



## Disruption, resiliency, and improvement

Today's nonprofit leaders and how they are addressing COVID-19 and beyond

February 2021

# Table of contents

Introduction	1
Nonprofits’ work before COVID-19	2
The arrival of the pandemic	3
How can nonprofits face these challenges long term?	6
In Closing	10

# Introduction

2020 was tough. The pandemic forced many nonprofit organizations (NPOs) to rapidly address the pandemic and economic downturn, and make difficult choices. These forces produced stressful changes (e.g., layoffs, reduced programming, remote work, organizational restructuring). Perhaps a silver lining, however, is that these changes often made organizations stronger and certainly increased their agility to respond to their mission. Necessity is the mother of invention, and many NPOs will emerge more efficient and innovative than before.

Strengthened organizational efficiency and innovation are important, because these NPOs have critical missions. A range of disruptive forces—new technologies; the blurring of public, private, and social sector silos; rising donor expectations; and the need to show measurable impact and return on investment—make running and leading an NPO, and achieving mission outcomes, both harder and more complex. This reality will not go away even after the COVID-19 pandemic is under control. The real question going forward will be, Can NPOs sustain and continue to make the sort of performance-enhancing changes that they were able to make during the pandemic?

With the belief that sharing difficult experiences provides important learning lessons for the NPO community, a team of Deloitte professionals interviewed 25 leaders from national NPOs to talk about their COVID-19 journey. We asked questions about what their organizational priorities were before the pandemic hit, what happened because of the pandemic, and what they project for their organizations going forward, all through the lens of their missions, organizational structures, revenue models, infrastructure, and workforce. Respondents included those from disease-focused organizations, research associations, professional societies, and grant-giving foundations. The senior executives that we spoke with lead organizations focused on a range of diseases and conditions, and also included professional associations representing broad categories of people in science, medicine, and health. The organizations included a mix of small, midsize, and large nonprofits, with FY19 revenues ranging from \$600,000 to \$2.7 billion.<sup>1</sup> Their wisdom and experiences are captured and synthesized in this report.

# Nonprofits' work before COVID-19

While 2020 was a particularly difficult year, preceding years also presented disruptions to the NPO sector. Technological advances were creating a range of challenges and opportunities. The ongoing need to address somewhat routine issues had leadership considering the benefits of systems upgrades, the value of cloud migration, and the need for cybersecurity. In addition, NPOs were starting to ponder the role that artificial intelligence and machine learning could play in advancing scientific processes as well as day-to-day operations. Opportunities presented by the increasing availability of massive data sets—for fundraising, customer experience, and scientific research—were on the horizon. Finally, the advent of 5G brought additional change and acceleration to all of the above.

Technology was not the only persistent disruption. The old swim lanes—where companies created jobs and wealth, governments provided public goods, and NPOs helped those who fell through the cracks or whose needs were not prioritized—were starting to overlap. This gave NPOs the opportunity to pull in public and private sector players to help scale and solve myriad issues. It also gave rise to new models of philanthropy—such as socially motivated for-profits and impact investors—which could increase competition for scarce talent and funding.

In addition to the above, and maybe because of it, donors were voicing increased interest in having a more engaging experience and focusing their funding on that which had measurable impact. They were requesting stronger ROI and accountability for how their donation created impact, putting pressure on NPOs to have thoughtful measurement and evaluation programs and embedding them into fundraising and operations.

# The arrival of the pandemic

Into this complex mix came the COVID-19 pandemic. While the disruptions already noted might have encouraged changes, the pandemic necessitated them. Cases emerged in China, Europe, and eventually the United States throughout the winter and spring of 2020. With March came the injunction within the United States to stay at home, socially distance, and close businesses and schools. The associated economic contraction put immense pressure on all organizations, and they were forced to react swiftly. This problem was particularly acute for NPOs that have a dependency on social engagement, whether in development, awareness, convening, volunteer, or care service activities.

“I’ve had to let so many good people go ... That’s the CEO’s job ... I have to do what’s right for the organization.”

— Disease-Specific NPO Leader

## NPO leaders faced immediate and potentially lasting changes to workforce

For the NPOs we talked to, there was the immediate task of moving their operations to virtual. Prior to the pandemic, organizations were already evolving to respond to changing workforce norms and expectations. These types of changes can be seen in the kinds of work being performed, in the workforce makeup, and where work is being performed.<sup>ii</sup> These changes were already forcing leaders to think about how to better align their workforce skills to their organizations’ needs.

