Accelerating Equity: Cancer Care for All
Episode 1 | Norman E. Sharpless, MD

Disclaimer: Transcripts are generated by human transcribers, and may contain errors. Please check the corresponding audio before quoting in print.

Transcript

[Intro]
Welcome to *Accelerating Equity: Cancer Care for All*, a podcast from AACI, the Association of American Cancer Institutes. Comprised of 102 academic and freestanding cancer centers across the United States and in Canada, AACI is dedicated to accelerating progress against cancer through research, treatment, and advocacy. Diversity and inclusion are key to fulfilling our mission. This podcast series is hosted by AACI president, Dr. Karen E. Knudsen, enterprise director of the Sidney Kimmel Cancer Center at Jefferson Health in Philadelphia. It's a component of Dr. Knudsen's AACI presidential initiative, which aims to mitigate and raise awareness of cancer disparities.

Karen Knudsen: Hello everyone. I'm Karen Knudsen, executive vice president of oncology services for Jefferson Health and director of our Sidney Kimmel Cancer Center. Most importantly, I also have the privilege of serving as the president of the Association of American Cancer Institutes, AACI. AACI's mission is to leverage the strength of North America's 102 leading cancer centers to accelerate progress against cancer. As I hope you know or have heard, the presidential initiative for AACI is to mitigate cancer disparities using the strength of these 102 centers with a goal toward assessing the current efforts of our major cancer centers, aligning and understanding best practices and addressing gaps through action.

And one of the key tactics of our mitigated strategy is to also use this podcast series to create awareness through interacting with key stakeholders and partners. For this first inaugural podcast, I'm absolutely thrilled to have Dr. Ned Sharpless with us, former cancer center director at UNC's Lineberger Cancer Center and, of course, serving us nationally now as the National Cancer Institute director. Thank you so much, Dr. Sharpless, for joining us, for your service, and for everything that you do.

Norman Sharpless: Well, thank you. It's really a pleasure to be here today.

Knudsen: Excellent. I'm really thrilled to have you and it's so incredibly timely. So, I would like to explore some territory about the role of NCI, and centers, and how we're working together to understand and mitigate cancer disparities. And of course, right now, the national attention is really directed toward multiple pandemics, multiple things we're facing national, of course, the COVID-19 pandemic, and then a heightened awareness of disparities and potential racism throughout health systems and in cancer care. So, this is occurring at multiple levels -- I know quite some attention to understanding what the underlying reasons are. And AACI is really working actively to try to be a key component of understanding that from the cancer perspective and providing solutions.

At last year's AACI meeting, we had a session understanding various ways that cancer centers, for example, are working to reduce the burden of cancer for people of color, especially Black communities, through efforts that are undertaken in all aspects of our business, waiting rooms, laboratories, patient education, office suites, and of course, through the NCI's appropriate focus on community outreach and engagement.

I know you're really well aware of all the things we're doing. Can you help our audience understand additional examples of how NCI is working in communities and through or with cancer centers toward these same goals?

Sharpless: Sure. Yeah. It's a really important topic to the National Cancer Institute and it's really great to talk about this with such an important partner as AACI in these endeavors. Now, I might mention a couple of things about it. So, first off, it's important to state that the NCI's really focused on funding research. So, we really want to drive the science behind why these disparities exist and particularly how you can address them. You know, the science of disparities seems to be really interesting. And often, they're multifactorial and they have complicated causes and interactions of race and

ethnicity, and socioeconomic status and education and access to care, and rurality versus urbanity, and a bunch of issues wrapped up in this. And so, sort of disentangling them can be very challenging.

But it's important to do because that's really how you begin to address them. So, you have to find out what's driving these disparate outcomes and really understand them and then focus resources to try and fix them. And so, we fund research across the waterfront on this -- but also those questions to understand why they occur and are there certain kinds of dissemination and implementation practices that work. And we do this a number of ways, but I think one of the most important ways we do this is through the cancer centers. And so, it's really interesting history.

