b>	<ul style="list-style-type: none"> <li>• One full-time equivalent PCP will be available for every 1,500 covered persons.</li> <li>• Each MHCP must attempt to provide at least one licensed medical specialist in those specialties that are generally available in the geographic area served, taking into consideration the urban or rural nature of the service area, the geographic location of each covered person, and the type of specialty care needed by the covered person population.</li> </ul>
<b>Provider Directories<sup>62</sup></b>	<ul style="list-style-type: none"> <li>• An MHCP must provide a list of all providers to subscribers, enrollees, covered persons or prospective enrollees upon request.</li> </ul>

<b>Travel Time and Distance Standards<sup>63</sup></b>	<ul style="list-style-type: none"> <li>• In population areas of 50,000 or more residents, two PCPs are available within no more than 20 miles or 20 minutes' average driving time for 90% of the enrolled population; in population areas of less than 50,000, two PCPs are available in any county or service area within no more than 60 miles or 60 minutes' average driving time for 90% of the enrolled population.</li> <li>• For remote rural areas, the superintendent shall consider on a case-by-case basis whether the MHCP has made sufficient PCPs available given the number of residents in the county or service area and given the community's standard of care</li> <li>• In its access plan, the MHCP should demonstrate that in population areas of 50,000 or more residents, at least one licensed acute care hospital providing, at a minimum, licensed medical-surgical, emergency medical, pediatric, obstetrical, and critical care services is available no greater than 30 miles or 30 minutes' average driving time for 90% of the enrolled population within the service area, and, in population areas of less than 50,000, that the acute care hospital is available no greater than 60 miles or 60 minutes' average driving time for 90% of the enrolled population within the service area.</li> <li>• For remote rural areas, the superintendent shall consider on a case-by-case basis whether the MHCP has made at least one licensed acute care hospital available given the number of residents in the county or service area and given the community's standard of care.</li> <li>• MHCPs are encouraged to facilitate a covered person's ability to obtain a second opinion from a participating health care professional regarding the covered person's request for a second opinion from, or referral to, a non-participating health care professional.</li> </ul>
<b>Balance Billing Protections<sup>64-65</sup></b>	<ul style="list-style-type: none"> <li>• The MHCP shall provide in the contract terms that the MHCP and the PCP or other participating health care professional shall refer a covered person to a non-participating health care professional and shall fully reimburse the non-participating health care professional at the usual, customary, and reasonable rate or at an agreed-upon rate.</li> <li>• The law requires insurers to pay for all out-of-network emergency services necessary to evaluate and stabilize the patient and removes any prior authorization requirements.</li> <li>• For nonemergency care, insurers have to reimburse out-of-network care provided at in-network facilities, not holding the patient liable for balance billing. If medically necessary care is unavailable in the insured patient's network, insurers are required to pay for the out-of-network services.</li> </ul>
<b>Appeals and Denials Process<sup>66-67</sup></b>	<ul style="list-style-type: none"> <li>• Health plans must provide written notice to a patient, patient's designee or patient's provider of whether the services are considered in- or out-of-network.</li> <li>• A patient, patient's designee or patient's provider can internally appeal an adverse determination within 180 days. The health plan medical director must make a determination within 30 days of the receipt of the appeal.</li> </ul>