No doubt that COVID-19 accelerated these changes. Tech issues were of immediate importance. Some NPO leaders we spoke with had made a concerted effort over the years to resource and modernize their technology infrastructure. For those leaders, their workforces were equipped and able to adapt to an unprecedented new working environment, transitioning relatively swiftly and without much disruption. Others, however, found themselves doing mass purchasing, planning, and deployment at a time that the rest of the country was doing the same. The effects of underinvesting in technology modernization over time became acute during, and exacerbated by, the emerging pandemic.

The NPO leaders we interviewed had to grapple with the needs of and implications for staff abruptly having to work from home and the needs the changed environment brought forward. In many organizations, leaders redeployed, transformed, or eliminated the need for positions focused on in-person events and fundraising at a time when new revenue was desperately needed. If any hiring occurred, the process was significantly altered by online interviewing and onboarding/training in a virtual environment. In our interviews, leaders observed that a significant portion of their time in the early weeks of the pandemic was spent focused on the workforce—retraining, working on culture issues, and ensuring productivity in new environments.

## NPOs leveraged deep understanding of their constituents to address needs

Just as social distancing caused disruption for the workforce, it also did so for patient populations. The effect of the pandemic goes far beyond those who get infected with COVID-19. NPOs are concerned about patients keeping up with regular appointments, including both for health maintenance as well as for participation in research. Patients who are living with chronic and debilitating conditions (particularly those that affect mobility) have indicated that they are suffering from an increased strain on their mental health, including depression, due to having less visitors and the lack of ability to engage with the outside world. NPOs expressed concerns around access to and the availability of medicines, especially for those patient populations who rely on products that have been mentioned as treatments for COVID-19 (e.g., hydroxychloroquine for the treatment of auto-immune diseases such as lupus and rheumatoid arthritis).<sup>iii</sup>

NPOs had an enormous responsibility to address COVID-19–related information needs. Many of the leaders we spoke with immediately created communications needs assessments, which informed their downstream communications strategy. Many created new workstreams focused on the interplay between COVID-19 and a particular disease, as well as ones addressing overall impacts of the virus on a practice area (for professional societies). To help alleviate fears from patient populations, NPOs also created resources on topics including medication availability, health-care setting safety, and supply chain logistics. One leader mentions, “We have seen significant problems for patients and families who are afraid of going into hospitals ... so we are seeing people being diagnosed later than they were before.” To reach their key populations, NPOs are also hosting webinars and virtual meetings to review these resources and answer any questions. Additionally, to gather insights, NPOs are using technologies, including new patient portals and mobile applications, that can relay real-time information about patients’ health.

“If you are on dialysis or had a transplant, (you are) much more affected than the average person. You can’t miss your dialysis appointments, as it can lead to death. It’s impossible for these people to social distance and get their medical appointments. Kidney failure wreaks havoc on health and finances, as over 80% of people diagnosed with kidney failure are unable to work within six months and only 10% can work part time). We need more data about what is happening to these populations.”

-Disease-specific NPO Leader

## NPOs’ revenues were significantly affected by the social distancing aspects of COVID-19 and the recession

“We went across our strategic priorities to ask which voices are we not bringing into this area, are there areas we need to explore (diversity in clinical trials), what are we doing, where are we missing the story, what can we commit to long term?”

– Grant-giving NPO leader

As the depth of the recession became apparent, donations to NPOs declined as individuals made tough personal financial choices. As the stock market plunged, major givers became more conservative, uncertain how long it would take for equities to bounce back. Finally, as social distancing became a long-term practice, in-person events—from galas, to walks, to rides—were cancelled.

Once the implications of the economic downturn became clear for organizations, they focused on financial forecasting. Each one had to revise its financial forecasting. One CEO shares, “Our most-likely-case scenario is having us down by 50% by year’s end. We were on track prior to the pandemic to having a record year of fundraising.” This sentiment was repeated numerous times in our interviews.

To respond to COVID-19–related financial forecasting, NPO leaders responded in two major and divergent ways: one where job eliminations occurred, and another where few or no layoffs took place. The story was decidedly uneven and based

largely on the financial structures of each organization and its relative reliance on meeting and conference revenue, dues payments, and year-to-year funding needs. All leaders who made staffing cuts expressed enormous and personal emotion with letting staff go during the pandemic. One leader shares, “You mentioned the toll. For me, knowing we’ve had to let so

many good people go ... You know the impact you are having on people's lives. I feel that way every day when I go to sleep. And yet, at the end of the day, I have to do what is right for the foundation and the patient population." Other leaders highlighted that they were able to assess their workforce and positions/roles quickly to retrain and redeploy staff to new positions.