I think the NCI has one of the strongest portfolios in health disparities research in the world. We may be the world's leading funder of health disparities research as far as I know. And if you look at the history of how that came about, it really was a large part through the cancer centers where a sort of almost weedy, bureaucratic change to the guide on what we recommend cancer centers do to focus on this notion of catchment area made -- on the order of a decade ago, had this tremendous impact where all of a sudden we told cancer centers they were going to be evaluated by how they conducted research to benefit their catchment area and all populations in this catchment area. And that meant, in particular, underserved populations in those catchment areas.

And that has been a really effective paradigm. Because that meant, all of a sudden now, the cancer center director and the provost, and the dean, and these leadership of these institutions all of a sudden cared about the quality of health disparities research at these institutions. And so, the really marvelous portfolio of cancer health disparities research the NCI funds is often largely directed to the cancer centers. And I think a lot of it is -- really was started in response to that pressure from the NCI to serve their catchment areas. The institutions themselves really want to do this. They want to be good cancer centers for the people they serve. And so, they're very excited to take this challenge on. It was not like [sic] the NCI had to twist anyone's arm. But I think it was that focus placed in the evaluation criteria that has been very, very important.

The last thing I'll say about it is that while we do, as I say, have a strong portfolio in this area and have made substantial increase in funding to health disparities research over the last few years, I still think it's important for the NCI to always ask, "Are we doing enough? Are we doing the right stuff?" And so, starting a few months ago right after the George Floyd events of the summer, the NCI created a real focus in this area called the Equity and Inclusion Program, which has a complex group of working groups and committees to really look at topics of racial justice and how the NCI can be productive in this area. And we sort of focused on three areas. One is the question of health disparities research. But equally important and often almost harder to work on sometimes is the issue of workforce diversity. So, are we really providing means to train a diverse group of next-generation cancer scientists and cancer caregivers?

And then a last area of focus is really on the culture of the NCI itself. Is it a place where we have an inclusive and welcoming community and it's good for all our employees? And so, that process has been really hard at work for the last several months and has been, I think, very, very successful. I'm sure you're aware that the NIH recently announced their own efforts in this regard, the so-called UNITE Initiative, which is focused on some of the same areas. And the NCI and the NIH have been working really closely together on these various initiatives to make sure that the NIH and the NCI are doing everything they can to address these important issues that are very much top of mind, as you mentioned.

Knudsen: Yeah, I actually -- I saw that announced yesterday. You know, really fantastic effort. I want to touch a little on both the themes that you brought up there of the fantastic examples the NCI's working on. With regard to health disparities research, I think you're right. We've done so much together, as a cancer community, to understand. Are there any gaps that come to mind of things where you feel like we're doing something, but not enough, or we're not yet started?

Sharpless: Well, you know, one area that some of the scientists at the National Cancer Institutes -- predominantly Bob Croyle and the Division of Cancer Control and Population Sciences and others that work in those areas have really focused

on -- we've been talking about it for a while. But it's been hard to get a handle on this experimentally -- is this notion of rurality. So, individuals who have decreased access to care because they live 400 miles from the nearest cancer center or whatever. And there's -- the statistics here are concerning.

So, if you compare outcomes for rural versus urban patients in the United States, there's a gap. And it's been getting worse every year since the 1990s. And so, what we can do to address this area of disparities is an interesting question. But it's hard to work on. So, rurality's actually surprisingly hard to define. You have counties like San Bernardino County in Southern California, which is the size of Switzerland. And almost everybody lives in the far east/western extent of the county and commutes to LA. And so, it's not rural in the sense that -- like, eastern North Carolina. But yet by any sort of population density or these rurality maps, they're both counted the same. And then you have these counties in Maryland where everybody owns horses and they -- it's very affluent part of the country.