	<ul style="list-style-type: none"> <li>• Once the patient has received an adverse internal appeal determination, the patient, patient’s designee or patient’s provider can either request a review by a panel selected by the insurer within five days of the receipt of the appeal or file for an external independent review within four months.</li> <li>• If the patient requests the panel review, the panel must complete its review within 30 days. If the patient selects the external review, a certified independent review organization (IRO) must review the appeal and make a determination as to whether the out-of-network health service will be covered, within 20 days of receipt of the request.</li> <li>• If the patient receives an adverse determination from the IRO, the patient, patient’s designee or patient’s provider can have the IRO determination reviewed by the superintendent of the Insurance Department in a public hearing. The hearing officers will provide a recommendation to the superintendent within 30 days of the hearing.</li> <li>• The superintendent’s decision is final and legally binding. The patient can only seek legal counsel and file a lawsuit.</li> </ul>
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<b>New York Case Study</b>	
<b>General Information</b>	<ul style="list-style-type: none"> <li>• State-based marketplace coverage managed by the Department of Health and Department of Financial Services (DFS).</li> <li>• The marketplace was created on April 12, 2012, under Governor Andrew Cuomo.<sup>68</sup></li> <li>• NY State of Health established regional advisory committees representing the five regions of the state.<sup>69</sup></li> <li>• Each committee is made up of members from consumer, small business, provider, insurance and labor groups.</li> <li>• The New York State of Health has four levels of insurance plans: Bronze level (60% coverage), Silver level (70% coverage), Gold level (80% coverage) and Platinum level (90% coverage)—with Bronze having lower premiums but higher out-of-pocket costs.<sup>70</sup> New York also provides catastrophic plans for those eligible.</li> <li>• Individuals in the 133% to 400% of Federal Poverty Level (FPL) range are also eligible for a premium tax credit.<sup>71</sup></li> <li>• In 2020, New York is offering 12 Qualified Health Plans, 15 Essential Plans and 10 small business plans on its marketplace.<sup>72</sup></li> </ul>
<b>Provider Access<sup>73-74</sup></b>	<ul style="list-style-type: none"> <li>• The network will include at least one hospital in each county; however, for Erie, Monroe, Nassau, Suffolk, Westchester, Bronx, Kings, New York and Queens counties, the network will need to include at least three hospitals.</li> <li>• The network will include a choice of three PCPs in each county, and potentially more based on enrollment and geographic accessibility.</li> <li>• The network will include at least two of each specialist provider type, and potentially more based on enrollment and geographic accessibility.</li> </ul>

<b>Appointment Wait Times<sup>75</sup></b>	<ul style="list-style-type: none"> <li>No provider appointment wait times are listed, but the following will be considered at the time of review: number of grievances filed by enrollees relating to waiting times for appointments, appropriateness of referrals and other indicators of plan capacity.</li> </ul>
<b>Provider-Enrollee Ratios<sup>76</sup></b>	<ul style="list-style-type: none"> <li>There must be sufficient providers in each area of specialty practice to meet the needs of the enrollment population.</li> </ul>
<b>Provider Directories<sup>77-78</sup></b>	<ul style="list-style-type: none"> <li>A health plan must post its directory on its website and update its website within 15 days of the addition or termination of a provider from its network or a change in a physician's hospital affiliation.</li> </ul>
<b>Travel Time and Distance Standards<sup>79</sup></b>	<ul style="list-style-type: none"> <li>For PCPs:             <ul style="list-style-type: none"> <li>Metropolitan areas: 30 minutes by public transportation.</li> <li>Non-metropolitan areas: 30 minutes or 30 miles by public transportation or by car.</li> <li>In rural areas, transportation may exceed these standards if justified.</li> </ul> </li> <li>For providers that are not PCPs:             <ul style="list-style-type: none"> <li>It is preferred that an insurer meet the 30-minute or 30-mile standard for other providers that are not PCPs.</li> </ul> </li> </ul>
<b>Balance Billing Protections<sup>80-81</sup></b>	<ul style="list-style-type: none"> <li>These protections define "surprise bills" for health care services and establish an independent dispute resolution process for such bills.</li> <li>They also hold consumers harmless for emergency services provided by physicians and hospitals, including inpatient services which follow an emergency room visit, and provides an independent dispute resolution process.</li> </ul>
<b>Appeals and Denials Process<sup>82</sup></b>	<ul style="list-style-type: none"> <li>Before a patient receives non-emergency service, doctors and hospitals must clearly communicate their health plan affiliations in writing or via website and verbally during appointment scheduling.</li> <li>Health plans that require pre-authorization must identify whether the services are considered in or out-of-network. The health plan must identify the dollar amount they will pay if the service is out-of-network.</li> <li>A patient, patient's designee, or a patient's provider can appeal an adverse determination by a utilization review agent. Decision for pre-service appeals is 15 days of receipt of appeal if there are two levels of internal appeal, and 30 days of receipt of the appeal if one level of internal appeal. Decision for post-service appeals is earlier of 30 days of receipt of the necessary information or 60 days of receipt of the appeal. If the plan has two levels of internal appeal, it is 30 days of receipt of the appeal.</li> <li>The utilization review agent will make an appeal determination that either upholds or reverses the adverse determination. The determination must include the reasons for the decision and notice of the insured's right to an external appeal.</li> <li>The patient has four months to initiate an external appeal to the Department of Financial Services after they receive notice from the health care plan, or such plan's utilization review agent, of a final adverse determination or denial or after both</li> </ul>



