

**72nd Meeting of the National Cancer Institute (NCI)  
NCI Council of Research Advocates (NCRA)  
National Institutes of Health (NIH)**

**Building 35, Conference Room 620/630  
NIH Campus  
Bethesda, Maryland**

**Monday, September 26, 2016**

**Members Present**

Mr. David Arons, Chair	Dr. June McKoy (by telephone)
Dr. Gregory Aune	Ms. Kimberly Newman-McCown
Ms. Mary Ann Battles	Ms. Heather Ortner
Ms. Julie Fleshman*	Ms. Senaida Fernandez Poole
Dr. Sue Friedman (by telephone)	Dr. Roberto Vargas
Ms. Shelley Fuld Nasso	Dr. Regina Vidaver

**Speakers**

Mr. David Arons, Chair, NCRA; Chief Executive Officer, National Brain Tumor Society  
Ms. Shelley Fuld Nasso, NCRA; Chief Executive Officer, National Coalition for Cancer Survivorship  
Ms. M. K. Holohan, Director, Office of Government and Congressional Relations, NCI  
Dr. Warren A. Kibbe, Director, Center for Biomedical Informatics and Information Technology, NCI  
Dr. Douglas R. Lowy, Acting Director, NCI; Chief, Laboratory of Cellular Oncology, NCI  
Dr. Dinah Singer, Acting Deputy Director, NCI; Director, NCI Division of Cancer Biology  
Ms. Amy Williams, Director, Office of Advocacy Relations; Executive Secretary, NCRA, NCI

\* *pending*

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## **Welcome, Introductions, and Opening Remarks**

*Mr. Arons, Ms. Williams*

Ms. Williams called the meeting to order and welcomed members and guests. She emphasized that the meeting would focus primarily on the Cancer Moonshot Blue Ribbon Panel (BRP) report. Mr. Arons welcomed Julie Fleshman to the NCRA. Ms. Fleshman is the President and Chief Executive Officer of the Pancreatic Cancer Action Network. Her NCRA membership is pending formal approval.

## **NCI Director's Update**

*Dr. Lowy*

Dr. Lowy, Acting Director, welcomed NCRA members and provided updates on the NCI budget, key NCI programs, and the Cancer Moonshot Initiative.

NCI will begin to implement BRP recommendations in fiscal year (FY) 2017. Funding will determine the size, scope, and speed of NCI's efforts. Regardless of Moonshot funding, NCI will continue to support investigator-initiated research and other meritorious research. Between FY 2013 and FY 2015, NCI increased funding for new and renewal awards by 25 percent. During that same period, the NCI budget grew by 3 percent. NCI must secure additional funding to sustain research project grants and other programs at the necessary levels.

NCI continues to prioritize research related to health disparities, particularly in populations that live in rural areas, have low socio-economic status, or are members of racial or ethnic minority groups. Three principles will guide NCI's work in this area: (1) develop better genomic, environmental, and treatment response information about cancer in minority populations; (2) ensure minorities are represented in clinical trials and preclinical cancer models; and (3) ensure that appropriate minorities are represented in research efforts from the beginning. Dr. Lowy discussed two new initiatives related to minority health. The Early-Onset Malignancy Initiative is the first minority-based cancer tissue bank. The initiative will be coordinated through the NCI Community Oncology Research Program and will include molecular characterization of fully annotated tumors of minority patients. A second initiative is focused on developing new cancer models from tumors arising in minority patients. NCI is emphasizing implementation research and dissemination of standard of care, which is aligned with the BRP recommendations to increase colorectal cancer screening, tobacco cessation, and human papillomavirus (HPV) vaccination. NCI's ongoing goal in this area is to link proposed implementation research to sustainable dissemination plans.

