Moonshot Resource Ideas for Montana

Attendees: N=69; Representing (some individuals represent more than one area) Survivor = 10; Caregiver = 6; Provider = 23; Policy = 20; Insurance = 3; Research = 7

Agencies Represented: US Senators Tester & Daines, House Representative Zinke, MT Governor, MT Insurance Commission, STAR Rehabilitation, Bozeman Health Cancer Center, Community Health Partners, Public Health, MT Hospital Lobby, Montana Cancer Consortium, Cholangiocarcinoma Foundation, Billings Clinic, Kalispell Regional Medical Center, Cancer Support Community Montana, Montana Bioscience Alliance, Living Independently for Today & Tomorrow, Inc (LIFTT), American Cancer Society, Genentech, and American Cancer Society Cancer Action Network.

Disclaimer: This is a summary of the ideas shared at the three Cancer Moonshot summits that were held in Kalispell, Bozeman and Billings, Montana. The recommendations are not necessarily supported by all the individuals and organizations who participated in the discussions.

Enhancing Care and Access:

Think about the entire care experience from point of diagnosis through cancer treatment and end of life care. What is a barrier for our patients? What policy, systems change or resources would make it easier for patients to get care in Montana? What could be done to improve disparities in cancer care?

1. **Physical Access:**
    a. BARRIERS: Transportation has many issues associated with it, both in rural and more urban areas:
        i. Rural challenges – include cost of travel, lodging (participant noted that ACS offers this but it has seasonal challenges), not only for inpatient but for primary care as well
        ii. Urban challenges – patient may have difficulty with transportation, access to treatment – family leave and caregiver support challenges. (Urban is a relative term given that Montana's largest city has a population of 109,000 and the second largest has 69,000)
        iii. Not all "urban" areas have specialists, so certain needs are unable to be met even in larger towns/cities.
        iv. Lack of access to care for people with disabilities throughout the entire spectrum of care - prevention, early detection, treatment, palliative and clinical trials.
    b. REQUESTS:
        i. Allow more interdisciplinary care through telemedicine to both satellite clinics and offsite settings (there are currently bills being considered but the infrastructure – i.e. broadband access in rural areas - is not sufficient)
        ii. Broaden reimbursement for telemedicine – allow providers to be reimbursed for services that meet patient where they are at (e.g. in nursing homes, at homes, etc.)

iii. Support interstate licensure compacts for MDs for both face-to-face outreach and telemedicine; also allow for second opinions. This is because regional centers of care sometimes cross over state lines.
iv. Rural communities need internet infrastructure - many are still on dial-up.
v. To improve access for people with disabilities, adopt the CDC and US Access Board Guidelines regarding accessible medical equipment and utilize person-first language and treatment strategies during care.
vi. Increase human and financial resources for Home Health care such as personal assistance options through Home and Community Based Waiver Systems. When improving transportation, make sure that they are accessible transit options. Increase in accessible, universal design housing options during new construction.

2. INSURANCE COVERAGE and USAGE:

a. BARRIERS:
   i. There is inconsistency among health plans (especially those that were grandfathered during the Affordable Care Act) about what is covered, where it is covered and by who/what provider; this applies not only to treatment but screening as well.
   ii. Patient health insurance literacy is a major issue – there is a lack of understanding of what is covered/how to use insurance (this is both rural and urban issue)
   iii. With a lack of home care, people in rural Montana are left alone without medical care when they get home, and therefore are more apt to stay in the hospital.
b. REQUESTS:
   i. Improve the provisions of the Affordable Care Act to ensure coverage of 100% of people.
   ii. Insurance companies should conduct extensive educational and culturally sensitive outreach to both urban and rural insured populations to ensure adequate understanding of insurance benefits.
   iii. Payers should reimburse for navigation visits, standard of care for those participating in clinical trials, dietician services, palliative care coordination, financial services, and palliative care in the home.
   iv. Need a congressional act to allow states the ability to regulate fees for air flights. Patients and payers are incurring enormous fees of over $100,000 when flighted out for care. This happens often in our rural state.
   v. Develop Tribal Sponsored Health Insurance Plans (TSHIP) plans on Montana reservations.
   vi. Congress needs to remove the "religious belief" exemption under the Affordable Care Act

3. CLINICAL TRIALS:

a. BARRIERS:
   i. Clinical trials are not always covered without the patient or someone else strongly advocating for it
b. REQUESTS:
   i. All early phase clinical trials should follow the NIH model of funding/coverage for patients.
   ii. Improve coordination of clinical trials through NCORP.
   iii. Improve the ability for smaller Cancer Centers manage their patients participation in clinical trials.