	<p>the plan and the enrollee have jointly agreed to waive any internal appeal. Providers appealing on their own behalf must submit the external appeal within 60 days of the final adverse determination.</p> <ul style="list-style-type: none"> <li>• The external appeal agent reviews the final adverse determination and then will make a determination as to whether the out-of-network health service will be covered by the health plan within 30 days of the receipt of the appeal request. If the out-of-network health service is not materially different from health services available in-network, it will not be covered. If it is materially different, the appeal agent assigns a panel to make a determination whether the service will be covered. The determination will be accompanied by a written statement that the out-of-network service will be covered or will uphold the denial of coverage. Note: there are also medical necessity, experimental and investigational, rare disease, clinical trial, and access external appeals.</li> <li>• For consumer-initiated appeals or provider initiated appeals where the provider prevails, the health care plan must make payment to the external appeal agent within 45-days from the date the appeal determination is received by the health care plan. For provider-initiated appeals, if the denial of coverage is upheld, the requesting provider pays the external appeal agent. However, if the service is covered in part, the payment for the external appeal will be evenly divided between the health plan and the patient's health care provider who requested the appeal within 45-days from the date the appeal determination is received by the health care plan.</li> <li>• Appeals may be expedited for a decision within 72 hours if a delay would pose a threat to the patient's health.</li> <li>• If the patient received a surprise medical bill, the patient, the patient's health plan, or provider can appeal the bill through an independent dispute resolution entity (IDRE). The IDRE must make a determination within 30 days of receipt of the dispute. The IDRE may direct a good faith negotiation for settlement if settlement is likely or if the health plan's payment and the provider's fee are unreasonably far apart. The review is binding and admissible in court.</li> </ul>
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<b>Pennsylvania Case Study</b>	
<b>General Information</b>	<ul style="list-style-type: none"> <li>• Moving from a federally facilitated to a state-based marketplace and operated by the Pennsylvania Health Insurance Exchange Authority.<sup>83-84-85</sup></li> <li>• As part of the move, Pennsylvania also applied for a state-based reinsurance program under Section 1332, which was approved in July 2020.<sup>86</sup></li> <li>• Both the exchange and reinsurance program are operational for plans that take effect beginning in January 2021.<sup>87</sup></li> <li>• In 2020, Pennsylvania has 12 plans participating in the exchange marketplace.<sup>88</sup></li> </ul>
<b>Provider Access<sup>89-90</sup></b>	<ul style="list-style-type: none"> <li>• A plan shall at all times assure enrollee access to primary care providers, specialty care providers and other health care</li> </ul>

