NCCN Patient Advocacy Summit:
Patient Concerns in 2014 – Big Data, Access and Palliative Care

On Monday, November 3, 2014, the National Comprehensive Cancer Network® (NCCN®) convened its fifth annual NCCN Patient Advocacy Summit in Washington, DC, *Patient Concerns in 2014 - Big Data, Access, and Palliative Care.* Moderated by Clifford Goodman, PhD, The Lewin Group, this year's summit brought together key stakeholders including patients, patient advocacy groups, academia, industry, payers and policy makers to discuss three topics of concern to patients in 2014: big data, access to care, and palliative care.

Opening Remarks

Following introductions and opening statements from Robert W. Carlson, MD, Chief Executive Officer, NCCN, the summit commenced with opening remarks from Gabriel Eichler, PhD, General Manager at PatientsLikeMe (PLM). Dr. Eichler provided background on PLM, a 10-year-old "patient-powered research network" that gathers data from patients and/or their caregivers on their experiences with their disease, symptoms, treatments, side effects, and quality of life. Relatively new to the oncology space, PLM's database currently includes about 300,000 patients reporting on nearly 2,000 conditions. The reported data is used in various ways with patients using it to connect with others with their illness, and to learn both about the potential paths their disease could take and what did and did not work in regard to treatments, side effects, etc. PLM uses the data to illuminate results across a patient population; data is aggregated, analyzed, and published in peer-reviewed articles on the results in open-access journals. Using ALS as an example, Dr. Eichler illustrated how one patient has responded to a series of questions about ALS disease symptoms over time. Although one patient's response is "little data," he said, when thousands of responses to the same questions are aggregated, that becomes big data that can have a huge impact.

Dr. Eichler then provided a few additional "little data" examples for diseases like multiple sclerosis and fibromyalgia. He showed an example regarding the incidence of nausea and vomiting related to various therapies that plotted patient-reported experience versus manufacturer-reported incidence of nausea. The results showed that there were substantial outliers for many of the drugs. This information could be very useful to patients, drug manufacturers and others.

Dr. Eichler also shared information about PLM's open research exchange project funded by a two-year grant from the Robert Wood Johnson Foundation. This project takes patient-reported outcomes to another level by giving patients the opportunity to help develop validated patient-reported-outcomes instruments. These new instruments will be critical in obtaining patient-reported outcomes in the future.

Big Data and the Patient Advocacy Perspective

An introduction to the big data discussion was provided by Daniel Auclair, PhD, Vice President of Translational Research, Multiple Myeloma Research Foundation (MMRF). Dr. Auclair noted that the genesis of big data in the health arena was the advent of electronic health records, which made the collection and sharing of data more efficient. Most cancer patients, he added, want to actively participate in their treatment and are willing to share information and data about their situation if asked, even if they may not benefit directly. According to Dr. Auclair, the value of big data lays not in its sheer volume, but in the "deep and integrative analysis" that can be undertaken from the data.

According to Dr. Auclair, big data has both benefits and drawbacks. For researchers, big data provides large volumes of very precise data that can potentially lead to development of targeted, more effective treatments. Big data also allows for greater access by more people and for faster dissemination of results that can lead to faster innovation.

For patients, contributing to and/or using big data results can help them feel empowered to make more informed decisions. A drawback is that data can be misinterpreted if it is not viewed in context. Therefore, it is important that doctors and other medical providers help patients interpret data to be sure they really understand it. Another drawback of big data for patients is that privacy can be compromised if the data are misused. Dr. Auclair believes that the more patients are asked to share information, the more protections should be instituted.

Dr. Auclair briefly mentioned MMRF's involvement with CoMMpass, a study that follows about 1,000 patients with multiple myeloma.[1] CoMMpass uses patient-reported outcomes to track patients' experience with the disease and compares patient-reported results with their medical records.

Dr. Auclair closed by stating that patients and patient-reported outcomes are the critical link that can turn little data into big data and that the more patients join in, the better for everyone.

<u>Roundtable Discussion – Big Data and the Patient</u>

Panelists for the day's first roundtable included Amy Abernethy, MD, PhD, Flatiron Health, Inc.; Dr. Auclair; Adrian Gropper, MD, Patient Privacy Rights; John Ioannidis, MD, Stanford University; David Purdie, PhD, Genentech; and Paul Wallace, MD, Optum Labs.