4. RESEARCH:

a. BARRIERS:

i. Restrictions that prevent health systems from participating in innovative programs and research because they partner with critical access hospitals. This discriminates against the "rural" disparate population.

b. REQUESTS:

i. Make Community Based Participatory Research (CBPR) more available in rural areas.

ii. Eliminate restrictions that prevent health systems from participating in CMS programs like Innovations in Health Care just because they partner with critical outreach hospitals.

5. PROVIDER/WORKFORCE:

a. BARRIERS:

i. In regards to pediatric oncology, oftentimes kids have to leave the state for extended periods of time for certain treatments

ii. There is a shortage of oncologists across Montana and the United States

iii. Lack of patient navigators to support patients through the continuum of care

iv. There is a lack of health care, home health and hospice type services available in the most rural of areas especially on our Native American reservations.

v. Due to low population in rural and frontier areas, specialists must travel across Montana and gain <u>easy access</u> to see patients. Visiting physicians face strict entry laws.

b. REQUESTS:

i. Support/fund self-advocacy/patient education programs (such as patient literacy and navigators) – must be provided to patient at point of care <u>when they need it/will be using it</u> (issue is some patients are given information at point of diagnosis or other times when they are unable to "hear" the resources available because they are focused on the immediate crisis)

ii. Fund research or a study on the ROI of reimbursing for patient navigators

iii. Provide additional Medicare slots for oncology residents

iv. Fund a demonstration model/pilot program for creative ways of reimbursement in rural areas. This may include developing an increase in how primary care physicians work collaboratively with oncologists.

v. Incentivize MD's to get into oncology and increase the use of Nurse Practitioners and Physician Assistants in cancer care. Provide an incentive for medical professionals to work in rural areas and on Indian Reservations.

vi. Indian Health Services (IHS) hiring regulations are prohibiting physicians and physician-assistants from working on the reservations. IHS hiring practices need to allow providers to work less than 5 days a week. In addition, providers need the option to work only in their specialized filed without being required to take ER and on-call shifts.

vii. Remove the requirement that visiting physicians must have a separate entrance, waiting room and receptionist.

6. SYSTEMS:

a. BARRIERS:

i. There are more opportunities for Montanans to pay for access to care but there is a lot of paperwork and the application process is complicated.

ii. American Indians have limited access to health care in Montana, and Indian Health Services is poorly equipped to provide solutions to care.

b. REQUESTS:

i. CMS needs to improve the process that happens for those who were insured through the marketplace and now through Medicaid Expansion.
ii. Improve incentives and technologies so that data can be better shared across health care systems.
iii. Overhaul Indian Health Services like was done with Veterans Administration.

Advancing Research Discoveries and Catalyzing Scientific Breakthroughs: This is really looking at strategies for integrating advances in cancer treatment into community care. How can we improve the ability for cancer centers to access entries into clinical trials and access to the newest and most up-to-date cancer treatments? How can we reduce barriers for Montana patients to access local and national trials?

1. **Financial Resources:**
    a. BARRIERS:
        i. There is a need for more financial resources for all research
        ii. There is a need for more funding for the infrastructure of clinical trials – this is especially important in a rural state like Montana.
        iii. Cost of genetic testing is still very expensive
        iv. It often costs the patient more to participate in clinical trials – travel to the research facility, travel to get more frequent testing, etc.
    b. REQUESTS:
        i. Invest more in all research not just for cures but for preventing, screening and improving quality of life.
        ii. Invest in supporting rural health systems infrastructure so that they can participate in clinical trials
        iii. Mandate coverage of genetic testing when qualifying risks are present.
        iv. Identify ways patients can get travel expenses reimbursed.
2. **Rural Participation in Research**
    a. BARRIERS:
        i. Not enough oncology residents slots available in rural states like Montana
        ii. Lack of integration of scientific teams doing the work. Biased against including community researchers on their team. An oncologist can apply and be denied for the same research multiple times then move to a known research institution and get the funding for the exact same project.
        iii. A community cancer center has to be "approved" for each individual study, and therefore is too difficult to have a lot of trials available for patients.
        iv. Some clinical trials require patients to travel out of state, and this burden makes it impossible to participate in the trial.
    b. REQUESTS:
        i. Make available more oncology resident slots in states like Montana.

ii. Challenge research institutions to diversify their research team to include community based researchers.
iii. Develop an accreditation system for all cancer centers that is controlled and monitored by a Central Government entity. Have strict standards that need to be met to "qualify" for certain tiers of trials which automatically let EVERY research site that is "preapproved" for that tier be a site for the study.
iv. Have a Clinical Research Coordinator for each community cancer center that is paid for by the study budget.