	<p>facilities and services necessary to provide covered benefits. Includes general acute inpatient hospital services, common laboratory and diagnostic services, anesthesiology, and other specialty services (oncology not included).</p>
<b>Appointment Wait Times</b>	<ul style="list-style-type: none"> <li>• None.</li> </ul>
<b>Provider-Enrollee Ratios</b>	<ul style="list-style-type: none"> <li>• None.</li> </ul>
<b>Provider Directories<sup>91</sup></b>	<ul style="list-style-type: none"> <li>• For plan years beginning on or after January 1, 2016, a QHP issuer must publish an up-to-date, accurate and complete provider directory.</li> </ul>
<b>Travel Time and Distance Standards<sup>92</sup></b>	<ul style="list-style-type: none"> <li>• A plan shall provide, for at least 90% of its enrollees in each county in its service area, access to covered services that are within 20 miles or 30 minutes' travel from an enrollee's residence or work in a county designated as a metropolitan statistical area by the U.S. Census Bureau, and within 45 miles or 60 minutes' travel from an enrollee's residence or work in any other county.</li> </ul>
<b>Balance Billing Protections<sup>93-94</sup></b>	<ul style="list-style-type: none"> <li>• A plan shall cover services provided by a nonparticipating health care provider at no less than the in-network level of benefit when the plan has no available network provider.</li> <li>• A plan is not required to pay a noncontracted provider at the same benefit level as a network provider for basic health care services sought by and provided an enrollee while outside the service area when in-network providers are available.</li> <li>• In November 2019, the Pennsylvania General Assembly introduced the Surprise Balance Billing Protection Act to protect patients from surprise medical bills from out-of-network providers. The bill passed out of committee but has yet to move beyond the House floor.</li> </ul>
<b>Appeals and Denials Process<sup>95-96-97</sup></b>	<ul style="list-style-type: none"> <li>• As previously noted, the ACA preempts the PA appeals and denials process, which PA has adopted through regulations.</li> <li>• Moreover, issues of network adequacy, contract review, credentialing, which are dealt with by the Department of Health, and prompt pay, which is dealt with by the Insurance Department, among other matters, are reviewed by the relevant department. The Departments continue to review as complaints matters that are not considered adverse benefit determinations as defined by the ACA and its regulations, in the same manner as before the passage of the ACA. (Examples of the type of complaints that should continue coming to the PA Departments, and not go to HHS, are complaints relating to contract exclusions, and issues relating to co-payments, formulary changes, out-of-network benefits, and services beyond the contractual limitation.)</li> <li>• Consumer complaints relating to pre-service authorization denials based on medical judgment, as well as consumer complaints relating to the amount of a payment, are handled pursuant to the federal external review process the issuer has implemented, and are subject to appropriate notice and appeal rights: either to an external review if involving medical judgment, or to a civil court upon conclusion of the internal appeal process if the complaint does not involve medical judgment.</li> </ul>