Dr. Lowy also provided an update on pediatric cancer programs. NCI has a new Specialized Programs of Research Excellence program that will focus on the Ras-MAPK pathway in type 1 neurofibromatosis and other conditions. Two pediatric "Provocative Questions" meetings were held in the past year. Nine questions in pediatric research that range from basic research to survivorship have been identified, and the work will continue. The pediatric NCI-Molecular Analysis for Therapy Choice (NCI-MATCH) clinical trial will begin next year. This work is aligned with the BRP recommendation calling for more immunotherapy research for pediatric cancers. The BRP also recommended pediatric cancer studies related to fusion proteins.

Dr. Lowy addressed ongoing work in the area of cancer genomics. The NCI-MATCH trial, part of the Precision Medicine Initiative (PMI), is underway and is focused on preclinical models to advance predictive oncology. The trial currently has 24 arms with the potential for 10 more. Vice President Biden opened the NCI Genomic Data Commons (GDC) at the University of Chicago in

June. The GDC will support the goal of accelerating progress in the prevention, screening, and treatment of cancer by providing a standardized and publicly accessible warehouse of data from The Cancer Genome Atlas (TCGA) and other sources.

Dr. Lowy reviewed the goals of the Cancer Moonshot Initiative: (1) accelerating progress in cancer research, including prevention and screening; (2) encouraging greater cooperation and collaboration; and (3) enhancing data sharing. Dr. Lowy acknowledged Dr. Singer for her contributions to the facilitation of the BRP and the development of the BRP report. NCI is now considering how to best implement the panel's recommendations.

In closing, Dr. Lowy reiterated his commitment to continued investment in investigator-initiated research and research areas beyond the scope of the BRP recommendations. NCI will continue to support broad areas of cancer research, reduce cancer mortality, overcome health disparities, and find ways to accelerate progress by working collaboratively on a range of projects from basic to applied science.

### Discussion

Ms. Fleshman noted that the BRP report implies a need for large, innovative, riskier projects that require bringing people together in new ways. She asked whether the BRP recommendations would change NIH funding processes/approaches relative to more non-traditional grants. Dr. Lowy expressed his view that many NCI projects are high-risk. He also thinks there will be an increased emphasis on team science.

Ms. Newman-McCown asked about the BRP's goals related to dissemination. Dr. Lowy stated that there are three areas of the BRP report that address standard of care: colorectal cancer screening, tobacco cessation, and uptake of HPV vaccination. He expressed his hope that HPV vaccination uptake will be aided by a regulatory change associated with changing the HPV regimen from three to two doses. NCI has also begun a demonstration project related to Lynch syndrome, which is associated with increased risk for colorectal and endometrial cancer.

Dr. Vidaver said that the data on disparities is generally broken out by race/ethnicity and asked whether NCI has tested alternate hypotheses, such as the effect of socioeconomic status, educational level, local levels of air and water pollution, and residence in a food desert. Dr. Lowy said that the data were broken out by race and ethnicity to see if it gives clues about the biological basis for various cancers. Dr. Vidaver suggested that analyzing the data in a different way might produce different results.

Ms. Ortner applauded NCI's commitment to data sharing, and asked how NCI plans to get researchers to actually share their data in practice. At the "big data" level, Dr. Lowy explained that there are three meetings scheduled in 2016 to address barriers to data sharing. At the individual investigator level, competition among investigators may actually spur discovery. Most investigators want to get their findings out quickly. If we have common clinical goals and sharing data is going to have a benefit for patients, NCI will insist the data is shared. For example, all data from NCI-sponsored clinical trials will be publicly available.

Ms. Battles asked whether the NCI-MATCH trial had produced lessons that could improve other trials. Dr. Lowy said the trial has reinforced the value of having a single institutional review board. Another lesson is that community oncologists can provide the NCI-MATCH treatments; it does not require a more specialized physician. The third lesson is that having a variety of drugs

available for the trial increases the number of eligible patients. A new initiative, the NCI Virtual Drug Formulary, will shorten the time to start a clinical trial, especially trials that involve combination treatment. Ten pharmaceutical companies have signed on to make their drug available for combination NCI-sponsored and other trials.