So, rurality is a hard thing to study. And it's confounded by things like race. There are places in eastern North Carolina or parts of the southeast, Alabama, Louisiana, where rural is synonymous with African American. But there are other parts of the country where that's not true. And it's confounded by things like socioeconomic status and access to education. And then access to care. And so, it's been hard to work on and to figure out what we can really do. So, Bob and colleagues have introduced this new paradigm that I think is interesting, which they've taken analyses from other areas and laid it now, you know, used the same framework for cancer research around this notion of persistent poverty.

And so, what they've really done is mapped in the United States the counties and zip codes that have -- not only have more than 20 percent of the population in that area live below the poverty line, but that's been the case for decades. So, in census data going back 40 years, these are counties that have been persistently poor for decades. And as you can imagine, those counties are -- more of them are African American than -- they're enriched for -- African American and Hispanic-enriched counties. But certainly many of them are not African American or Hispanic counties, predominant counties. So, there's a race element to it and ethnicity problem.

But that's not the entire problem. And if you think about that -- and they're mostly rural -- there are a few urban areas that meet that definition. But by the vast majority are rural counties in the United States that have been persistently poor for decades. And that is a real structural challenge. If you think about how to get in, you know, you have a great new monoclonal antibody that treats lung cancer very effectively, works great given in a major cancer center in an urban area. But it may have complex care, it may have side effects, it may be difficult to administer. And you have to then move that therapy to these structurally challenged counties and areas, that's a real problem.

So, I think this access issue is now -- the good news in cancer research is we have things that work better and better and we have effective therapies. And now getting those new treatments to everyone because even people who live in these -- the situations that are challenged is an important priority. I think it's going to be really critical if we want to address national cancer statistics. And still an area where we have a lot more work to do.

Knudsen: Yeah. I really appreciate you calling that out as a highlight and a priority area. For research and we've -- as AACI would really like to be your partners in this. And one of the things you talked about was a geospatial mapping and understanding of where the major cancer problems like for which there's a gap. So, one of the things that AACI has done recently is asked all of the 102 centers, not just the NCI centers, to map out their catchment area. "Let us know, what is the population that you're serving?" So that we can truly understand what's being covered and where are some deserts of areas where major centers are not setting their catchment area.

So, we're just completing that first phase of analysis. It was an AACI milestone -- if this says anything about interest -- in that all 102 cancer centers gave us their information on the catchment area. And the next deep dive is their understanding of what the challenges are in that catchment area and what best practices they're using to mitigate them. So, that's really one of our next phases. So, we'll be working in close partnership with the NCI and disclosure there.

Sharpless: And I think -- if I could say one other thing about that. That's a really important effort and a really interesting research question out of all this. The kind of thing NCI wants to fund is how is telehealth going to change all this? Because now, it may be that some of these geographic barriers that really used to constrain access to care will not be so formidable if you can do a lot of this by virtual visit. So, I think -- but not everything works by telehealth, right? So, that's a research question. What are the things we can do over the internet and what are the things we can't do? And that's something we're going to have to figure out if we really want to address these access barriers.

Knudsen: I very much agree. We've seen in some of our centers, we did our own internal surveys on telehealth to try to understand the state of where we are. And we saw some centers reporting up to 5,000 percent increases over short periods of time in telehealth. So, understanding from a research perspective what is the impact on patient care, on outcomes, on patient reported outcomes, on the perception of the provider and their ability to conduct correct cancer care in their mind that they have a confidence in is a really important area for us.

So, because, as you pointed out, we have patients in rural communities who lack access to specialists, are there things the NCI can do to help support telemedicine for cancer care outside the research mission?

Sharpless: A lot of the issues related to telehealth are really the providence of CMS because much of this is guided by what payers will pay for. And this is -- some of the barriers to utilization of telehealth have really been because of payer issues. There are other challenges, too. There's malpractice coverage and state licensure issues that when patients may live in one state but seek care in a different state. So, there are some weedy payer and administrative issues that limit utilization telehealth that the NCI really can't do much about. They're other parts of the federal government or their state government.