<b>Washington Case Study</b>	
<b>General Information</b>	<ul style="list-style-type: none"> <li>• State-based marketplace managed by the Office of the Insurance Commissioner.</li> <li>• Washington was one of the first states to create a state-based marketplace, with Governor Chris Gregoire signing the legislation in May 2011.<sup>98</sup></li> <li>• The marketplace is governed by an 11-member board of directors with the insurance commissioner and administrator of the Washington Health Care Authority as nonvoting members.<sup>99</sup></li> <li>• In May 2019, Washington enacted legislation establishing standardized health plans and a public option that is intended to be operational as of 2021.<sup>100</sup></li> <li>• The state also created additional premium subsidies that are set to be available by 2022.<sup>101</sup></li> <li>• In 2020, Washington is offering nine plans on its exchange.<sup>102</sup></li> </ul>
<b>Provider Access<sup>103</sup></b>	<ul style="list-style-type: none"> <li>• An issuer must maintain each provider network for each health plan in a manner that is sufficient in numbers and types of providers and facilities.</li> <li>• An issuer may use facilities in neighboring service areas to satisfy a network access standard if a type of facility is not in the service area, or if the issuer can provide substantial evidence of good faith efforts on its part to contract with the facility in the service area. This includes cancer care hospitals.</li> </ul>
<b>Appointment Wait Times<sup>104</sup></b>	<ul style="list-style-type: none"> <li>• The issuer must ensure sufficient qualified staff is available to provide timely prior authorization decisions on an appropriate basis, without delays detrimental to the health of enrollees.</li> </ul>
<b>Provider-Enrollee Ratios<sup>105</sup></b>	<ul style="list-style-type: none"> <li>• The ratio of primary care providers to enrollees within the issuer's service area as a whole meets or exceeds the average ratio for Washington State for the prior plan year.</li> <li>• Insurers must report to the insurance commissioner any changes affecting the ability of their network providers and facilities to furnish covered services to enrollees.</li> <li>• Triggering events requiring written notice to the commissioner within 15 days include:             <ul style="list-style-type: none"> <li>○ Reduction of 10% or more in the number of specialty providers, mental health providers or facilities participating in the network</li> <li>○ Termination or reduction of a specific type of specialty provider where there are fewer than two of the specialists in a service area</li> <li>○ An increase or reduction of 25% or more in the number of enrollees in the service area since the annual approval date</li> <li>○ The termination or expiration of a contract with a hospital or any associated hospital-based medical group within a service area</li> <li>○ A 15% reduction in the number of providers or facilities for a specific chronic condition or disease participating in the network where the chronic condition or disease affects more than 5% of the issuer's enrollees in the service area</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>• Written notice to the commissioner must include the insurer’s preliminary determination whether the identified changes in the network require an alternative access delivery request.</li> </ul>
<b>Provider Directories</b> <sup>106</sup>	<ul style="list-style-type: none"> <li>• Provider directories must be updated at least monthly and must be offered to accommodate individuals with limited-English proficiency or disabilities. An issuer must post the current provider directory for each health plan online, and must make a printed copy of the current directory available to an enrollee upon request.</li> </ul>
<b>Travel Time and Distance Standards</b> <sup>107</sup>	<ul style="list-style-type: none"> <li>• For PCPs, the network includes such numbers and distribution that 80% of enrollees within the service area are within 30 miles of a sufficient number of PCPs in an urban area and within 60 miles of a sufficient number of PCPs in a rural area (from either their residence or work).</li> <li>• An issuer must provide one map for the service area for specialties found on the American Board of Medical Specialties list of approved medical specialty boards. The map must demonstrate that 80% of the enrollees in the service area have access to an adequate number of providers and facilities in each specialty. Subspecialties are subsumed on the map.</li> <li>• When an enrollee is referred to a specialist, the issuer must ensure the enrollee has access to an appointment with such a specialist within 15 business days for nonurgent services.</li> </ul>
<b>Balance Billing Protections</b> <sup>108</sup>	<ul style="list-style-type: none"> <li>• The enrollee’s obligation must be determined using the carrier’s median in-network contracted rate for the same or similar service in the same or similar geographical area.</li> </ul>
<b>Appeals and Denials Process</b> <sup>109-110-111</sup>	<ul style="list-style-type: none"> <li>• Health plans must provide written notice to a patient, patient’s designee or patient’s provider of whether the services are considered in- or out-of-network.</li> <li>• A patient, patient’s designee or patient’s provider can internally appeal an adverse determination. The health plan must make a determination within 30 days of the receipt of the appeal.</li> <li>• The health plan will make a determination that either upholds or reverses the adverse determination. The determination must include the reasons for the decision and procedures for filing a request for an independent review. Some plans may provide an additional level of internal review.</li> <li>• Once the patient has received an adverse appeal determination, the patient, patient’s designee or patient’s provider can file for an independent review.</li> <li>• A certified independent review organization (IRO) will review the appeal and make a determination as to whether the out-of-network health service will be covered by the health plan, no later than the earlier of within 15 days of receipt of the necessary information or within 20 days of receipt of the request. The determination will be accompanied by a written statement that the out-of-network service will be covered or will uphold the denial of coverage and include the reasoning for the decision.</li> <li>• The IRO decision is final and legally binding. If the IRO upholds the denial, the patient can only seek legal counsel and file a lawsuit.</li> </ul>