Dr. Vargas asked about how NCI is translating its health research into the development of health policy. NCI works with other NIH Institutes and Centers and other federal agencies to support implementation science and to improve uptake of standard of care. Dr. Vargas also asked how NCI could invest more in forming partnerships with programs that have engaged people who do not speak English and rural and medically underserved populations. Dr. Lowy said that NCI plans to use supplemental funding to support implementation and dissemination research in these areas, and he is encouraging NCI divisions and centers to partner more closely with community oncology research programs.

Ms. Andi Dwyer of Fight Colorectal Cancer asked whether NCI will dig more deeply into the data that show an increase in colorectal cancer for individuals who are younger than 50 years old. She also asked whether NCI is working with U.S. Preventive Services Task Force (USPST) to apply non-trial data. Dr. Lowy said that one potential approach is to ask USPST to look specifically at data related to screening for subpopulations.

Ms. Danielle Leach of St. Baldrick's Foundation expressed her hope that NIH/NCI receives the appropriations necessary to support the Cancer Moonshot. If funding doesn't materialize, she asked if NIH/NCI will seek to leverage private and not-for-profit funding to coordinate implementation of BRP recommendations. Dr. Lowy said that there must be a team effort to implement the recommendations and that NCI will work with private philanthropic organizations to explore partnerships and co-funding opportunities.

Ms. Ellen Sonet of CancerCare asked whether Dr. Lowy thinks that payers will be more generous for combination therapies. Dr. Lowy said that reimbursement for standard of care within clinical trials varies by state and must be handled state by state. There have been discussions about doing pilot programs with payers, such as Centers for Medicare & Medicaid Services (CMS), for services, such as tumor sequencing.

### **Cancer Moonshot Task Force: Update and Overview**

*Dr. Lowy*

Dr. Lowy gave the Cancer Moonshot Task Force overview in place of the White House Cancer Moonshot Task Force's Dr. Danielle Carnival, who was unable to attend the meeting. The Task Force was created by executive order and is comprised of cabinet secretaries and heads of agencies such as the Patent and Trademark Office (USPTO), the Food and Drug Administration (FDA), CMS, NIH, and NCI. Dr. Lowy noted that making 10 years' progress on cancer research in 5 years will require an infusion of funds, changes in policy, and a change in the ways of working. Dr. Lowy outlined a number of initiatives already in process as a result of the Task Force's work:

- USPTO will fast-track patent applications related to cancer. FDA will make more drugs available to the public through expanded access and has created a new center of excellence.
- NIH Director Dr. Francis Collins and Department of Health and Human Services Secretary Sylvia Mathews Burwell were among those who met at the United Nations with the Health Ministers of South Korea and Japan to sign an agreement to work on genomic and proteomic analysis of cancer.

- The Department of Defense, the Department of Veterans Affairs, and NCI will collaborate on a study of the genomics and proteomics of lung cancer.
- A new NCI formulary is being created, leveraging the lessons learned through the NCI-MATCH trial. Researchers will be able to obtain compounds through one preapproved “formulary” list and test them for new purposes or in new combinations, thereby alleviating the need to negotiate with each company independently for individual research projects. This approach will expedite the start of clinical trials and will bring new treatment options to cancer patients faster.
- NCI is partnering with the Department of Energy (DOE) to use DOE’s powerful computers to speed up progress in understanding the Ras pathways and to support work in other areas of precision medicine.

Dr. Lowy explained that the Blue Ribbon report will be part of the Cancer Moonshot Task Force report, which will also be accompanied by an executive summary including the Vice President’s perspectives.

### Discussion

Ms. Loyce Pace of LIVESTRONG asked how the Moonshot Initiative is coordinating with the NCI Center for Global Health (CGH) to ensure that lessons from working with low- and middle-income countries are shared. Dr. Lowy said that great work is going on in low- and middle-income countries, but the work is largely uncoordinated. The NCI CGH has issued P20 planning grants for low- and middle-income countries to coordinate their efforts. Another international effort is being co-funded by the Bill & Melinda Gates Foundation to see whether one dose of the HPV vaccine would be effective in those younger than 17. This would make the vaccine more affordable and feasible and could reduce the incidence of cervical cancer, which is a serious problem in many parts of the developing world.