At the time of the interviews, nearly six months into the COVID-19 response, many leaders acknowledged that COVID-19 substantially accelerated the changes that the organization may have needed to undergo when it came to workforce assessment and efficiency. One leader emphasizes, "We needed to protect the mission at all costs, which has allowed us to do difficult but necessary things, and we are building back a stronger organization." Leaders emphasized that, while difficult, changes to the workforce were often needed, but would have been handled much differently if not for this accelerated timeline. One leader emphasized this point, saying, "We are having to be more intentional and selective about how we are bringing people on, their skill sets, how they contribute to the organization's growth and bottom line."

"I felt much less equipped to deal with this issue personally. Our young staff thought [our organization] should become a voice for what is going on in the world, but the organization, historically, has not taken a stand on issues like this. Navigating that and working with employees who were very upset was challenging."

– Disease-Specific NPO Leader

#### NPO leaders led responses to addressing systemic racism

Almost every NPO leader we interviewed discussed not only the importance of strong diversity, equity, and inclusion (DEI) efforts in their organizations, but also of the need for new and additional efforts. Many described the need and desire to create or enhance and review internal DEI programs, as well as the need create a response for the organization's constituents.

NPOs, especially those in the health field, are working toward health equity and inclusion, especially for their patient populations—many of whom are underrepresented minorities and those with limited access to medical care, leading to poorer health outcomes.<sup>iv</sup> Leaders from disease-focused NPOs spoke about the need for equity in health care and acknowledged clear public health disparities along racial and ethnic lines. "We are placing greater focus on different voices," one leader maintains. "Systemic racism and racial justice [are priority issues]."

Racial and ethnic disparities in health were already recognized, and racism is widely accepted as exacerbating health inequity.<sup>1</sup> "What the events in 2020 did was cause us to look at ourselves and create a response," says one NPO leader. While many leaders felt their organizations and leadership teams had adequately "met the moment," some leaders noted their concern that they had not done enough, or still had an inadequate response to systematic racism. Many were creating new plans and programs for both internal and external audiences and were engaging staff in both.

Another leader spoke to the *operational changes* undertaken to ensure that racial equity remains at the center of organizational discourse. Specifically, the leader described the benefits of creating a working group to identify relevant and emergent topics for potential programming, integrating diversity into grant-making decisions, and identifying other strategies to promote DEI. "Previously, we decided to assume that diversity was automatic for us—but looking at where we are now in 2020, we can't make that assumption anymore," cites one leader. The national reckoning for social justice has served as a forcing function for many organizations to accelerate their activities in this area both for operational and strategic ends.

<sup>1</sup> Alan R. Nelson, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, Institute of Medicine Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care, 2003.

# How can nonprofits face these challenges long term?

Now that they've moved through the initial shock of the pandemic and created response plans, many NPOs are using the **disruption as an opportunity to fine-tune how they deliver on their mission**. While many NPO leaders acknowledged the challenges ahead, they expressed unwavering commitment to their organizational mandates and service to their constituents. NPO leaders maintained that changes made in urgent response to COVID-19—including strategic pivots, new styles of working, a broader range of funding sources, the decentralization of competencies and skills, the optimization of technology, and more—were, to a large extent, needed in any case and had long been in the making. We reflected on the challenges they faced, and we offer these recommendations to help guide NPO leaders into the future.

## Recommendation 1: Having a clear organizational and communications strategy enables organizational impact and resiliency

In response to unanticipated COVID-19 disruptions, notably the decrease in revenues and (often) cuts to staff, leaders reassessed existing strategic plans and priorities to ensure organizational sustainability and relevance of priorities.

In reviewing the interviews, **organizations with a clear strategy and evaluation plan were better able to navigate the crisis**. Ensuring an organization has a clear level of strategic focus with, perhaps, a smaller set of clear priorities may be better for an NPO, especially if it can then measure progress toward success in those prioritized issues.

“All of us believe that our mission has never been more important. We were made for this moment—this is our moment to give it our all.”

– Disease-Specific NPO Leader

Most leaders agreed that their strategic plans and priorities were still relevant, but longer-term planning became a challenge. One CEO forcefully answered the question of “How is it to plan in these times?” with the answer “Impossible!” While that may be, we would argue that it's now even more **important to struggle with and work through long-term strategic planning**. One leader acknowledged the importance of critically assessing their organizational strategy by saying, “We need to be honest with ourselves on what is critical, what are the things that only we can do?” The exercise itself will work organizational muscles related to perceiving and anticipating disruption, understanding how cause and effect might play out, “game-planning” adaptations to disruption, and so forth. While the future might not be predictable, getting used to responding to unwelcome or unanticipated changes will certainly help organizations in the long run.