Other than that, I think we can do research that's very important research to show what are the benefits of telehealth and what are the drawbacks of it? And then provide that information to these policymakers, to CMS, and to the state and to private payers and state governments that make these decisions. So, I think the argument for why we think this is beneficial to our patients is something the NCI can help make through well-designed studies. I think also an important thing to mention that sometimes gets forgotten about is telehealth is a real boon for clinical trials research, right?

So, you can accrue patients by telehealth. You can do consent over the phone. We can now have oral agents shipped directly to patients. And the ability to do teleconsent, for example, has been really important to our research mission as well and something we don't lose sight of. But I think that we also have to be very clear that not everything can be done by telehealth. And we can't just assume that this is going to work for all aspects of patient care. And so, it is an interesting and important research question is to what things, what aspects of patient care work really well in the virtual setting and what things will we never really -- we'll always have to do in person. And I think this can be surprising.

Obviously, things like screening mammograms and colonoscopy and infusions have to be done in person. That's not a surprise. But I think also there are some aspects of patient care, understanding the symptoms, and palliative medicine. These things may be where the ability to actually lay eyes and hands on the patient is very, very important. But maybe not. I mean, this is a research area. But I think that left to their own devices, the payers and state agencies will want to revert to the status quo. And if we really want this change that many of us think is beneficial for patients to persist, then we have to provide the evidence that it really is valuable.

Knudsen: Yeah. I very much agree with that. And I think you'll find receptive partners in the AACI centers and wanting to help garner that research. We certainly have become subject matter content experts over the last year with the wealth of information that's been gained. But also a real desire, to your point, to want to insert telehealth into the cancer care continuum at all of the right places, where it is appropriate and beneficial to the patient. But at the same time, understand where telehealth is not probably best placed. So, really terrific point of view there.

One of the things that you also touched on was looking at diversity of your own workforce at NCI. And that's also something the AACI centers have been very keen to try to understand. I think that we all believe that change starts with self-awareness. So, we, in conjunction with the Cancer Letter, did lead a survey of all the centers to ask, "What is our leadership team look like?" And there were some important learnings that were resulting from that data that I believe have already begun to take hold and take action. According to the survey we had, there are many opportunities for increasing diversity in the cancer center workforce.

Many individuals are already in the pipeline. For example, especially for a cancer center director. So, in your opinion, having lived this life as a cancer center director and now as the head of NCI, are there other things that we might consider to better train, promote, and support individuals so that we can achieve the diversity that we'd all like to see in cancer center leadership?

Sharpless: Yeah. I think this is a really important goal. I think we first, honestly, have to be very frank and say that if we need to do this, that having a diverse workforce, having doctors and leaders that look like the patients they serve is a really important goal for all of us and there should be uniform agreement on that that that's something -- an area we want to move toward. And I think that we also have to admit that one solution that's sometimes proposed for this problem is to fund -- because it's relatively easy for funders like the NIH and NCI to dedicate monies to specific topics -- to fund topics of research. And that may be, you know, like cancer health disparities research, that may be a useful thing to do. But that, by itself, will not solve this problem, right?

So, there are plenty of really great cancer health disparities researchers who are not underrepresented minority scientists and there are plenty of underrepresented minority scientists who don't work on cancer health disparities, right? So, you can't address the problem just by increasing the spend on cancer health disparities. There may be other reasons to do that. But if you really want to promote the diversity and the research workforce, and the faculty and the cancer centers, the great institutions we serve, then additional solutions might be needed. You know, the NCI has tried to do many things in this area. It's relatively straightforward for us to fund training initiatives. That is something that is well within the law of the kinds of activities we're allowed to support with federal monies. And so, for many years, the NCI's promoted diversity and training through a number of initiatives.

One of the better known is the CURE Program, which is "Continuing Umbrella for Research Experiences" run out of the Center for -- CRCHD at the NCI. And it's been a very successful program. It's trained over 4,000 scientists. Many of these are people who are now in leadership positions that are well-known scientists. But as successful as the CURE program has been, there's still a pipeline problem. There still are not enough great scientists at the junior faculty level, particularly with regard to African American scientists. But I think also a problem for other underrepresented minorities like Hispanic scientists.