Mr. Arons asked Dr. Lowy to convey to the Task Force that the NCRA would like the opportunity to meet with them, as initially planned for the current NCRA meeting. He explained that there are a number of policy issues that warrant discussion, including but not limited to reimbursement issues that impede patient participation in cancer research. In closing, Mr. Arons asked Dr. Lowy to reach out to the NCRA members to see if advocates can help advance the Cancer Moonshot or NCI’s work.

### **Advocate Engagement in the Cancer Moonshot: Observations**

*Mr. Arons*

Three members of Cancer Moonshot Blue Ribbon Working Groups (WGs) were present at the meeting and were asked to discuss their experiences. Mr. Arons, a member of the Clinical Trials WG, explained that each WG was asked to prepare two to three recommendations and to then select one recommendation as the most important. His WG not only considered specific issues related to clinical trial participation. His WG also considered how their ideas would affect health disparities, break down silos, relate to the experience of all patients, and contribute to survival and quality of life. Ms. Fuld Nasso, a member of the Implementation Sciences WG, said that her group focused on prevention as well as quality of life, survivorship, and symptom management issues. Ms. Leach, a member of the Pediatric Cancer WG, explained that her group focused on the unique differences between adult and pediatric cancers and proposed ideas that would drive increased understanding of childhood cancers, including drug resistance.

## **Legislative Update**

*Ms. Holohan*

Ms. Holohan said that with only days left in FY 2016, she expected the passage of a continuing resolution (CR) through December 9 to keep the government funded. As expected, the CR does not contain funding for the Cancer Moonshot, because the initiative is not yet fleshed out. The House Appropriations Committee would give NIH an increase of \$1.25 billion. NCI would receive an increase of \$124 million. The Senate Appropriations Committee would give an increase of \$2 billion to NIH. NCI would receive an increase of \$216 million. NIH and NCI have very strong congressional support, but this is a complex process. There is strong advocacy to get funding in FY 2017, but the outcome may depend on the outcome of the election.

## **BRP Report Recommendations Overview**

*Dr. Singer*

Dr. Singer reminded the NCRA that the BRP is a subcommittee of the NCI National Cancer Advisory Board (NCAB) and comprises 28 members who are tasked with providing expert advice on the scientific vision and goals of the Moonshot. The BRP identified seven areas in need of examination and created WGs in those areas. WGs included subject matter experts from across the cancer research community and were supported by NCI staff members. Each WG was charged with identifying two or three priority recommendations. The recommendations were also influenced by public input. NCI launched a public input repository, which received 1,600 suggestions. The BRP also invited public input through email and held listening sessions.

Dr. Singer provided an overview of the BRP report. The WGs submitted a total of 14 recommendations, all of them scientifically important. One of the recommendations was converted to a demonstration project, and a couple of recommendations were combined. Dr. Singer briefly reviewed the 10 recommendations and the three proposed demonstration projects outlined in the report.

### Recommendations

1. A network for direct patient engagement.
2. A cancer immunotherapy translational science network.
3. Therapeutic target identification to overcome drug resistance.
4. A national cancer data ecosystem.
5. Research on fusion oncoproteins in pediatric cancer.
6. Symptom management research.
7. Precision prevention and early detection: implementation of evidence-based approaches.
8. Retrospective analysis of biospecimens from patients treated with standard of care.
9. A human tumor atlas.
10. New enabling technologies.

### Demonstration Projects

1. Prevention—Lynch Syndrome Demonstration Project
2. Therapy—Pediatric Cancer Immunotherapy Network Demonstration Project
3. Emergent Technologies—Tumor Pharmacotyping Demonstration Project

Several cross-cutting themes were identified by the WGs including identifying biomarkers, sharing data, working collaboratively and in public-private partnerships, working on prevention, and improving the lives of patients. **Note that the full BRP report can be found online at [www.cancer.gov/brp](http://www.cancer.gov/brp).**

#### Discussion

Mr. Arons noted that several of the BRP recommendations involve the creation of networks. Dr. Singer said she was not surprised by this, as NCI has been using team science and forming consortia for quite a while. The approach is now more accepted in the community, and investigators are eager to be part of the networks.