Finally, **communications-related needs were often mentioned by leaders when discussion turned to business capabilities that were key to their ability to meet their constituents' needs**. For example, some NPOs that serve patient populations directly found that patients turned to their organization as a source for information related to the pandemic, as well as for ongoing treatment and care information. Several created a web page to answer COVID-19–related questions, and also developed rapid response webinars and used other tools to reach their target audience. The overall urgency to ensure that an organization's communications strategy—its channels, audiences, and content—could meet the needs of the moment emerged as an important capability. Ensuring that communications are evolving with the needs of the key constituents is of paramount importance.



## Recommendation 2: Fundraising needs to be diversified and revitalized

Fundraising and financial planning was brought up in every single interview. While several organizations with fewer than 500 employees received funds through the Coronavirus Aid, Relief, and Economic Security Act, leaders were still intently focused on how to revise their fundraising strategies, many of which have leaned heavily on events-based and grassroots fundraising to date. Annual galas, large conferences, and walk-a-thons—staples for many NPOs—are no longer possible in their typical forms, and leaders have long been considering other ways to either pivot them to virtual or provide additional sources of development resources. Many organizations had seen declines in the uptake on some of these fundraising vehicles, but the pandemic forced a response.

This is a moment that matters on the NPO fundraising landscape. The quote “Never let a good crisis go to waste,” attributed to Winston Churchill, applies here. Not only do tweaks to the fundraising model need to be made, but deeper change is warranted. **Techniques do exist to help organizations get more sophisticated about traditional donations** (e.g., using big data, analytics, sophisticated segmentation, and more targeted and tailored communications). It may be **time to think consolidation and M&A, to merge organizations with similar missions** and even fundraising bases.

“Business development has been a tough space ... Our focus needs to shift to fundraising, which the pandemic scaled back.”

— Disease-Specific NPO Leader

Some NPOs are spending more one-on-one time with sustaining and corporate donors, while others are looking to develop and execute new communications campaigns that use fresh messaging and channels to target new donors. For example, one leader shared that expanding fundraising to social media platforms has proved advantageous. Implicit in these questions are issues related to the diversification of donors, reliance on event-based fundraising, the possibilities of new media to yield new revenue, and whether organizations possess the right skill sets and capabilities to adjust to disruption and deliver on a mission. Additionally, organizations are looking at how to diversify the methods in which money is provided—from **small donations, major gifts, endowments, grants, fee-for-service revenue streams, and impact investors**.

While fundraising dollars are down overall, we also heard from leaders that expenses are currently down—mostly due to cancelled leases, reduced events-based costs, and limited leadership and staff travel—but it’s unclear if any reductions are short-term or one-time savings. These overall reductions in operating expenses have helped balance some of the fundraising losses, though leaders expressed concern that they would need to revise their fundraising strategies overall for the future, knowing that annual galas and walk-a-thons are impossible until we no longer need to follow COVID-19 social distancing precautions.

## Recommendation 3: Aligning to an operating model to streamline costs

NPOs come in many shapes and sizes, but a constant we heard was the need to understand where every cent was spent in the organizational budget, and to **assess the operating model for maximum efficiency**. NPOs can focus on optimizing their operating models by looking at factors such as workforce and talent, geography and physical location, and governance model.

NPO leaders will have to continue to pay close attention to the changed workplace and workforce needs. The pandemic forced a move to virtual work like nothing we’ve experienced before. NPO’s preparations were decidedly a mixed bag. Some roles didn’t easily translate to a virtual environment (e.g., administrative roles or call center staff) but, after the initial adjustment, NPO leaders moved on to address other organizational needs. Staff working virtually are also changing locations, which will create a permanently changed workforce footprint after COVID-19. Workplace-culture needs were elevated to a higher place in line, as well, as video conferencing replaced in-person sessions.

## Talent:

These factors create opportunity to bring on talent and embrace alternative talent models, shaping the future of NPO work. Organizations should now be thinking about **reaching into talent markets where the organization is not located** and evolving the work-from-home paradigm to let staff mostly work from where they are. Models that involve focused time together for brainstorming and collective planning could be more cost-effective in the long run. This could facilitate some staff to move out of expensive cities (where a nonprofit salary doesn't go far enough) and mostly work from home with a periodic commute to an office. Downstream benefits for NPOs include the ability to recruit and retain higher performing staff who would not previously have been considered for positions that were onsite only.