So, there aren't enough at the junior faculty level and there certainly aren't enough at the leadership level. When we look at any analysis of who is in our grant-funded pool -- so, we are very, very committed to training experiences. We thought about other ways -- are there things we can do to reach earlier into the pool, so we have, like, the YES Program, which tries to get -- includes experiences for even high school and middle school students to try and get them interested in cancer research. And then keep them involved in cancer research through undergrad and graduate school and post-doc and becoming eventually scientists in cancer or caregivers in cancer. So, that -- training side is an area where, I think, the NCI's thought creatively.

But it's certainly not a problem we've solved. There's another school of thought on this which is, maybe the creation of cohorts at institutions would be beneficial. If you talk to people who have been successful from underrepresented populations -- who have been very successful, and they often mention that one of the things that was important to their success was a good mentor or a good community that supported them at an early stage in their career. And so, the idea is that if we funded cohorts of underrepresented minority scientists at institutions that are really committed to diversity in faculty training, that would be beneficial.

The most visible example of this to date is this thing called the FIRST Initiative, which is a Common Fund initiative led by the NIH. It's Francis Collins's supported effort. But it's really being administered by the NCI, working with the National Institute of Minority Health and Health Disparities at NIH. So, the NIMHD and the NCI are really administering this program. And it will provide funding to academic institutions to create -- on the order of 12 faculty from underrepresented populations who will then presumably benefit from the commitment of the institution to faculty diversity, but also from the interactions with each other.

And those two things, I think, are important, you know, with regard to training and career development. But I'm also very interested in how do we solve the problem of just getting more grants to underrepresented minority PIs? And there it's a little more challenging. The NIH is governed by laws regarding who we can fund. And we are not allowed to predicate awards based on race, ethnicity, or gender, or other issues like that. So, we have to be driven by peer review and secondary counsel review as stated in the law.

But I still believe there are opportunities for the NCI to consider the diversity of our portfolio and make sure that we fund -- we have to make sure that we fund not all areas in one -- not all science in one area so we can have -- all breast cancer grants, and no colon cancer grants. And similarly, we couldn't have all our grants go to one city or one state. So, we are allowed to use things like geographic diversity and topic diversity when considering funding decisions. And I would argue we should also be using diversity of the scientists themselves as one of many considerations we make grant decisions.

And so, we've started to talk about how to implement that within NCI in a way that is -- always supports excellent, outstanding, top-notch science, but also facilitates the diverse population researchers. One luxury the NCI has in this regard, the good news or maybe bad news, depending on your perspective, in this regard for the NCI is that we get so many great grants. I mean, we have these very low paylines because we get thousands of applications from the best scientists. It really isn't difficult for us to pick wonderful science to support using select pay. It's not a challenge to find great grants that we're, you know, not typically be able to get through normal funding mechanisms.

Knudsen: The cancer centers, as I know you know, are really good partners in this as well, trying hard to reach into the K-12 population and show wide swaths of our communities that we serve what a career in cancer looks like, cancer research and cancer care. And we talked a lot about the underrepresented minority pipeline enrichment strategies which are critical. But what about women? It's arguably a different type of situation where women at higher numbers are entering the pipeline yet are not reaching up in equitable levels into leadership roles.

Sharpless: Yeah. I think there our data are very clear that the number of women who are getting grants and getting into leadership is increasing. It's going up. The trajectory's positive. It's just too slow. So, it needs to be accelerated. But that's different from our data regarding African American PIs in the RPG pool, which is -- we don't see the same progress. With one exception, by the way, which is interesting, which is for some reason that I don't fully understand, the SBIR award, the award given to start-up companies, to commercialization opportunities, we haven't seen the uptick in female PIs there that we've seen in other mechanisms like RO1s and SPORES and center grants.