Ms. Fleshman asked Dr. Singer to describe how a partnership with an organization might work. Dr. Singer said that there are a number of ways to engage partners, including bringing in co-funders, sitting on steering committees, and bringing together organizations that have already engaged communities. NCI is open to any model.

Dr. Vidaver asked whether work was ready to begin on all of the BRP recommendations. Dr. Singer said that most of them are ready to go. For those that require additional work before they can proceed, NCI is in the process of defining next steps.

Ms. Fleshman asked what would happen with the recommendations that came out of the WGs but were not among the highest priorities. Dr. Singer said that NCI may revisit the recommendations to see what might be done outside the scope of the Moonshot.

Dr. Vargas asked whether consideration was given to encouraging collaborations between scientists and policy-makers to help develop health policy, and he asked whether there is a commitment to reduce health disparities. Dr. Singer said the BRP was charged specifically with looking at scientific opportunities. The Task Force will address policy issues, including those identified by the BRP. Reducing health disparities was a topic that cut across all WGs, and it remains a priority for NCI.

Ms. Battles asked Dr. Singer to define success for the Cancer Moonshot. Dr. Singer said that success would mean having made progress on the BRP recommendations. Examples include completing pilot studies; having a better understanding of cancer; having a direct patient engagement network; and having a better understanding at the molecular and cellular levels of how a tumor evolves and how to intervene, at least for a few cancers. New computational models would be available to predict whether a patient is likely to respond to a therapy. There would be a better understanding of fusion proteins, and new therapies would be developed so that they are no longer driving pediatric cancer. Immunotherapy would be much more successful, and we would have a better understanding of T-cell regulation.

Dr. Aune asked how to get information about the Moonshot Initiative out to the public and increase patient engagement. Dr. Singer said that it is necessary to show that patients can benefit by participating. The NCRA members can help in this area.

Ms. Ortner asked if there were plans to include new voices in the implementation stage. Dr. Singer said that there are plans to engage NCI boards. NCI can also issue a request for information. The need for broader input must be balanced with the need for speedy implementation. Dr. Singer would welcome the board's input.



Dr. Friedman asked whether symptom management efforts will include people who have a predisposition to cancer who may undergo surgical or other interventions. Dr. Singer said this was discussed within the Prevention WG, and it may be possible to include individuals with a predisposition to cancer in these studies.

Ms. Pace asked about the scope of the symptom management recommendation. Specifically, she inquired as to how far out from diagnosis the recommendation covers and whether the recommendation is limited to physical symptoms. Dr. Singer said that the intent is to cover the patient's entire life. Symptoms can include clinical, emotional, and psychological symptoms.

Ms. Sonet asked what incentive the community oncologist has to involve his or her patients. Dr. Singer said that the Clinical Trials WG discussed incentivizing physicians and engaging rural residents. These ideas were passed along to the Task Force.

Mr. Arons asked Dr. Singer about rare or recalcitrant cancers. She said that the WGs generally did not focus on specific cancers or tumors but rather focused on the "big questions" to be addressed for all cancers.

Ms. Dwyer asked about the short- and long-term implementation plans, including the demonstration projects that involve Lynch syndrome. Dr. Singer said that it should be possible to initiate the demonstration projects quickly. The Lynch syndrome project will connect groups already working on this and bring it to a national scale.

#### **National Cancer Advisory Board (NCAB) and Clinical Trials and Translational Research Advisory Committee (CTAC) Updates**

*Ms. Fuld Nasso, Mr. Arons*

Two NCRA members who are liaisons to other NCI boards, Ms. Fuld Nasso and Mr. Arons, gave reports from the most recent NCAB and CTAC meetings, respectively.