Dr. Goodman opened the session by asking what comprises big data as it relates to health care. Panelists agreed that big data is made up of administrative, clinical (including deep molecular and biosensor data), environmental, family and social, and consumer data. Dr. Purdie said he envisions a future where all data is considered patient-centric. Patients sit at the center with their own patient-generated data,

[1] In 2011, the MMRF launched the CoMMpass Study, the first of its kind in myeloma. A collaboration of world-class researchers in over 90 institutions — a "dream team" of cancer specialists — the CoMMpass Study is helping researchers gain access to each patient's genetic analysis to help them learn how patients respond to therapies. The findings cannot be patented and all the data are placed on a public portal (the MMRF Researcher Gateway). The resulting data set will be the largest, most comprehensive catalog of multiple myeloma including the largest set of whole genome sequences.

while data from providers, the environment and the other categories form concentric circles around them, but patients own the data that relates specifically to them, said Dr. Purdie.

Dr. Wallace observed that big data changes the research equation as it allows researchers to ask the questions they want to ask and determine the data they need to answer it, rather than posit questions based on what the data will support. He said that researchers will need to refine their data-seeking behavior as much as they refine data-protection behaviors. For example, he believes there will need to be a much more iterative process between investigators and patients.

"What are the future data sources and how may they be used," asked Dr. Goodman. Dr. Ioannidis noted that there is ever-more new data, and that its availability is growing fast. According to Dr. Ioannidis, approximately 99% of data collected today would not have been collectable 10 years ago. “We need to start preparing now for what data we might be able to obtain in the future, and think about how we will collect and organize it”, he said.

Drs. Wallace and Abernethy both spoke about the need to include family in the provision of patient data. Dr. Abernethy remarked that thinking about data as patient-centric causes three fundamental changes: first, datasets become easier to link because one starts with the individual and links from there, creating an ecosystem of data; second, the data is more relevant, because it starts with patients and families; third, it allows people to think more clearly about issues of ownership and privacy, and how to have more useful discussions about those. Dr. Wallace concurred that organizing data around an individual, rather than an average, was important; but, he noted that it does raise questions about how to protect ownership and privacy. He believes there are ways to manage data in deidentified ways that respect privacy but still create linkages, so that one can both personalize and protect data.

Dr. Gropper supported the concept of patient-centered data collection and referenced the work of the JASON taskforce, a high level advisory group of scientists working on standards and policy related to health IT. This taskforce recently issued a report recommending the use of “application programming interfaces” (API) in electronic health records.[2] These interfaces work to make data available to an institution, physician, and patient in a consistent manner. The patient can exercise policy-based controls over how and where their data goes. He added that once the consent process was automated, this process could be scaled.

Dr. Goodman inquired about how far away we are from such a system. According to Dr. Gropper, the standards are about 12-18 months away, and work has already begun to create FHIR, which stands for “Fast Healthcare Interoperability Resources.” To address this interoperability, society will need to engage in conversations about what it means to control one’s data. For example, today, certain mobile or internet applications ask users if their data can go into that app and be shared, and that requires thinking about what a “yes” answer might mean. We will now need to teach people about what different answers would mean in regard to their health data.

[2] *Data for Individual Health.* AHRQ Publication No. 15-0006-EF, November 2014.

Dr. Goodman asked the panelists to address some of the issues around full sharing of data. Dr. Purdie said that, to date, patients have not really understood the personal benefit that data-sharing could have for them. They have shared it "for the greater good," but have yet to see how they can benefit. When they realize they are really co-owners of information, patients can become partners with health care and industry. Dr. Purdie said that companies like his could start to get large-scale real-time information about their products' effects and outcomes, how easy or hard it is to access, and other data that is currently either nonexistent or exists only in small controlled clinical trials. This data could help companies develop better, more effective treatments that address patients' needs and concerns.

Dr. Wallace commented that what it comes down to for him is "the need to rethink everything." He elaborated further, noting that, to date, people have associated data with events, which is the genesis of the clinical trial. We are "hunters and gatherers" in that we hunt down, gather, and protect data, and there is an entire culture around how to do this, he said. But moving forward, extensive data will be generated almost as a "byproduct" of care. Much like our ancestors moved from being hunters and gatherers to farmers, we will need to cultivate new techniques and tools to create value from that data. Clinical trials will still continue to provide important information, but we will be able to do so much more, like quickly replicate them with people who have previously been excluded because of comorbidities, or supplement them with real observational data to get deeper into efficacy and efficiency. We can use the ever-growing data all around us to be "more active and clever" in getting the information we need, explained Dr. Wallace.