3. **System of Clinical Trial Implementation**
    a. BARRIERS:
        i. The costs of oncology drugs are too expensive.
        ii. There are shortages of oncology drugs - especially once it reaches generic status.
        iii. The system of clinical trial research is too difficult to use for patients and practitioners.
    b. REQUESTS:
        i. Develop US Government owned oncology drug manufacturing facilities that produce and sell oncology drugs to end users, at cost, or very small margin.
        ii. Implement Research Trial Navigators in the community cancer centers.
        iii. Improve www.clinicaltrials.gov website to be more user friendly.
        iv. Eliminate TV advertising for pharmaceutical companies.
        v. Develop screening protocols that are less invasive, more accessible and more affordable.
        vi. Subsidize and increase research for genome testing and personalized medicine.
        vii. Engage pharmacy companies at a national level regarding research of drugs for different cancers & NCI designated cancer centers.

Strengthening Prevention & Diagnosis: Although prevention and early detection are vital to reducing cancer and finding cancer at an early stage, only about half of Americans utilize preventive health services. Think about the systematic barriers to meaningful cancer prevention and diagnosis, and identify how government and public health efforts can improve the efforts in Montana.

1. **Policy :**
    a. BARRIERS:
        i. Obesity is rising in Montana, as with the rest of the U.S., and yet our children are not getting the exercise needed to maintain healthy weight.
        ii. Children and young adults are not being protected from things that are known carcinogens.
        iii. Genetic testing is not accessible to most patients even when a high family risk occurs.
    b. REQUESTS:
        i. Tobacco is sold to our military on base without taxes, and therefore at a very inexpensive rate. Our military is coming out of service with a high rate of tobacco use (both smoking and

spit). Either do not sell tobacco on military bases or increase the cost of tobacco to match the rate sold off base. Use the extra money to pay for health care for veterans.

ii. Mandatory cancer prevention education and **daily** physical education class in school-age children during school.

iii. Pass a law making it illegal for youth under age 18 to use artificial tanning beds.

iv. Change the law that makes it illegal for non-parent adults to apply sunscreen for children during school, daycare and other care-related programs.

v. Recognize breast MRI and dermatology checks as preventative screenings, and therefor pay for it at 100% through health insurance/ACA.

vi. For people with qualified family risk, include genetic testing as an approved test covered by health insurance.

vii. Pass House Bill H.R. 1220- Removing Barriers to Colorectal Cancer Screening Act of 2015. It was introduced in March of 2015 and needs to be passed today.

2. Financial Resources needed:

a. BARRIERS:

i. Prevention efforts with individuals and on the community level are not being funded at a rate that will produce a change in health behavior.

ii. Cancer screening tests are not always available in a location or manner that allows people to get a regular screen.

b. REQUESTS:

i. Funding and environmental/system changes to reduce obesity, increase physical activity and improve nutrition.

ii. Develop financial incentives in the Affordable Care Act for participating in health behaviors and annual screening/doctor checkup.

iii. Funding allocated to FQHC's for colorectal cancer screenings, follow-up and treatment if necessary.

iv. Fund mobile colorectal units to go to rural areas and reservations. Costs covered for providers to administer tests and perform diagnostics. Would reduce barriers such as multi-day travel for colorectal prep and test in rural areas.

v. Allow all breast diagnostic procedures to be covered by insurance as part of prevention screening, i.e., follow-up ultra sound, MRI, or biopsy.

Unleashing the Power of Data: This is all about having data connected through the continuum so providers and patients have access to their medical records. What would it take to change the current cancer care continuum so that all data is connected and there are no hurdles to access?

1. BARRIERS:
    a. There is not an effective Health Information Exchange in Montana.
    b. There is a national shortage of Certified Tumor Registrars (CTR), limited options for training, and for cancer centers to be accredited under the Commission on Cancer, data must be assimilated by a CTR.
    c. Pouring through data related to cancer is hard, with many messages that are not accurate. It is hard to determine what is "scientific" information.
2. REQUESTS:

a. We need more training programs available for Certified Tumor Registrars, and immediately allow qualified (but uncertified) professionals who have been doing this work for years to be grandfathered in to fulfill this task.
b. The government needs to regulate the Electronic Medical Records or require that any system that is sold be compatible with others without an additional charge so they can “talk” to each other.
c. High speed Internet is not available in rural communities – they are left to use dial-up. This infrastructure is necessary for EMR systems, as well as telemedicine.
d. Develop a best-practice portal for scientific data, prevention, diagnosis and treatment.