Ms. Fuld Nasso said that the President's Cancer Panel (PCP) gave an update to NCAB on the HPV project in which a number of centers came together to promote adoption of the vaccine. The uptake rates for the vaccine are increasing for both boys and girls. NCAB also received an update on the PCP's upcoming report on connected health. There was also a presentation on access to drugs of cancer patients and ongoing work on rational payment pricing models.

Mr. Arons said that CTAC received a budget update for FY 2016. Barbara Mroczkowski talked about the NCI Chemical Biology Consortium, which focuses on potential drugs not adequately explored by pharmaceutical companies. CTAC received an update on an immunotherapy trials network and discussed the National Clinical Trials Network. Dr. Arons also explained that all disease steering committees have been asked to develop strategic plans for periodic review by CTAC. CTAC also discussed the GDC, which Dr. Kibbe will be addressing.

#### **Cancer Moonshot: Genomic Data Commons, Data Sharing, and the Cancer Research Knowledge Ecosystem**

*Dr. Kibbe*

Dr. Kibbe explained the various components of the data sharing ecosystem referenced in the BRP report. He reinforced that one of the major goals of the Cancer Moonshot Initiative was to

accelerate data sharing. For NCI, this means supporting open science, supporting data reusability, supporting the goals of precision oncology, and improving patient access to clinical trials. Data sharing and analytics is foundational to all the work outlined in the BRP recommendations.

Dr. Kibbe explained that we have a number of data sharing platforms that comprise the data ecosystem referenced in the BRP report. First, we have those that support discovery, such as the GDC. Next, we have platforms that address how we bring patients into the research process and how to return useful clinical information to patients. Finally, we have platforms designed to help create a national learning system for cancer. The GDC represents a new way to make data available to the cancer research community and is designed to ensure we collectively glean the knowledge to make the right care available to patients. The GDC is built upon the FAIR principles: Findable, Accessible, Attributable, Interoperable, Reusable, and Recognition. Attribution and recognition are critical to incentivizing data sharing (not just publication), which allows everybody to reap the full value of all of the research. The plan is for the GDC to validate and harmonize data from researchers, institutions, clinicians, and patients to enable the sharing and analysis of data. The data will include imaging data, genomic and proteomic data (e.g., APOLLO), clinical data, and population-level data (SEER).

The GDC will play an important role in helping to understand the metastasis and progression of cancer, and it will foster an understanding of cancer biology. The GDC will leverage the rapid development of digital technology to create a structured and organized way to collect and analyze large amounts of data. Data sharing is a prerequisite for the development of a national learning system for cancer. Since January 2015, all NIH-funded projects that generate genomic data must be put in an openly accessible repository; for NCI-funded grants, we see this being the GDC.

The GDC currently contains 32,000 cases; the number of cases is expected to double within a few years. The cases currently come from a variety of sources, including TCGA and TARGET. Cases from Foundation Medicine and the Database of Genotypes and Phenotypes will be added shortly. In the coming years, data from NCI-MATCH, the Clinical Trial Sequencing Program, the Cancer Driver Discovery Program, the Human Cancer Models Initiative, and the APOLLO study will be added. NCI also hopes that other data sharing efforts will contribute to the GDC (e.g., GENIE, ORIEN, the Oncology Precision Network, CancerLinQ). At some point in the future, patients may be able to submit their own data. We hope the GDC will be accessible via multiple commercial cloud platforms.

In summary, Dr. Kibbe explained the GDC is moving toward a cancer knowledge system that supports genomic investigations of cancer, incorporates clinical annotations, promotes biological investigations of cancer genetic variants, and supports integrative models for high-dimensional data.

### Discussion

Dr. Vargas stressed the importance of involving individuals not fluent in English in the design of data collection platforms and asked about plans to involve end users in the design of the patient portal to the database. Dr. Kibbe said that health disparities have been an important part of the discussions about GDC. However, the GDC is currently a research tool and is not patient-facing. There are currently English and French portals, and a Spanish portal is likely to be developed in the future. If the GDC becomes accessible to patients, addressing the needs of diverse groups will be critical.