And I've no clear explanation for that. It has improved a little bit in recent years. But still, at the NCI and across the NIH entirely, that mechanism has lagged versus other mechanisms. And I think that's an interesting question. Starting companies is really important. That's how you translate things, new ideas to the patients. And so, why we've been less successful in engaging women in that topic is something I think a lot about and I'm worried about. But how to really speed the process in terms of leadership grants for women is an important concern.

The NIH and the NCI have really become worried about some of the culture issues that exist at institutions that persist -- sort of low-levels of maybe unrecognized or uncommented on sexist behavior that compromises the career development, particularly of women who are junior faculty. And we had a robust effort across the NIH, including the NCI, to look at what's being done extramurally that -- where we can have an effect. And so, the NIH really had an advisory committee

director report on this topic on gender harassment. And I was briefly on that working group until I got sent to the FDA for a sabbatical for nine -- [laughs] and had to be removed. But I'm still well aware of the progress of the effort.

It delivered a set of recommendations a few months ago that have been taken up by the NIH. And it's -- it again, is always limited a little bit by what we can do in terms of our extramural funding authorities because of the law. But nonetheless, I think it's a very substantive and important set of recommendations. And it's many things. Many of the things are cultural to say, well, we find gender harassment unacceptable. Everybody deserves an environment that will foster their career and will be a place that people want to work and feel as inclusive and welcoming.

But it's also we require institutions to assure that PIs are in good standing with regard to this. So, some of the misbehaviors that have occurred in the past have been when institutions don't tell the NIH about faculty that have significant complaints against them and for whatever reason, the institutions are unwilling to come forward with that information. So, we made clear that kind of behavior's unacceptable, you know, when there are people that are not good mentors, that we become aware of that. And we -- and the institutions take actions to mitigate those.

So, we're really trying to focus on the conditions that all women need to be successful. Because we have the data already that if that's the case, women can get RO1s, women can write UO1s and VO1s. They will be successful scientists and they will get grants and rise to leadership positions, that they're sort of just not held back by old institutional norms that are something we shouldn't tolerate going forward.

Knudsen: Yeah. Well, that's really good to hear, you know, across, again, all these comprehensive efforts and lots of parallel efforts going on at all of our centers. So, look forward to sharing experiences and working together toward that end.

So, Dr. Sharpless, another question for you arises as a result of the fact that we do have this new dynamic and a new presidential administration. To your point, the NCI director reports to the president and we wonder if you could give us a sense of what might be coming under this new administration and their interest in the cancer mission?

Sharpless: Yeah. It's still early days. I mean, we're only less than two months into the new administration. But clearly, there's every possible sign coming from this administration they're very interested in cancer research. So, already, we've had a visit to the NIH by the president, by the vice president, and virtually by the first lady. The first lady was so interested in cancer research, she actually asked us to take her on a visit to a cancer center. So, we went and visited VCU, the Massey Cancer Center with Dr. Winn. Because she wanted to see what they were doing with regard to reaching communities that are served by VCU, particularly through an initiative to work with faith-based leaders in the community. Really nice visit.

So, clearly, everybody in this administration is pretty interested in cancer research. As everyone, I think, is aware, the president and the first lady, and the vice president, by the way, have strong personal connections to cancer. And the president has been very forthright about his interest in seeing cancer progress advance as rapidly as possible. So, there's a lot of excitement at the present time. And exactly the form of new initiatives in cancer research, I think, are still under discussion.

But I believe that we have the opportunity now to build on the good trajectory we've had over the last few years of improving outcomes and decreasing mortality and lots of new approved drugs and devices for cancer. So, build on that good trajectory. And now, with a strong leadership at the -- from the present administration to really do some exciting new things in cancer through -- whether that's entirely through the NCI or other parts of the federal government remains to be seen. But I think that we'll have to stay tuned and see the details.