Dr. Goodman asked Dr. Ioannidis to address the upsides and downsides of drawing conclusions about what works in the real world vs. retrospective types of data sources. Dr. Ioannidis noted that the upsides of using big data include huge sample sizes, far bigger than those for clinical trials, which would allow for analysis of atypical situations or subpopulations that the smaller trials would not include. More questions could be answered than with a clinical trial, and linkability would allow one to analyze results at different exposures or events, which is very expensive to do in a clinical trial, he said.

On the downside, with so much data and so many variables, there could be problems with multiplicity. Dr. Ioannidis explained multiplicity as the problem of finding things even though they are not really there.[3] He suggested ways to bypass this problem, including organizing the search space better, developing more possible hypotheses, and validating interesting findings in multiple other datasets. Another downside is that big data is not validated. If interesting findings emerge from the analysis of big data, a randomized trial may be needed to confirm the results. Additionally, the individual pieces of data that comprise big data are not collected rigorously and could therefore contain errors, he explained. For example, while whole genome sequencing data might be 99.99% accurate, related administrative data might contain mistakes, and according to him, "the credibility of the evidence is the credibility of the least credible piece."

[3] In statistics, the **multiple comparisons**, **multiplicity** or **multiple testing problem** occurs when one considers a set of statistical inferences simultaneously or infers a subset of parameters selected based on the observed values. Errors in inference, including confidence intervals that fail to include their corresponding population parameters or hypothesis tests that incorrectly reject the null hypothesis, are more likely to occur when one considers the set as a whole.

Dr. Goodman summed up the discussion, stating that big data is another tool in the toolkit and that each tool has its strengths and weaknesses, but that they may be able to be used in complementary ways. He then asked Dr. Auclair how MMRF was thinking about applying these new opportunities to cancer patients. Dr. Auclair said that one way was through the CoMMpass study, which is looking at how drugs are performing in actual patients while at the same time analyzing the molecular structure of those patients' cancer, to better understand how the genetics of a given patient affects how that patient responds to treatment. The data is being put into an open access researcher gateway so that other investigators can use it. Additionally, the clinical data being generated is being put into a patient gateway where patients can add their EMR data and their patient reported outcomes. This data, combined with data from ongoing clinical trials, provides a wealth of information that can make a huge difference going forward.

Dr. Abernethy returned to the issue of data quality, noting that data quality is essential for good results. Her research experience has revealed that the more data is embedded into point of care and made relevant for doctors and patients, and the more they use those data for care, the more likely they are to cycle back and correct data quality problems or get it right the first time. This gets back to the concept of patient-centricity because it means that the person is motivated to assure that the quality of data is in line with what they expect, she said. It also enforces the relevance of participating in sharing data, because patients see how the data is being used in their own care.

Turning to a question from an audience member, Dr. Goodman asked the panelists to discuss how health care providers are being trained to access and apply big data. Dr. Abernethy believes this is a problem. Duke Cancer Institute recently opened the Learning Health System Training Program to help develop evidence-based medicine version 2.0. In essence, the goal is to show doctors how to combine and use evidence-based medicine principles of the past, high quality research findings and patient level data in their practice, without sacrificing efficiency and one-on-one patient contact. This may require physical redesigns of clinic space as well as new ways to communicate with patients while using computer technology. Dr. Purdie commented that, in the past, medical students shied away from statistics, but now many more are actually getting MBAs along with their medical degrees, so they might be more amendable to data. Dr. Ioannidis noted that medical schools have not done a good job training doctors about evidence-based medicine in the past, but now that there will be an immediate interface with data and a patient, it will have to be addressed and big data presents a great opportunity to enhance this training.

Dr. Goodman relayed several audience questions regarding patient awareness of these data projects and patient consent—essentially how can we assure all patients have opportunities to contribute to big data and how do we ensure they know what they are consenting to? Panelists agreed that electronic data must be available to patients to allow for patients and their caregivers to review data prior to their appointments, enabling them to ask informed questions and collaborate with their care team when making treatment decisions.

