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The Honorable Richard E. Neal Chairman, Ways & Means Committee U.S. House of Representatives Washington, D.C. 20515 The Honorable Kevin Brady Ranking Member, Ways & Means Committee U.S. House of Representatives Washington, D.C. 20515

### **RE: Rural and Underserved Communities Health Task Force Request for Information**

The American Society of Clinical Oncology (ASCO) is pleased to provide a response to the Committee's request for information on Rural and Underserved Communities. ASCO commends the Committee for its partnership with the Rural and Underserved Communities Health Task Force to address this important issue.

ASCO is the national organization representing nearly 45,000 physicians and other health care professionals specializing in cancer treatment, diagnosis, and prevention. We are committed to ensuring that evidence-based practices for the treatment of cancer are available to all Americans.

Access to health care presents a special challenge for patients in rural areas and underserved communities. Further, access barriers to care can jeopardize chances of a successful outcome for patients with cancer. Nearly one in five Americans (over 59 million) live in rural areas. Cancer patients living in rural areas of the United States are diagnosed at later stages, have a higher proportion of their cases unstaged at diagnosis, and are often in a more advanced stage of illness when referred to home health agencies.<sup>1</sup> In response to these issues, ASCO launched its <u>Rural Cancer Care Task Force</u> aimed at reducing disparities and improving outcomes for patients and survivors living in rural communities.

Health care-related factors that influence patient outcomes in rural and/or urban underserved areas. List additional systems or factors outside of the health care industry that influence health outcomes in these communities.

Transportation Barriers

<sup>&</sup>lt;sup>1</sup> US Department of Health and Human Services: Health resources and services administration. Federal office of rural health policy: Defining rural population. <u>https://www.hrsa.gov/rural-health/about-us/definition/index.html</u>.

For rural patients, transportation issues exacerbate barriers to obtaining high-quality cancer care. According to a 2008 study, patients living in large rural towns travel a median of fifty-one minutes to get to any oncology professional, and those in small or isolated towns travel fifty-nine minutes. In order to reach the nearest academic-based care, they must travel a median of eighty-three and ninety-seven minutes, respectively.<sup>2</sup> Patients with cancer living in rural areas may also need to take time off of work to accommodate lengthy travel times or require a family-member or caregiver to do so. Given the high poverty levels in many rural areas, some patients face additional financial barriers to accessing transportation, including not having enough money for gas or a vehicle.

#### **Insurance Coverage Barriers**

Historically, rural areas have fewer residents covered by employer-sponsored health insurance compared with those living in urban areas. Moreover, nearly two-thirds of the rural uninsured live in states that have not expanded Medicaid, leaving a coverage gap for those who have incomes below 100 percent of the federal poverty level. This makes them ineligible for tax credits tied to the Affordable Care Act but places them above their state Medicaid eligibility levels. The fact that the proportion of services covered by Medicaid and Medicare is higher in rural areas compared with private health insurance coverage has significant implications for the reimbursement of rural providers. Given the payment differential and potential impacts on revenue, physicians may be unable to accept new Medicaid patients, thereby exacerbating access problems in rural areas.

### Obstacles to accessing clinical trials

Research has demonstrated significant geographic variation in rates of participation in cancer clinical trials. A major barrier is finding a clinical trial close enough to be considered feasible by rural patients. Small rural cancer centers often do not often have sufficient volume of patients to support dedicated clinical research nurses/staff, often leading to poor trial accrual. Recent data suggest that the rural-urban disparities in outcomes largely disappears with uniform access to clinical trials, which are part of the standard of care for cancer.<sup>3</sup>

For rural patients covered by Medicaid, there are additional barriers to accessing clinical trials. Medicaid is the only major payor not federally required to cover routine care costs associated with clinical trial enrollment such as laboratory tests, physician visits, and screenings when a patient enrolls on a clinical trial. While some states have chosen to require this coverage, many states have chosen not to require this important coverage, making clinical trials even more cost prohibitive for these patients.

#### Difficulty accessing palliative care and supportive services

<sup>&</sup>lt;sup>2</sup> Onega T, Duell EJ, Shi X, et al: Geographic access to cancer care in the U.S. Cancer 112(4): 909-18, 2008.

<sup>&</sup>lt;sup>3</sup> Unger JM, Moseley A, Symington B, et al: Geographic distribution and survival outcomes for rural patients with cancer treated in clinical trials. JAMA Netw Open 1(4): e181235, 2018.