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Provider Access: Requires that networks meet standards for enrollee accessibility to certain providers  
Appointment Wait Times: Requires that networks meet standards for minimal appointment wait times for enrollees  
Provider-Enrollee Ratios: Requires that networks meet specific provider to enrollee ratios in their service areas  
Travel Time and Distance: Requires that networks meet specific time and distance standards for enrollees in their service areas  
Provider Directories: Requires that networks present and update a directory of their participating providers  
Balance Billing: Addresses the surprise bills and the practice of provider billing for the difference between the provider’s charge and the health carrier’s allowed amount  
Appeals/Denials Process: Establishes a process to address patient grievances for adverse out-of-network coverage determinations  
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- <sup>104</sup> Network access – General standards. WAC 284-170-200.

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<sup>105</sup> Maintenance of sufficient provider networks. WAC 284-170-230.

<sup>106</sup> Provider directories. WAC 284-170-260.

<sup>107</sup> Network access – General standards. WAC 284-170-200.

<sup>108</sup> Notice of consumer rights and transparency. WAC 284-43B-050.

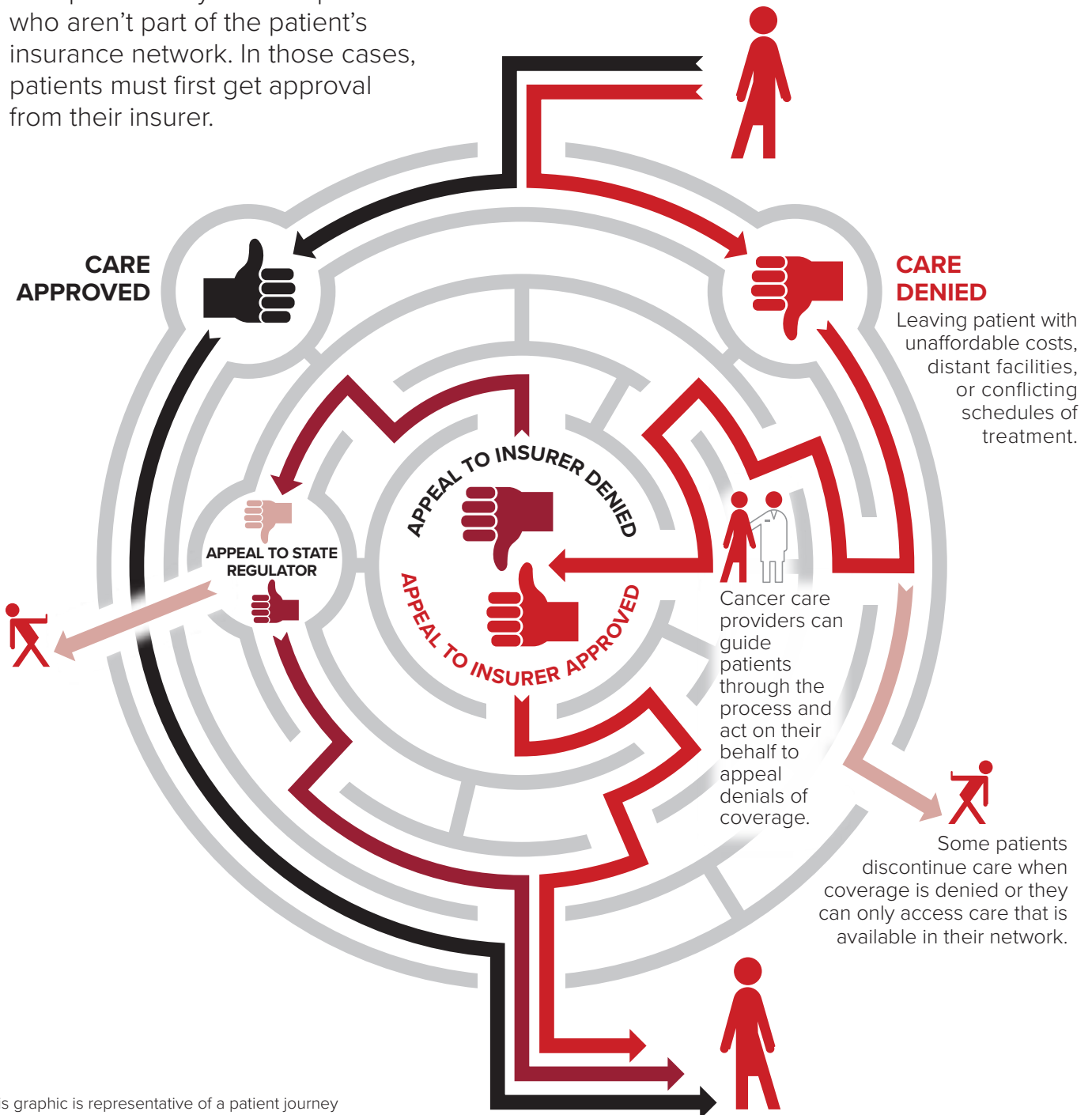
<sup>109</sup> Requirement for carriers to have comprehensive grievance and appeal processes—Carrier’s duties—Procedures—Appeals—Rules. RCW 48.43.530.