Dr. Gropper said one solution is to move from multiple portals of consent to one single point, where patients could manage who could see and use what data. Dr. Auclair added, instead of being a one-time

event, consent needs to be an ongoing dialogue between patients and care providers. Dr. Ioannidis said that it was important for patients from all races and educational levels to have access or else the data collected as part of big data is not generalizable, so there would need to be a lot of outreach to underrepresented populations. Dr. Abernethy suggested that the need for an "information-mobile" that goes into various communities to reach people—similar to a blood mobile. Finally, Dr. Wallace suggested that physicians might need to allocate their time so that they are spending more with the people who need more assistance and less with those who are technologically savvy or highly educated.

To conclude the discussion, Dr. Goodman asked each panelist to describe the next most important action or use of big data in oncology. The responses included developing learning guidelines, measuring how big data influences patient and clinician behavior, enhancing the role of advocacy groups, conducting randomized trials of big data to see if the data impacts outcomes, developing improved decision-making tools, and determining the most important data to be collected.

ACCESS

Patient Perspective on Access Issues

This session began with opening comments from Dana Malick, MPP, State and Local Campaigns Team, American Cancer Society Cancer Action Network (ACSCAN), who talked about how cancer patients are experiencing the new health care coverage opportunities. Ms. Malick pointed out two important benefits of the new law: (1) that people with cancer cannot be denied coverage because they are sick; and (2) that they cannot be charged more than other people for their insurance. However, as she subsequently explained, the new coverage opportunities also contain some challenges for people with cancer. She examined these challenges first from the perspective of a plan shopper not yet diagnosed with cancer, and second, from the perspective of a shopper who has already been diagnosed.

According to Ms. Malick, healthy insurance shoppers are typically generally looking for an affordable (e.g., low premium) health plan that includes their primary care doctor in network, adequately covers the medicines they already take, and provides reasonable coverage for emergency room or urgent care visits. As long as those people remain healthy, the plan they selected using those criteria may work out fine for them. However, once someone is diagnosed with cancer, that plan will most likely not meet his needs. For example, the low monthly premium cost means he will assume a higher burden of treatment costs because of higher copays and coinsurance; his primary care doctor might be nearby but the closest network oncologist might be located 45 minutes away; his expensive specialty medicines may not be well covered; and the high deductible he never expected to reach may need to be paid all at once for cancer surgery.

Insurance plan shoppers already diagnosed with cancer should consider a different set of factors, continued Ms. Malick. To minimize total cost over the year, people with cancer should consider paying a higher monthly premium in exchange for paying less towards their care and treatment in terms of copays and coinsurance. Further, they should be sure their oncology providers are in-network, and that specialty drugs are adequately covered. She noted that many people may not have sufficient education

to understand these tradeoffs. In addition, even if they do, a lack of transparency in the plans can make it difficult for people to find the answers they need.

To illustrate her point, Ms. Malick walked the audience through trying to get information about a specific health plan in the state of Washington. The example revealed that the plan actually had tiered reimbursement, which was not evident on its summary pages, and that some cancer drugs were considered medical benefits (rather than drug benefits), which is very confusing and leaves consumers unsure about what gets covered and at what level. In the end, the shopper would be unable to determine what he or she would be expected to pay under this plan.

Roundtable Discussion: Addressing Patient Access Issues

Dr. Goodman started the discussion by asking each panelist to introduce him or herself and to offer a brief reaction to Ms. Malick's comments. The panelists and their responses follow:

Dr. Alan Balch, PhD, Patient Advocate Foundation and National Patient Advocate Foundation, commented that his experience working with patients trying to obtain insurance was exactly as Ms. Malick described. Tom Farrington, Prostate Health Education Network, explained that patients who are diagnosed after buying a plan often face "sticker shock in addition to the confusion" of trying to figure out their options. Jax Ferguson, MBA, Eli Lilly & Company, noted that she had recently helped her brother navigate the exchange, and it was hard even for her, a supposed "expert." Michael Kolodziej, MD, Aetna, acknowledged it was complicated. Laurel Todd, MBA, Biotechnology Industry Organization, commented that some patients may not have many options due to the specific types of providers and therapies they need. Last, Ray Wezik, JD, International Myeloma Foundation and State Patients Equal Access Coalition (SPEAC), said that he fully agreed with Ms. Malick's presentation.

