

New York's Health System Transformation:

What It Means for Medicare and Medicaid Consumers and Consumer Advocates, and Recommendations for Making New Models Work Better

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Medicare Rights is a national, nonprofit consumer service organization with deep roots in New York, as this is where the organization was founded and is currently headquartered (with staff also in Washington, D.C. and Maine). Medicare Rights works to ensure access to affordable health care for older adults and people with disabilities through counseling and advocacy, educational programs, and public policy initiatives. Medicare Rights is invested in educating and engaging people in the changes that will affect their health care, and seeks to understand how advocacy organizations can effectively shape new systems to ensure that the voices of people using these systems are heard.

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Executive Summary

Spurred on by the Affordable Care Act (ACA), state and federal agencies—led by the Centers for Medicare & Medicaid Services (CMS), its Center for Medicare & Medicaid Innovation (CMMI), and others—have been implementing initiatives intended to achieve improved quality and increased value of health care services. These changes, large and small, fall under an umbrella this report refers to as health system transformation. New York's foray into health system transformation has led the Medicare Rights Center to attempt to determine the role consumer advocates and advocacy organizations should play in the implementation of new health care models.

Medicare Rights enlisted the expertise of a panel of individuals and asked them to analyze the current state of health system transformation in New York, focusing specifically on three challenges a changing health system creates for advocacy organizations: (1) the need to understand new risks, (2) the need to educate consumers and others about new realities, and (3) the need to engage consumers in designing, implementing, and monitoring new models. In response to these challenges, Medicare Rights has proposed nine policy principles to aid in the development, implementation, and evaluation of new health system transformation models—specifically, models that affect older adults and people with disabilities—and to inform stakeholders of how to develop new health system transformation models while also keeping consumers and consumer advocacy organizations meaningfully engaged at all stages of implementation.

Drawing from the proposed policy principles, the insights of our expert panel, and its own experience in the development of the Fully Integrated Duals Advantage (FIDA) program and Independent Consumer Advocacy Network (ICAN) in New York, Medicare Rights recommends the following actions for government, providers, insurers, and consumer advocacy organizations to make health system transformation work for all New Yorkers and ensure that consumer advocates are prepared for and are engaged stakeholders in the development of new health system transformation models:

- Ensure clear communication from all parties. Communication between consumer advocacy organizations, federal agencies such as CMS and state agencies like DOH, as well as providers and insurers, is pivotal to the success of new and emerging models.
- Ensure transparency in policies and results. Among other things, consumers, advocacy organizations, and providers should know what rules insurers are operating under and what protections are provided to consumers.
- Meaningfully engage providers. The lack of positive provider involvement in certain health system transformation models is an underlying reason for low patient participation; engaging providers at the outset of development is important to the success of new models.
- Meaningfully engage consumers. Consumer involvement should be built into the structure of health system transformation and should continue into the implementation and evaluation of programs, with government mandating consumer outreach and meaningful engagement—not tokenism.
- Support consumer advocacy organizations. In order to ensure consumer advocacy organizations can represent and protect consumers as policymakers undertake expansive and multifaceted changes to health systems, consumer advocates need opportunities for funding support.

Introduction to the Report

Health system transformation is a collection of reform efforts or programs designed to change how health care is paid for and delivered. Spurred on by the Affordable Care Act (ACA), state and federal agencies—led by the Centers for Medicare & Medicaid Services (CMS), its Center for Medicare & Medicaid Innovation (CMMI), and others—have been developing, launching, and monitoring an array of demonstration projects and other initiatives intended to stem the tide of rising health care costs while improving the quality of patient care by changing how providers are paid for health care services and how those services are delivered to patients. In New York, state government and local health care providers have participated deeply in health system transformation through the state's Medicaid program and through federal health care payment and delivery initiatives. As a result, New York health care consumers, and the advocacy organizations that, like Medicare Rights, protect and promote consumer interests, are at the vanguard of significant changes to the health care system.