## Location:

With many offices and locations closed indefinitely, NPOs are taking a hard look at how they pay for and use physical space. For those NPOs that rely on a chapter-based model, leaders are **streamlining the number of physical locations** to reduce lease costs, with several focusing on regional hubs. The focus on a centralized, rather than federated, model allows NPOs to keep all budget, decision-making, and operational decisions at the headquarters and then use **shared services and outreach programs** to service the needs of their network.

While changes to geographic footprint may offer some cost efficiencies, the calculus by which such a shift should take place is not one size fits all. For example, as overall revenues went down in early 2020, one leader said that they have gone from 60 locations to 29. The shift has meant that this organization elected to get out of leases early, forgoing renewal or future real estate additions and potentially saving in operational costs. On the other hand, another leader called the chapter model an "HR nightmare that you can drown in" as the overall coordination and logistics to provide standardized support increases overall resource costs. As NPOs continue to find ways to streamline their operating costs, leaders should consider how their operating models support their overall strategy, and whether efficiencies (e.g., shared services or outsourced functions) can be gained.

## Recommendation 4: Demonstrating impact is critical for stakeholder engagement

NPOs are looking at different ways to create and communicate impact to their key internal and external stakeholders. While aligning to the mission has been critical during the pandemic, NPO leaders are also looking at new ways to engage and connect with their stakeholders moving forward. One leader states, "[The d]isruption that sticks out to me is a pivot to NPOs being able to quantify their impact on the community. That has gone from being able to show services they can provide to the community and be more output-focused, now we are showing output and outcome of service. Now there is a greater move toward impact and greater ROI. [We n]eed to get more sophisticated in blending and braiding funding of public and private sectors ... [We have to be able to] package their services at a bigger level—performance-based contracts to social impact bonds/pay for success projects/impact financing." Customer segmentation and **human-centered design approaches offer excellent tools to see which consumers want and to tailor offerings to them**. Knowing a customer's preferences can bring confidence that priorities are the right ones on which to focus.

Some NPOs are beginning to **partner with impact investing entities** that provide outside funding centered on the impact of programs. One leader, whose organization received a second round of funding from one of these firms in early 2020, says "We've been driving our growth strategies, which we need to articulate that to outside investors ... who are interested in our programs, what we do, and our outcomes." There is an opportunity to expand beyond the traditional funding models, but may require more sophisticated outcomes and impact measurement.

Demonstrating organizational impact is important for both external and internal stakeholders. NPO leaders highlighted how essential it is for their staff to be able to see and understand how they are contributing to the overall mission and impact for their stakeholders. One thing we noted: **if an organization had access to collaborators or stakeholders globally, they seemed to have a broader aperture about how to achieve impact**. Perhaps this creates a growth mindset and an orientation on achievement. Given the way we're seeing other nations and regions combat and manage the COVID-19 pandemic, it's clear that US-based NPO leaders could embrace many innovative approaches in health care and biomedical research more broadly.

## Recommendation 5: Optimizing technology as a pathway for a sustainable future

Many NPO leaders interviewed felt they adequately met the technology moment when the pandemic hit. Some had the foresight to buy laptops for every employee, while others had not effectively planned for the disruptions to services, including call centers. All felt they'd "made it through," but **NPOs' effective use of technology remains a latent opportunity** with exponential potential to streamline and protect.

Technology may be used to improve operational efficiencies, freeing up human resources to focus on mission delivery. Existing tools and platforms can provide ongoing analysis and deliver real-time insights that may be helpful to organizations in their program delivery, fundraising, and other operations. Technology tools can strategically augment resources for one-off projects and scale resources as demand for projects and priority enhancements fluctuates. Some leaders interviewed for this report have used technology to new benefit. For example, a trade association used the pandemic to create new apps to better deliver information to constituents. Some leaders we interviewed found that their efficiency in delivery of services went up significantly when they began operating virtually.

Cloud services and storage, as well as engaging technology in ways to drive improved performance, still hold untapped potential to save resources and create opportunities to achieve mission. It isn't that being tech-savvy mattered in this pandemic; it's that the pandemic made it crystal clear it's important to be *proactive* about technology and to think ahead. That point was punctuated in the pandemic. Organizations that don't plan and become more tech-savvy will be left behind, or worse—leave themselves vulnerable to bad actors and cybersecurity breaches.