Dr. Goodman asked the panel to discuss the current state of patient assistance programs and if they have changed as a result of the Affordable Care Act (ACA). Ms. Ferguson stated that Lilly's Patient Access to Cancer Care Excellence program (PACE) has not changed and is still helping un-and under-insured patients gain access to pharmaceuticals they need. However, she said what has changed is utilization of the program, which is down 20% from 2013. She assumes this is because patients now have better access due to health reform. Finally, Ms. Ferguson noted that patient needs are shifting, and that "copay assistance is easily becoming the single most important demand from patients newly diagnosed with cancer." Unfortunately, she added, the pharmaceutical assistance programs are not designed to address that problem.

Ms. Todd noted that the ACA does not mandate changes in patient assistance programs, but she believes the Centers for Medicare and Medicaid Services (CMS) is discouraging their use. Dr. Balch said that his organization, Patient Advocate Foundation, has actually seen a 10-15% increase for assistance, mostly from patients covered by Medicare. The majority of his organization's clients make less than $23,000 per year. Not only are more of these patients seeking support, but the amount of support they are seeking is increasing, he said, noting that debt relief on behalf of patients doubled between 2012 and 2013 as patient burden per patient has increased. Mr. Farrington agreed with his fellow panel

members, stating that some programs serving prostate cancer patients are running out of money earlier each year, perhaps due to increased need per person.

Dr. Kolodziej commented that, historically, insurance companies do not like programs that provide coupons or discounts for patients to use in the pharmacy, because these could be inducements for doctors to prescribe the higher-cost medicines. Additionally, he said some analysts have written that these programs might actually allow the pharmaceutical companies to charge whatever they want and falsely escalate the cost of the drug. Mr. Wezik added that patient assistance programs are crucial for patients, but that the transparency about eligibility is lacking in many cases.

Ms. Todd changed the direction of the conversation slightly by noting that drugs are only one component of the patient experience. She pointed out that much of the cost of cancer care results from physician and hospital charges. Dr. Balch agreed, saying that the patients he assists have debt related to the whole experience—hospital, medical, drug, and transportation costs. However, there are far fewer assistance programs for non-drug costs, he said.

Dr. Goodman asked the panelists for their thoughts about a health care system that depends on patient assistance programs. Mr. Farrington said that it would be better not to have such as system, but as long as we do, the programs need to be there. Ms. Ferguson commented that, in the long run, a system reliant on charity is unsustainable given the current environmental constraints on those who provide the assistance.

Turning to the subject of health plans, Dr. Goodman asked what it would take to help people really understand the pros and cons of different plans, considering their complexity and lack of transparency. Dr. Balch cited the findings of a small survey conducted by his organization. Initially, about 80% of respondents said that a low premium was the most important aspect of a plan. Some respondents then received extensive navigation assistance from his organization or others recommended to them. After the signup period was over, the individuals were asked what they chose. The results showed that only 40% chose based on premiums, with the balance choosing based on plan specifics. Dr. Balch commented that this result shows that consumers can learn how to choose wisely, but he also acknowledged that the level of navigation provided is not sustainable in a larger population.

Dr. Goodman then asked if plan premiums and cost-sharing requirements are changing in relation to increasing costs of cancer care. Similar to what Ms. Todd has discussed, Ms. Malick noted that, while many people focus on the cost of drugs, in actuality, patients incur costs for many services before they ever get to drugs. These include things like lab work, diagnostic testing, hospitalization, and, in many cases, surgery. These costs are related to their medical deductible, not their drug coverage. She said that this often gets overlooked because drug costs “are a bit sexier to discuss.” Dr. Balch agreed that this is a huge issue and relates to the point he made earlier about the lack of patient assistance programs for non-drug costs.

The discussion then turned to doctors’ roll in discussing cost with patients. Dr. Balch said that it would be ideal to have a point-of-care discussion about cost as doctors want patients to be able to comply with treatments, but this is not often done because doctors are unaware of prices or are not incentivized to

spend that time talking with patients. Mr. Farrington pointed out that in addition to discussing costs, physicians should make it clear to patients what level of benefit they are likely to receive from a treatment, so patients can make an informed decision about accepting that treatment or not.

Dr. Kolodziej opined that doctors are "kind of immune from the price tag." He noted that the American Society of Clinical Oncology (ASCO) and NCCN are each involved in efforts to make that information available at the point of care. He also described that when he was in practice, all patients immediately saw the practice's financial counselor to determine what their out of pocket costs would be, and he expressed dismay that this does not routinely occur for all patients everywhere.