Since New York is so deeply involved in this national project, much of the success or failure of health system transformation in this state will affect and be affected by how consumers and advocacy organizations interact with a changing environment. It also means that consumers and consumer advocates must be capable of adapting and responding quickly to new opportunities and challenges. Private philanthropic funding made available to consumer organizations after the passage of the ACA meant that Medicare Rights was prepared to respond to new opportunities, such as educating Medicare beneficiaries about how their benefits changed as a result of the ACA and shaping new policies and health care delivery models made possible by the ACA, including the financial alignment demonstrations. This report explores the extent to

which consumer advocacy organizations need to prepare themselves—and the consumers they serve—to similarly respond to New York's foray into health system transformation.

This report begins by exploring what health system transformation will mean for New York's consumer and consumer advocacy organizations. The report then summarizes some of the thoughts and ideas of a panel of health care experts Medicare Rights convened to analyze the current state of health system transformation in New York, focusing specifically on the opportunities and challenges these changes create for advocacy organizations like Medicare Rights. The last section of the report draws on the collective wisdom of the panelists' many years of experience with health system transformation to propose a set of policy principles and recommendations to aid in the development, implementation, and evaluation of various new models with the aim to keep consumers' best interests at the center of new health system transformation models.

We note that affordable health coverage is a necessary precursor for any kind of broader health system transformation; before any health care system can be meaningfully transformed, it is important that as many people as possible have access to care and feel like stakeholders in their care delivery and in the development of new and proposed care models. With accessible, affordable care as a foundation, the experiences and recommendations in this report should inform policymakers and advocacy organizations as they work to make the health system work better for consumers, regardless of specific proposals and timelines.

Health System Transformation Matters to the Public and to Consumer Advocacy Organizations

Most new models under the health system transformation umbrella have multiple moving pieces that work in the background, largely out of sight of people receiving health care. In many cases, the minutiae of these models are not important for people to understand before they show up for a doctor's appointment. As a result, providing too much information about these programs threatens to overwhelm people seeking health care, especially if the information is irrelevant to someone's actual experience, unnecessary for health care decision-making, or comes at the wrong time. vi

At the same time, some people want to know—and all people using the health care system have a right to know—how new models and programs are affecting or could affect their care and costs. More broadly, people need to know how to navigate the health care system. If health system transformation initiatives meet their goals, people will experience better quality care, fewer unnecessary treatments, and better coordination among their providers, in addition to many other potential benefits. On the other hand, changes in payment and delivery systems could present people with significant difficulties in accessing care or create confusing new protocols and incentives that neither they nor their providers have previously encountered. In short, people using the health care system should understand at least the basics of how new programs work because:

 These programs will determine whether and how they get needed health care, for instance how their health care providers make decisions;

- These programs are being tested now but may become the norm, and the more one understands them, the more one is likely to succeed in accessing needed care; and
- Individual consumer voices are essential to shaping and assessing the success of new programs.

If consumers and their caregivers are to be meaningfully educated for and engaged in health system transformation, a key conduit for such education and engagement should be consumer advocacy organizations. Advocacy organizations need to keep people abreast of relevant changes to the health care environment. Advocacy organizations need resources to invest in developing expertise related to new models and also need to relay accessible and meaningful information to their clients in a timely fashion.

Consumer advocacy organizations also need to know enough about health system transformation to then respond to consumers' difficulties navigating these new systems. Even in the best-designed program, there will be those who fall through the cracks or whose needs go unmet. One of the vital roles of advocacy organizations is to step into these situations and, using their expert understanding of the health care system, address client problems to ensure people receive the care they need. For that reason, it is important for advocacy organizations to learn enough about these new programs to be able to counsel, educate, and advocate for their clients and communicate issues and problems to ease implementation and help evaluate the success of the programs.

Advocacy organizations must ensure that consumer priorities are designed into health system transformation in the planning and development stage. In many cases, insurers, government agencies, providers, and other stakeholders have not adequately engaged consumers, patients, caregivers, and consumer advocates in planning and developing new models.