Dr. McKoy suggested that patients be given the opportunity to comment on matters related to tissue and data collection. Dr. Kibbe said the GDC comprises patient-consented data and is used consistently with the respective consents. Ms. Battles asked what patients will be told about how their

specimens and data will be used. Dr. Kibbe stressed that engaging patients on an ongoing and meaningful basis requires that they have an opportunity to participate with consent and to withdraw their consent at any time.

Mr. Arons asked how NCI can ensure that SEER data, which is collected from the states, will be of high quality. Dr. Kibbe said that the SEER data have quality checks and are curated before they go into the database. While SEER covers only 30 percent of the United States, NCI believes those states have the infrastructure to provide the high-quality data, and this is a representative sample.

Mr. Arons asked what would motivate other groups to contribute their data to the GDC. Dr. Kibbe said that cost is likely to be the initial driver. After investigators have analyzed their datasets, they are unlikely to want to bear the cost of maintaining or sharing their data. This may make them more willing to hand the data off to NCI.

Dr. Vargas asked whether the GDC will include data about disparities not related to race or ethnicity (e.g., an individual's food environment or other exposures). Dr. Kibbe said that many projects are now collecting those data, but they are not doing so consistently or on a national basis. SEER collects a little of this information, but it doesn't collect enough. As more data comes in, we will be able to identify which data points have relevance and can inform new models of risk.

Dr. Aune asked when investigators are required to submit their data. Dr. Kibbe said that researchers have 12 months after the clinical trials are closed and data analyzed to release the data. For other types of projects, requiring submission 12 months after project completion is reasonable. Dr. Aune also asked if the sequencing data was standardized relative to the time of collection (i.e., collection at time of diagnosis and/or relapse). Dr. Kibbe said this varies project by project. PMI places an emphasis on repeated sequencing, and we expect more projects to include serial sampling, which is critical.

Ms. Battles asked whether NCI would be responsible for notifying a patient represented in the GDC if new discoveries suggest the patient may be at risk for disease, should get additional screening, etc. Dr. Kibbe agreed that there was great value in doing this, but he did not see it as something the GDC would own.

Dr. McKoy asked whether there will be an opportunity for patients and advocates to comment on the GDC on an ongoing basis. Dr. Kibbe said that getting ongoing input (as we did via IdeaScale for the Cancer Moonshot) should become a normal part of everything we do, but this was not likely to be driven by the GDC.

Mr. Arons suggested that the NCRA could provide input and help to solicit community input as NCI considers how to implement all BRP recommendations. Dr. Singer said it was worth considering reopening a new IdeaScale site to receive public comments specifically on implementation, as opposed to recommendations. Mr. Arons said that members and others could drive stakeholder comments to that site. NCI could also issue a request for information.

#### **Facilitated Discussion: BRP Recommendations and the Cancer Moonshot**

*Mr. Arons*

Mr. Arons invited NCRA members to suggest ways to help move the BRP recommendations forward. He personally reiterated his suggestion that the NCRA request a meeting with the Cancer Moonshot Task Force. This would be an opportunity to share NCRA perspectives with the Task

Force and for the NCRA to learn about the White House's plans for funding and addressing the BRP's policy recommendations. It would also be an opportunity to discuss what NCRA members can do to advocate for the Cancer Moonshot and move it forward.

Ms. Fleshman said that advocates can probably be most helpful with the policy recommendations. Dr. Singer said that the policy issues are within the scope of the Moonshot Task Force and having the community reach out to the White House about policy would be valuable.

Dr. Vidaver suggested that the BRP seek international endorsement of its report and ask for commitment to an international Cancer Moonshot. Dr. Singer said that nine countries have already signed memoranda of understanding to collaborate with the United States on the Cancer Moonshot. They did not endorse the BRP, but if the Task Force asks them to, they would likely agree.

#### **Wrap-Up**

*Mr. Arons, Ms. Williams*

In her closing, Ms. Williams acknowledged that there are a lot of unknowns and questions as the Task Force embarks on implementation of the Moonshot. The community will have to come together to make this initiative a success.

#### **Adjournment**

The meeting adjourned at 4:06 p.m.