One initial clue is the president has involved heavily Eric Lander, who is a well-known geneticist and leader in biomedical research, and a director of the Broad Institute in Boston, and well-known to the cancer research community. And Eric has

now been elevated to a cabinet level position, which is the first time that this is -- had a scientist of that quality in the cabinet. So, I think that's exciting to have a scientist of that quality who knows so much about cancer research guiding some of this national mission, I think, is really a good opportunity to get this right.

Knudsen: Yeah. I agree. It will be a new opportunity. And we very much look forward to hearing what these outcomes look like and what the charge will be from the president of things that we might do to enhance the cancer research mission and the cancer care mission. So, great points and we look forward to assisting as we can as the 102 cancer centers. Well, this is a milestone. This is our first podcast.

So, what I want to tackle in our last set of topics is another milestone, a really important one for all of us. It's how we all came to be here. And it's the 50th anniversary of the National Cancer Act. And I'm really looking forward to what unfolds in the rest of this year as we get an opportunity to look backwards at the progress that's happened over the last 50 years while we plan the next 50 of progress and hopefully elimination of cancer. Can we talk -- maybe tie in our theme? So, how does cancer health equity figure into this 50th anniversary celebration and can you give us an overview of what we might expect in this next year as we celebrate 50 years of the National Cancer Act?

Sharpless: Yeah. I think this is a really important anniversary, and, you know, clearly there's a lot of people who don't actually know what the National Cancer Act did [laughs]. And so, I think that understanding why that Act was so important is really the answer to your question about what it's doing today, what it means for a topic like cancer health equity right now. And so, it did a lot of important things. Maybe most important to AACI is it really effectively created the modern cancer center program.

Cancer centers did technically exist prior to the NCA, but they weren't anything like they are now. The centers program for the NCI is really an amazing resource, I think, in part because of this federal designation, this perimeter from a federal statute saying that we're going to create these centers. And they became things that institutions really, really wanted to have and became -- would work very hard to obtain NCI designation. And that's been very good for the NCI because these institutions recruit great scientists and focus on cutting edge care and focus on their catchment areas. They often use a lot of their state researchers and their clinical revenue or other funds to support cancer research.

And so, I think the whole enterprise of cancer research has been lifted by this federal law saying we're going to have cancer centers. Another really important thing the National Cancer Act did was create SEER -- basically, the SEER database of cancer statistics, and said that the nation has to have a good accounting of cancer incidents and mortality, which led to this elaborate structure of SEER contractors and interactions with the CDC, state data that we collect every year. And now we have really good data on cancer outcomes in the United States. We know numbers of cases. We know if incidence is going up and down. We know if mortality's going up or down.

And those data are actually critical for a topic like cancer health disparities because you really have to know -- if you can't measure, you don't really know what the problems are. And it would almost be shocking to a non-cancer researcher to realize that this kind of a data set doesn't exist in every disease area. There are really important topics in American health where the data are not nearly as good. So, the one that became very strikingly obvious to me when I first started it in the federal government was data around opioid deaths. That is -- there's no SEER for opioid deaths, right? I mean, those data become available through a hodge podge of state and local databases that are cobbled together.

And so, to really tell what's happening in an important topic like that, often the data are years out of date and they're not uniformly collected across the country. And so, there's real issues with interpreting those sorts of national statistics. And SEER has obviated that for cancer where we have really, really strong statistics. In fact, I like to say that SEER is probably the most important set of cancer data and statistics in the world.

Knudsen: It's our single book of truth that we all rely on.

Sharpless: Yeah. And you take it for granted because you don't realize that we don't have this for other disease areas. It's sort of relatively unique to cancer. Then also the National Cancer Act created this sort of link between the NCI directly and Congress and the White House. So, it gave us the ability to write this so-called bypass budget, where we tell Congress every year directly what we would use extra monies for.