<sup>110</sup> RCWs relating to assignments of independent review organizations (IROs) [Internet]. Office of the Insurance Commissioner Washington State. Available from: <https://www.insurance.wa.gov/rcws-relating-assignments-independent-review-organizations-iros>

<sup>111</sup> How to appeal a health care insurance decision [Internet]. Office of the Insurance Commissioner Washington State; p. 1–63. Available from: [https://www.insurance.wa.gov/sites/default/files/documents/appeals-guide\\_3.pdf](https://www.insurance.wa.gov/sites/default/files/documents/appeals-guide_3.pdf)

## THE PATH TO COVERAGE AND TREATMENT FOR CANCER PATIENTS

Patients who receive a blood cancer diagnosis face a complex journey as they navigate their treatment options. It's especially complicated for patients requiring **out-of-network** care provided by medical professionals who aren't part of the patient's insurance network. In those cases, patients must first get approval from their insurer.



This graphic is representative of a patient journey as found in the report: **Accessing Out-of-Network Subspecialty Cancer Care in Marketplace Plans: Key Findings from a Scan of Four States.** See report for full details.

**Out-of-network coverage successfully obtained**

The right treatment, in the right place, at the right time

# HOW STATES CAN HELP

Regulations can be enhanced to improve the patient experience

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**Adopt robust network adequacy standards** — or refine current standards— to ensure patients have access to a wide variety of providers.

Patients should be able to work with highly specialized doctors and hospitals, when they need them, without having to travel great distances.



**Hold insurance plans accountable** for maintaining high-quality networks by requiring notification to regulators when changes occur and taking action as necessary.

Increasing regular communication between plans and the state proactively mitigates network adequacy issues that could negatively impact patient access to timely care.



**Simplify the patient experience** through increased transparency and streamlined appeals and grievances processes.

Combining a simple, searchable provider network with the availability of appeals and determinations data could help patients be better-informed as they select a plan. States should also ensure a simple, streamlined external appeals process is available to patients.



**Invest state resources in departments of insurance.**

State regulatory bodies with more resources can more effectively engage with both plans and consumers, and they can develop tools to support consumers as they navigate the marketplace.



**Provide enhanced, easy-to-understand educational information and support** services to providers and patients about how they can appeal insurer decisions.

States should develop patient-friendly education materials and require plans to educate their members — particularly for patients with diagnoses like cancer that require complex treatment. States should also invest in programs to provide assistance directly to consumers.



**Implement protections to ensure access** to medically necessary cancer care even when out-of-network, or when cost-sharing or other factors may put it out of reach. Restructure these policies to protect and support the most vulnerable populations.



**Develop and enforce cancer care-specific network adequacy standards** that would ensure all networks allow timely access to cancer-care services.