In sum, health system transformation has created a complex system of numerous, evolving models that are experimental and, therefore, it is still unclear which models will best serve consumers. As a result, consumer advocates have important roles to play in looking for adverse consequences affecting consumers, aiding consumers in navigating new models, and making sure consumers have a voice in the process. With this overview in mind, the next section of this report will explore how health care transformation is actually playing out in New York, laying the groundwork for ways that advocates can bridge the gap between policymakers and consumers, and become more involved in educating and supporting their clients within the shifting landscape.

Opportunities and Challenges for Consumer Advocacy Organizations as Health System Transformation Unfolds

New York's health system transformation landscape is both sprawling and multi-faceted, so consumers need assistance understanding this complex system. VII Consumer advocates like the Medicare Rights Center serve important roles for people navigating the health care system, including that of:

- Educator, ensuring that people know what they need to make good health care choices;
- Counselor, helping people troubleshoot and solve access and affordability problems; and
- Advocate, representing people with individual problems while working for public policy change on behalf of larger populations.

To better understand how advocacy organizations should adapt to a changing health care payment and delivery landscape, Medicare Rights interviewed experts who are knowledgeable about new and emerging initiatives and how they may affect consumers, caregivers, advocates, and others. Viii While interviewing this informal panel of providers, hospital administrators, insurers, advocates, and other stakeholders, Medicare Rights aimed to better understand the current reality of health system transformation for consumers, the roles consumer advocates should play on behalf of the public, and the tools and support advocates need to fulfill those roles. The interviews shed light on three interconnected challenges facing advocacy organizations and other stakeholders: the need to understand new risks, the need to educate consumers and others about new realities, and the need to engage consumers in designing, implementing, and monitoring new care models.

It is important to note that payment and delivery system transformation is occurring within a broader health care policy landscape, one that shifted significantly following the recent national election. The panel interviews synthesized here were conducted well before this shift. Thus, a challenge not identified by the panel, but now at the forefront for consumer advocates and others, concerns basic access to affordable health insurance coverage. A new Congress and Administration are revisiting coverage gains made possible by the ACA. This debate and its end result present new priorities and challenges for advocacy organizations and could have wideranging implications for health system transformation.

Challenge 1: The need to understand new risks.

"Advocacy groups need to analyze the different payment arrangements in health system transformation and find where there are points of vulnerability for the consumer. Then the question is: How do advocacy groups arm the consumer against these risks?"

The panel enlisted to help the Medicare Rights Center better understand consumer advocate roles in health system transformation agreed that the numerous initiatives under health system transformation create new risks for consumers—as well as new opportunities for better coordinated, higher value care. Several of those interviewed saw organizations like Medicare Rights as able to serve a vital protection role because, unlike providers and payers, independent advocacy organizations are not financially tied to health system transformation's outcomes.

"[Consumer advocates] still have the purest voice. They don't have any skin in the game regarding payment. If [consumer advocates] can monitor this transition to value-based payment . . . that's a huge role. What will [consumer advocates] need to understand and sift through in order to address problems? Part of it is clinical—[consumer advocates] need an understanding of how the system currently works: what is life like for a primary care provider? How do we support [these providers] in order to make sure they're able to put [new models] into practice?"

"An ombudsman, like the Medicare Rights Center, has to be the advocate. The sellers can't possibly have the beneficiary's best interest in mind all the time."

Another way that new models could threaten consumer decision-making ability and, ultimately, access to good and affordable care, is by prioritizing certain metrics over others—and thereby not always showing a complete picture of care delivery and satisfaction. Or, metrics themselves may not be designed to fully evaluate a model. Given this, advocates and others can and should suggest ways to better monitor initiatives so that consumers are better served. Put most simply, in order to effectively monitor new programs and protect consumers, it is essential that their advocates understand how new models are measured and rewarded, and what consumers need to know about such measurements.