Dr. Goodman asked whether network adequacy is impacting the care patients receive. Ms. Ferguson commented that patients should be able to choose the services and care sites they need to adequately treat their cancer. Ms. Malick agreed and said she was seeing a trend towards less choice in health plans offered on exchanges. Dr. Balch noted that the health care law designers recognized that narrow networks might be an issue initially, and have slated 2016 as the time to review this issue.

Dr. Kolodziej countered that, at this point in time, no one really knows if network adequacy is an issue. He believes it will ultimately be legislated and that no one will like the outcome because cost will be a factor, and there is sometimes "a ten-fold spread" in price for the same services between providers. However, there is no "proof" that one place or person is 10 times better than another. We must have more information about performance and quality, and there must be more transparency about cost, he said.

To close the discussion, Dr. Goodman asked the panelists how patients can determine value. The panelists agreed that transparency around costs and impact of treatment are key for patients to make value determinations. Ms. Todd stated that "value is a discussion and not an algorithm," and other panelists shared this view in that each patient values different things. The final opinion, stated by Dr. Kolodziej, was that value cannot yet be defined, because as the prior discussion on big data showed, too many data points are missing.

Palliative Care

<u>Physician Perspective on Palliative Care Issues</u>

The final session opened with an overview of palliative care presented by Linda Sutton, MD, Duke Cancer Institute. Dr. Sutton noted that several studies have shown various benefits of palliative care, including longer survival rates and reduced future cost of care. She also remarked that many people, including doctors, do not actually know what palliative care is. Many think "palliative care" refers only to end-of-life, or hospice, care. Dr. Sutton explained that palliative care encompasses end-of life-care, but is much broader, ideally focusing on addressing pain and other aspects of suffering (e.g., spiritual, psychological) at any point in a person's illness. Dr. Sutton believed that a definition found in a *Johns*

Hopkins Magazine article by Andrea Appleton encompassed the true meeting of palliative care: "medical care that addresses all the dimensions of suffering." [4]

According to Dr. Sutton, only a very small percentage of people who could benefit from palliative care receive it. This is due both to a lack of palliative care doctors and the current concentration of palliative care services in the in-patient setting only, she said. African-American and Hispanic populations are especially likely to have limited access to palliative care services, as are patients not treated in large hospital systems or academic medical centers, she added.

Improving access to palliative care will require addressing how it is paid for, according to Dr. Sutton. The American Medical Association (AMA) recently suggested new billing codes for end-of-life conversations and advanced care planning, and Medicare seems to be supportive. Other insurers are also piloting models of care that address access to palliative care. Dr. Sutton closed her talk by noting that patients want palliative care, because they value a better quality of life over a longer life, and that is what palliative care can provide.

Roundtable Discussion: Palliative Care and the Patient

Panelists for this discussion included Rebecca Kirch, JD, American Cancer Society (ACS); Dr. Kolodziej; Shelly Fuld Nasso, MPP, National Coalition for Cancer Survivorship; Dr. Sutton; and Jennifer Temel, MD, Massachusetts General Hospital.

Dr. Goodman launched the discussion by asking Dr. Temel to discuss her study finding that patients who received palliative care lived longer.[5] Dr. Temel clarified that the purpose of her study was to determine whether patients who received palliative care reported a better quality of life than those who did not (they did), not whether they lived longer. The increased survivorship finding was somewhat unexpected. Dr. Temel said the research results did not explain why patients lived longer, but her speculation is that when people feel better and have a better quality of life, they are healthier. Dr. Sutton reinforced this viewpoint.

Dr. Goodman asked how this research finding could be used by advocates. Ms. Nasso said that it would help her organization advocate for better reimbursement of upfront care planning, among other things. She pointed out that survivorship care can also be seen as palliative care, because it helps people cope with the longer term effects of their illness. Ms. Kirch stated that Dr. Temel's research "was a game changer" for ACS that inspired a new legislative agenda and public awareness campaign. She has been involved in helping to draft two new pieces of pending federal legislation: (1) the Patient Centered Quality Care for Life Act, and (2) the Palliative Care and Hospice Education and Training Act. The first focuses on bringing palliative care for adults and children with serious illnesses into mainstream medicine sooner, whereas the second focuses on developing palliative care teams but also teaching all

[4] "Palliative care helps patients and their families have the tough conversations." Johns Hopkins Magazine, Winter 2013.