And that's relatively a privilege to be able to speak directly to Congress and talk to them about the opportunities in cancer research, and also maybe the NCI director or presidential appointee, which has a lot of implications for the NCI, meaning there's more turnover in the NCI leadership than at other parts of the NIH. And I think there's a better connection to the White House and HHS because of the presidential appointment. And then some of the advisors to the NCI are presidentially appointed, like the president's cancer panel and members of the National Cancer Advisory Board.

It created a national lab, so it gave the NCI some space to create a biomedical research facility that's federally run. This is really the only large federal biomedical research facility in the United States. And it was absolutely vital, for example, during the pandemic. If you need somebody all of a sudden to get a bunch of antibody kits and see which of these hundreds of kits works and which ones don't, that's a good project for a federal lab. And we were able to do that very quickly, for example, up at Frederick National Lab.

But it's also how the NCI's done important things like the Cancer Genome Atlas and the RAS Initiative and some of the real signature projects of the National Cancer Institute. It did many other things beyond those examples but it's really important infrastructure. It also provided initial funding to the NCI, which I'm sure was very important to the NCI director back then. So, the financial support was important. And maybe the most important thing the National Cancer Act did, we kind of forget about this now, but it was really revolutionary at its time, was it made cancer a disease one could talk about. So, it was no longer this whispered diagnosis that people were sort of scared to mention publicly that they had.

It took cancer from a disease in the shadows to something that we would nationally talk about. And people like Ann Landers and Mary Lasker and Sidney Farber had these national conversations about what it meant to have a cancer diagnosis and why cancer wasn't necessarily a death sentence. So, it provided hope for these patients. And I think that's really been a big part of the national advocacy movement. All these great advocacy groups that we have now in the United States that are really trying to advance cancer progress and cancer research were sort of empowered, if you will, to some extent by the National Cancer Act.

So, it's a really important set of authorities and a change in the national mindset regarding cancer. And therefore, it's an anniversary worth commemorating. I think at the same time, though, it's really important to say that we're not celebrating this. I mean, we still have 600,000 Americans die per year of cancer in the United States. We have not ended cancer in the 50 years of the National Cancer Act. And so, while we have made, I think, a tremendous amount of progress, there's still, from the point of view of the patients, we haven't made enough progress.

And so, we really need to take this moment to tell the American public and Congress why this has been a good investment to date and why we need to keep this up, what we will do in the next years and decades with regard to cancer progress and why the opportunities right now are particularly bright.

Knudsen: Yeah. I really thank you for that overview. And from my perspective, the National Cancer Act gave us something invaluable -- a mission and a sense of purpose and something to get behind, and a platform for which to show that research, be it the most fundamental, basic cancer research or health care delivery research, population-focused or clinical research, has an impact. It improves lives for patients and their families. And I'm so thankful to the NCI as being the place that can convenes all of us, or at least all the NCI-designated centers and many of the AACI centers who are partners, toward that goal. Agreed. We have so much more to do. But where would we be without the National Cancer Act at this moment?

So, I do want to pause to at least take a deep breath and look at the progress that's happened and be thankful. And you've been a huge part of that, Dr. Sharpless, in your leadership of NCI. I want to thank you for everything that you do. The AACI members, all of the 102 centers are your partners toward this common mission and common purpose. And we really look forward to the next several years of determining how we can accelerate progress against cancer. So, thank you very much.

Sharpless: Well, thanks so much for the opportunity to speak today. It's great to catch up and talk about areas of mutual benefit. And as I said at the outset, the AACI's been such an important partner for the NCI for our progress. And the news is good. We're really making progress against cancer at an amazing rate. We need all to work together for that common goal. And the AACI's always been so helpful in that regard to the NCI.

Knudsen: Thank you. Thank you so much, Dr. Sharpless.

[Outro]
Thank you for listening to *Accelerating Equity: Cancer Care for All*, a podcast from AACI, the Association of American Cancer Institutes. AACI is accelerating progress against cancer by empowering North America's leading cancer centers in their shared mission to alleviate suffering. Learn more at aaci-cancer.org.

[end of transcript]