"[Consumer advocates need] to understand how Medicare is using . . . metrics . . . and how those metrics impact quality measures. For example . . . Medical Loss Ratios (MLRs). Is it really such a bad thing when a Medicare Advantage Plan has an MLR of 82%? Couldn't that mean that they were more efficient in using their premium dollars on non-clinical interventions? Consumer organizations need to have a good understanding of what goes into the MLR: what [governments] count as 'medical services' versus what gets counted as 'administrative costs.' The MLR requirement is a blunt tool... maybe some social interventions should be considered 'medical services' rather than 'administrative costs' because of their effects on the patient's wellbeing. Consumer organizations should be the voice making that case."

In general, expert panel interviews emphasized the importance of consumer advocacy organizations becoming experts in health system transformation. By building a knowledge base, organizations can pinpoint the new risks consumers face, as well as opportunities to improve consumer care and experiences within the health care system. Once advocacy organizations acquire this information, they then need to communicate it effectively to consumers and providers.

Challenge 2: The need to educate consumers and others about new realities.

"Most people find our health care system inscrutable and difficult to navigate. They don't understand it now, much less all the changes happening from health system transformation. We need to help people make a well-informed decision and let them know what's on the horizon. [We need to] help them when something goes wrong. No one is doing this."

The panel emphasized the complexity of various new payment and delivery models and how difficult it can be for consumers—and even professionals—to find unbiased program information.

"The presumed solution is to put everything about health system transformation online, which is . . . not how [many] consumers will access this type of information. So for the most part, consumers don't know anything. For example, [the New York State Department of Health (DOH)] has made quite a bit of information related to the Delivery System Reform Incentive Payment Program, the New York State Health Innovation Plan, and Value Based Payment Reform available on its website for public consumption—however, consumers do not access the DOH website in the same way professionals at a [consumer advocacy organization] would, and consumers lack the context to fully understand what implementation of these programs really means for them."

A lack of available and useful information not only makes it more difficult for people to navigate their own care but may also create resistance to programs that might be embraced if they were understood. Many new programs, for instance, are changing providers' financial incentives (e.g. moving from fee-for-service, where there can be a financial incentive to increase the quantity of services, to bundled payments, where there can be a financial incentive to decrease the quantity of services). Yet, many patients are unaware of such changes and continue to make health care choices based on outdated views of the incentives that may influence their providers.

And it is not just consumers and caregivers who need help understanding and conveying messages related to new programs. Health care providers need educational materials, too, in order to help ensure that they are bought into new models and that their patients are making informed decisions about the care they receive under these models.

The first few years of New York's Fully Integrated Duals Advantage (FIDA) program, serving Medicare and Medicaid enrollees with long term care needs, is emblematic of the importance of engaging providers in the new models of payment and care. During FIDA's rollout, outreach to providers was limited and, as a result, many providers could not answer patient questions about FIDA, chose not to participate in care coordination activities, or did not know how to help patients navigate this new kind of plan. Subsequently, FIDA initially suffered from low enrollment and those who were enrolled did not always receive the full benefit of FIDA's enhanced care coordination benefits. Members of the panel agreed that models beyond FIDA would benefit from engaging providers and allowing them to assist in educating consumers.

"The problem is that doctors (who would normally be the ones to educate their patients) are both under pressure and confused. They're simply overwhelmed by the number and sheer breadth of these models. Those implementing these new models are the ones also providing the education, but only to certain individuals and on a program-by-program basis. As such, the overarching health system transformation landscape gets lost—this makes consumers act negatively toward changes that come as a result of new models."

"Providers use consumer engagement as a way to put the responsibility on the consumer. They say 'we engaged and they didn't.' [Real consumer engagement] is one-by-one. We need to be engaging providers and the people who work [in

hospital and other settings] in helping others get access to the system. Group consumer engagement means trained providers. This is a huge job."

"The main question is <u>how</u> to inform consumers."

While the panel recognized the importance of education, several interviewees also pointed out that it was not clear which aspects of complex new programs—which, as noted previously, often operate behind the scenes—are important for consumers to know and how to disseminate that information so that people will actually use it when making health care decisions. It was frequently noted that a balance should be struck between the extremes of providing too much irrelevant information that unnecessarily complicates health care navigation and making sure consumers are not left making health care decisions without the comprehensible information they need to make those decisions. The general consensus was that summaries of key aspects of new models are what is needed, and that these should be presented to consumers and their caregivers at the right time, for instance when a person is at the doctor's office.