As with other recommendations, the recommendation for NPOs to enhance their use of technology is made with the needs of individual organizations in mind. Technology is not a cure-all, and the timeline for enhanced uptake should depend on an organization's mission and resources. What we heard from NPO leaders is that the pandemic forced new ways of looking at operations and strategy and, moving forward, technology can be a helpful piece of that equation.

# In Closing

Deloitte's [future of health](#) vision puts the empowered consumer squarely at the center. This is exactly how the nonprofit sector orients to their role. A move towards the “future” of health has accelerated because of COVID-19. Changes in health care and science that might have taken years have been ushered in swiftly because of the pandemic. Like organizations, in other sectors, nonprofits were caught off guard have had to face many changes. Now, these organizations must not only assimilate the pandemic changes and the impact on fundraising, how they work, their organizational models and modes of service delivery, and a changed convening paradigm that is all-virtual, but must also prepare for what still lies ahead for the future of health. Nonprofits have a unique ability to help shape and lead future disruption in their marketplace, both internally in terms of how they are organized but also externally in terms of what they do for their stakeholders and how they deliver it.

The COVID-19 pandemic will pass, but the disruptions NPO leaders described to us will almost certainly continue. Many organizations in the NPO sector will have to adjust programming and optimize resources in order to achieve their mission and sustain operations. There will likely be some consolidation and some NPOs may not survive the financial downturn and litany of change. As leaders of nonprofit organizations respond to the urgent needs of their constituents as well as to sustainability of their organizations, leaders will also have new opportunities to assert their agency and solidify their strategies to lead into the future. If leaders lean into this change, the chance that they will create more impact for their stakeholders, clients and patients will be that much greater leading to a healthier future, faster.

---

<sup>i</sup> Charity Navigator, "[Home page](#)," accessed December 16, 2020.

<sup>ii</sup> Jeff Schwartz, Steve Hatfield, Robin Jones, and Siri Anderson, "[What is the future of work?](#)," Deloitte Insights, April 1, 2019.

<sup>iii</sup> Peter Baker, Katie Rogers, David Enrich, and Maggie Haberman, "[Trump's Aggressive Advocacy of Malaria Drug for Treating Coronavirus Divides Medical Community](#)," *New York Times*, April 6, 2020.

<sup>iv</sup> Erin K. Stokes, et al., [Coronavirus Disease 2019 Case Surveillance — United States, January 22–May 30, 2020](#), Centers for Disease Control and Prevention, June 19, 2020.

Authors:

**Margaret Anderson**

Managing Director  
Federal Health  
Deloitte Consulting LLP  
[marganderson@deloitte.com](mailto:marganderson@deloitte.com)

**Kurt Dassel**

Managing Director  
Federal Health  
Deloitte Consulting LLP  
[kdassel@deloitte.com](mailto:kdassel@deloitte.com)

**Kimberly Myers**

Principal  
Federal Health  
Deloitte Consulting LLP  
[kimyrs@deloitte.com](mailto:kimyrs@deloitte.com)

**KC Decker**

Senior Manager  
Federal Health  
Deloitte Consulting LLP  
[kcdecker@deloitte.com](mailto:kcdecker@deloitte.com)

*The authors would like to thank Christina Cadrecha, Jessica Chiu, Erin Bernstein, and Sanjana Basker for their support in the development of this report.*

**Organizations Interviewed Include:**

Allen Institute  
American Kidney Fund  
American Society of Clinical Oncology  
American Society of Hematology  
FasterCures, a center of the Milken Institute  
Leukemia & Lymphoma Society  
Michael J. Fox Foundation  
Multiple Myeloma Research Foundation  
National Multiple Sclerosis Society  
New York Stem Cell Foundation  
Pancreatic Cancer Action Network  
Sjögren's Foundation  
Task Force for Global Health



## About Deloitte

Deloitte refers to one or more of Deloitte Touche Tohmatsu Limited, a UK private company limited by guarantee (“DTTL”), its network of member firms, and their related entities. DTTL and each of its member firms are legally separate and independent entities. DTTL (also referred to as “Deloitte Global”) does not provide services to clients. In the United States, Deloitte refers to one or more of the US member firms of DTTL, their related entities that operate using the “Deloitte” name in the United States and their respective affiliates. Certain services may not be available to attest clients under the rules and regulations of public accounting. Please see [www.deloitte.com/about](http://www.deloitte.com/about) to learn more about our global network of member firms.