[5] Temel JS, Greer JA, Muzikansky A, et al: Early palliative care for patients with metastatic non-small-cell lung cancer. N Engl J Med 363:733-742, 2010.

clinicians primary palliative care skills. These efforts are backed by a new advocacy effort called the Patient Quality of Life Coalition. Ms. Kirch feels confident that as the public becomes more aware of palliative care and pushes for it, these bills will move forward.

The panel members generally agreed that studies like Dr. Temel's showing various benefits of palliative care have moved the discussion about end of life planning beyond the "death panels" of the recent past. Efforts by organizations such as the AMA, ASCO, and the American Association of Hospice and Palliative Care Medicine have also pushed the envelope. At the same time, they acknowledged ongoing stumbling blocks, including appropriate prescribing and use of opioids for pain associated with cancer, and the fact that some population groups see palliative care as "second class care" that denies them access to expensive drugs and treatments.

Dr. Goodman asked how palliative care might be delivered in the future and whether it would be integrated into other health care or considered a "stand-alone" or "add-on". Dr. Sutton believes it should be integrated into existing health care, and Dr. Kolodziej envisions a model where a palliative care physician would be part of an integrated delivery system, contributing to better health outcomes and a substantial return on investment (ROI) in terms of saved future costs. In Dr. Kolodziej's model, payment might be on an episode or capitated basis.

Dr. Goodman questioned whether a positive ROI was assured. Dr. Sutton opined that there would always be a positive ROI, but that it would lessen as patients live longer. Ms. Nasso referenced a study presented at the most recent ASCO meeting showing that, while it might not always lead to a high ROI, palliative care does not add cost and it provides patients better benefits. Ms. Kirch argued that the focus should really be on the better quality of life that palliative care provides, and that lower cost is essentially a "collateral benefit" until proven otherwise. She posited that palliative care is the ultimate patient-centered care because it addresses what is important to the patient and his/her family.

Responding to a question about whether payers like Aetna would cover palliative care, Dr. Kolodziej said that he would want to know which specific element or elements of palliative care contributed to the better outcomes, or, as he put it, "which element is the secret sauce." That element is what would be considered for coverage. He also mentioned Aetna's Compassionate Care program that provides advanced care planning to eligible enrollees. Dr. Temel responded that it would be difficult to isolate one component of palliative care as the one that makes the difference, because palliative care, as a whole, brings an added layer of support and clinical care to patients.

Dr. Goodman questioned which physicians should be handling palliative care and which providers should be reimbursed for it. Dr. Temel argued that all specialists taking care of patients with life-threatening illnesses should have some competency in talking about palliative care concerns and providing pain relief through opioids or other drugs, although she acknowledged that there will always be variation in skill levels.

Regarding the need for more physician education and training on palliative care issues, Ms. Kirch noted that both the Institute of Medicine and ACS have some new communication training programs to help physicians become more adept at handling the "tough conversations" they may need to engage in with

patients. Dr. Sutton suggested that non-physicians like nurses and social workers also could be trained and then, as Dr. Kolodziej mentioned previously, integrated into accountable care organizations (ACO) or medical homes. She also reiterated that even with additional providers, the need is likely to far exceed the supply. Ms. Nasso stressed the importance of making palliative care available in the community, since most patients are not treated solely in the hospital setting, noting that the goal of palliative care is to keep patients out of the hospital.

Dr. Goodman then asked if palliative care might someday be consolidated into a practice guideline or pathway. Dr. Sutton remarked that NCCN already publishes the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) for Palliative Care , which offers a standardized treatment approach and defines the metrics for effective care. Ms. Kirch pointed out several additional efforts to define and measure palliative care, including the National Consensus Project, a new National Palliative Care registry, a Joint Commission advanced certification program, and the Commission on Cancer's (CoC) accreditation program. These efforts are all breeding credibility.

Dr. Goodman closed the session by asking how each panelist would advise someone to ask for and obtain palliative care-type services. All of the panelists agreed that patients should not be afraid to talk to their health care team and their families about their concerns and wishes, or to push for the help they want. Ms. Kirch also recommended the website www.prepareforyourcare.org that helps patients discover what will be most important to them during the remainder of their lives.

Conclusion

Dr. Goodman wrapped up the Summit by noting the interrelationship of the topics presented. He said that the final message of the day was that more and better information from patients and others can lead to patient empowerment, which in turn leads to their ability to demand and obtain better access to the care and treatment they need.