The availability of supportive care and other specialists needed by patients with cancer is low or nonexistent in many rural areas, despite poverty, mental illness, and other psychosocial problems being prevalent in many rural counties throughout the country.<sup>4</sup> One study of rural cancer survivors demonstrated poorer mental health functioning, as well as greater symptoms of anxiety, depression, distress, and emotional problems compared with urban cancer survivors.<sup>5</sup> Mental health specialists who can assist cancer patients are lacking in rural areas compared with urban areas: Only 2 percent of health social workers practice in rural areas, and specialized oncology social workers are essentially nonexistent in rural towns.<sup>6</sup>

Rural residents also have poorer geographical access to palliative care and hospice services. A study involving a palliative care needs assessment of 236 rural hospitals in seven Rocky Mountain Region states found that, while most hospitals provided contract hospice services and advanced care planning activities, fewer than half reported having a formal palliative care program or pain service. Moreover, only 9 percent of employed clinicians have actually received formal palliative care training.<sup>7</sup> For those rural areas that struggle to provide adequate access to hospice services, reported obstacles included financial challenges associated with low patient volume, medication costs, and insufficient Medicare reimbursement; along with recruitment and retention of staff.<sup>8</sup>

For more information on patients with cancer in rural communities and the policy issues that impact them, please see ASCO's issue brief on <u>Rural Cancer Care</u>.

### What successful models show a demonstrable positive impact on health outcomes within rural or underserved communities (i.e. social determinants of health, multiple chronic conditions, broadband access, the use of telehealth/medicine/monitoring)?

Rural or underserved communities are best served by models that can provide high quality care despite limited resources and fewer trained personnel. "Hub and spoke" organizational models are expressly designed to accomplish this, by utilizing a central hub housing a full suite of services and providers with relevant expertise, alongside smaller satellite facilities that can triage and route patients appropriately.

 <sup>&</sup>lt;sup>4</sup> Locke BL, Winship J: Social work in rural America: Lessons from the past and trends for the future, in Lohmann N, Lohmann RA (eds): Rural Social Work Practice. New York, NY, Columbia University Press, 2006, p. 3-24.
<sup>5</sup> Burris JL, Andrykowski M: Disparities in mental health between rural and nonrural cancer survivors: a preliminary

study. Psychooncology 19 (6): 637-45, 2010.

<sup>&</sup>lt;sup>6</sup> Whitaker T, Weismiller T, Clark E, et al: Assuring the sufficiency of a frontline workforce: A national study of licensed social workers—Special report: Social work services for children and families. Washington, DC: National Association of Social Workers; 2006.

<sup>&</sup>lt;sup>7</sup> Fink RM, Oman KS, Youngwerth J, et al: A palliative care needs assessment of rural hospitals. J Palliat Med 16(6): 638-44, 2013.

<sup>&</sup>lt;sup>8</sup> Casey MM, Moscovice IS, Virnig BA, et al: Providing hospice care in rural areas: challenges and strategies. Am J Hosp Palliat Care 22(5): 363-8, 2005.

Importantly, this model is highly scalable and can be adjusted based on geographic needs.<sup>9</sup> A related model in cancer is Project ECHO, which uses case-based learning to build local capacity, providing physicians in communities with the tools needed to deliver care comparable to that of academic specialists. The ECHO model has demonstrated success in amplifying an organization's ability to share best practices and to decrease cancer disparities in rural areas.<sup>10</sup>

### What should the Committee consider with respect to patient volume adequacy in rural areas?

ASCO has concerns regarding the sustainability of oncology practices in rural settings, in part because of the large volume of beneficiaries covered by public programs. The relative lack of commercially insured patients decreases reimbursement and practice operating margins, even when overall patient volume is comparable to practices in non-rural settings. This financial issue is further exacerbated by the expenses involved in drug procurement, which in rural settings may be higher because small practices may not have sufficient volume to achieve discounts or other considerations that allow economies of scale. All of the above makes it more difficult for rural practices to cover their costs for facilities and administrative support.

### What successful models show a demonstrable, positive impact on addressing workforce shortages in rural and underserved areas? What makes these models successful?

Workforce challenges are a main obstacle to healthcare services for patients in rural and underserved areas. In 2005, ASCO commissioned the Association of American Medical Colleges (AAMC) Center for Workforce Studies to conduct an oncology workforce study focusing on medical oncologists, hematologists/oncologists, and gynecologic oncologists. The study, Forecasting the Supply of and Demand for Oncologists (2007), found that supply was projected to increase only twenty percent between 2007 and 2020, with capacity for oncologic visits projected to rise even less at fourteen percent. Demand for services, however, was projected to grow by forty-eight percent during that same time.<sup>11</sup>

In anticipation of the shortages projected as part of this 2007 study, ASCO initiated the Workforce Information System (WIS), to assemble the latest data on the supply of oncologists and cancer incidence and prevalence. The first report of findings from the WIS was published in 2013 and noted the following:<sup>12</sup>

• The number of oncologists age 64 years and older has been growing more rapidly than the overall number of oncologists.

<sup>11</sup> American Society of Clinical Oncology: Forecasting the supply of and demand for oncologists: A report of the American Society of Clinical Oncology (ASCO) from the AAMC Center for Workforce Studies. <u>https://www.asco.org/sites/new-www.asco.org/files/content-files/research-and-progress/documents/Forecasting-the-Supply-of-and-Demand-for-Oncologists.pdf</u>

<sup>&</sup>lt;sup>9</sup> Elrod, J.K., Fortenberry, J.L. The hub-and-spoke organization design: an avenue for serving patients well. BMC Health Serv Res 17, 457 (2017) doi:10.1186/s12913-017-2341-x

<sup>&</sup>lt;sup>10</sup> Arora S. Project ECHO: Ensuring that best practice cancer care and precision medicine reach the last mile. Journal of Clinical Oncology 2018 36:15\_suppl, e18685-e18685.

- Incoming pipeline issues including the stagnate number of residency slots in internal medicine and oncology-focused fellowships, caused by inadequate funding available for expansion of these programs.
- Changes to organizational structures, including practice mergers and closures.

Loan repayment programs have been established to address workforce shortages in these communities but have been limited in oncology. Those oncology providers who do practice in rural areas face a number of barriers to receiving continuing education, including distance to teaching hospitals that typically provide educational programs and scarcity of time that can be diverted away from patient care due to lack of coverage. The hub-and-spoke model has been used to increase workforce capacity and is often facilitated by the use of technology, such as telemedicine. Strategies to improve rural cancer care include improving access to research and participation in clinical trials among rural cancer patients.

To improve provider and training ASCO supports increasing the availability of lower-cost, more easily accessible education opportunities for rural oncology providers and improving mentorship and training opportunities to reduce isolation among early-career oncologists.

# There are known, longstanding issues with the availability and integrity of data related to rural and urban community health. What data definitions or data elements are needed to help researchers better identify the causes of health disparities in rural and underserved areas, but are unavailable or lack uniformity?

In 2017, ASCO released a joint statement with the American Association for Cancer Research (AACR), the American Cancer Society (ACS), and the National Cancer Institute (NCI) to foster cooperation across the cancer research community. The four national entities committed to ensuring that all patients, regardless of social demographics, socioeconomic status, or the communities in which they live, benefit from cancer research. The current peer-reviewed research supports the assertions in the joint statement, that disparities are driven by a range of multi-level patient, community, and structural factors, including inequities in health care quality and delivery.

Our collective understanding of the underlying drivers of cancer disparities is growing, but the joint statement makes several recommendations for continuing to advance the research on, and the science of, disparities. The first recommendation: *Defining and improving data measures and tools for cancer disparities research* is particularly relevant to the Committee's RFI on rural health and underserved communities.

In underserved and rural areas, patient data is often incomplete, inaccurate, or over-simplified and usually does not consider many social and community factors. Cancer research is limited by a lack of comprehensive, consistent data on factors that impact disparities in cancer care and patient outcomes including patient social status and demographics, community and lifestyle factors, and biology and genetics. Widespread variation in data collection methodology has also compromised the utility of select data sets for disparities research. These limitations are also noted in the data ASCO currently collects and makes available to its **committees** and its members via ASCO's <u>Center for Research and Analytics</u>

(CENTRA), or through participation in an ASCO Quality <u>Improvement Programs such as the Quality</u> <u>Oncology Practice Initiative</u> (QOPI) and <u>CancerLinQ</u>.

ASCO and a community of organizations, clinicians, and researchers, have come together to address the need to obtain high-quality, computable data from the clinical care environment. The foundation of this initiative,  $mCODE^{TM}$ , will provide data standards that can be adopted by a wide variety of stakeholders to drive quality if care, patient engagement, and research progress. To learn more about  $mCODE^{TM}$ , please see mCODE, a Core Set of Common Cancer Data Standards, Established.

## Are there two or three institutional, policy, or programmatic efforts needed to further strengthen patient safety and care quality in health systems that provide care to rural and underserved populations?

To address a barrier to care for patients enrolled in Medicaid, ASCO calls on Congress to enact the *CLINICAL TREATMENT Act* (H.R. 913), which would guarantee Medicaid coverage of the routine care costs for clinical trials participation.

We also strongly support efforts to address the impact of utilization management policies on patients with cancer and cancer providers, including the *Improving Seniors' Timely Access to Care Act* (H.R. 3107), which would help to alleviate burdens and delays created by prior authorization within Medicare Advantage plans, and the *Safe Step Act* (H.R. 2279), which would put in place important patient safeguards from step therapy protocols for ERISA-governed health plans. These improvements would be particularly beneficial for overburdened practices in rural areas.

Additionally, we support the *Cancer Drug Parity Act* (H.R. 1730), which would ensure that patient cost sharing for oral anticancer drugs is no less favorable than for IV drugs anticancer drugs. Increased access to oral anti-cancer drugs can help alleviate the geographic burdens that patients with cancer in rural and underserved areas face.

Thank you for your commitment to improving health care for patients in rural and underserved communities. If you have questions on any of the issues discussed in this response or about care of individuals with cancer, please contact Tyler Hanson at <u>Tyler.Hanson@asco.org</u>

Cc:

The Honorable Danny Davis, Co-Chair, Rural and Underserved Communities Health Task Force The Honorable Terri Sewell, Co-Chair, Rural and Underserved Communities Health Task Force The Honorable Brad Wenstrup, Co-Chair, Rural and Underserved Communities Health Task Force The Honorable Jodey Arrington, Co-Chair, Rural and Underserved Communities Health Task Force