"Explain this information to people via case studies, in simple language; make it accessible; incorporate it into every communication you have with individuals. You don't need to deal with details, so it's okay not to have them all."

In addition, the panel identified some specific areas around which consumers and their caregivers could benefit from more information, including the overall purpose of health system transformation and the need for information-sharing within new models.

"Consumers need to have a little bit of an understanding of why they're getting tons of calls from multiple care coordinators [affiliated with] multiple providers. [Consumer advocates] should tell patients that the hope of health system transformation is that we can improve the health care system and improve their health care experience by finding this balance of giving the patient what he/she needs/wants, but doing so in a way that makes the most sense and has the most impact. That needs to be conveyed to consumers in some way, and [consumer advocates] could be in the position to communicate that."

"People need to know that data-sharing is key."

"Consenting to data-sharing is beneficial: the more providers have access to information, the better the care can be . . . The stories we hear are people who don't share data and end up getting hurt as a result."

Not only did the panel believe consumers need general education on the purpose for new models and the potential benefits of data sharing, but they also believed that consumers needed targeted information to help them navigate their health care decisions. For example, consumers pondering a knee replacement should have access to comprehensible information about how a bundled payment system could affect the surgeon and rehabilitation center they

choose, their cost sharing, the incentives that could be influencing their providers, who they can go to for more information, and how to actually request and receive the procedure.

"Are we educating consumers about how to get the right kind of health care? Some people just don't know how to use the health care system to access care and to do that at the right time. It's all about finding the right care at the right time from the right providers."

The panel also believed that educating consumers (and providers) about health system transformation can empower consumers and lead them to be more engaged in their own health care and, by extension, in health system transformation. Consumer engagement is vital to ensuring that changes to our health care system are successful in their main aims of providing better quality care and value to health care consumers. This experience introduces the third challenge for consumer advocates: engaging consumers.

Challenge 3: The need to engage consumers in designing, implementing, and monitoring new models.

"How do we . . . make the health care user come to life and become engaged? We don't believe you can successfully implement health system transformation without having the consumer involved."

Although one of the primary goals of health system transformation is to improve the value and quality of care patients receive, the panel shared the view that consumers' voices are absent from the development, implementation, or evaluation of new programs. In particular, value-based payment models, which are increasingly prevalent, hinge on two key assumptions: 1) providers will offer better quality care if they are paid to do so; and 2) quality of care can be meaningfully measured. These assumptions are especially important to consumers, who are the intended beneficiaries of quality improvements, yet it is government, insurers, and providers who usually decide how quality measures are designed, used, and adjusted. Since policymakers are pegging consumer outcomes to these quality measures, it is consumers who need to provide input regarding which metrics are the right ones and how they should be used.^{ix}

Some health care providers are already finding that quality measures do not necessarily line up with patient experiences and that providers are not always in a position to resolve this.

"Physicians are caught in the middle—we're just trying to help our patients and do the best we can; but we need to negotiate what is quality based on measures from Medicare, health plans, and [state]government. Usually these measures have nothing to do with the everyday life of the patient and what they think is important in terms of making them feel better . . . Patients . . . want to know that they feel better and are continuing to get healthier. They aren't as concerned with what I'm reporting to the government about their progress—that isn't quality to them. [Consumer advocates]

could determine how to ensure that as policymakers create new quality measures for health system transformation initiatives, the provider and consumer perspectives are included and accurately reflected."

The panel agreed that in order to be successful, value-based payments need to lead to better health outcomes and patient experiences, not just to better quality measures. For that reason, quality measures should be tied to actual patient experiences, priorities, and preferences.

"A good place to start is to check in with consumers who are represented on quality boards—they're now expert at this because they've been involved in discussions from the beginning. It's remarkable how much effort is going into evaluating certain measures. There's a whole industry dedicated to this. If [one or two consumer advocacy organizations] could help develop priorities related to the ABCs of quality measures, it could be a rallying cry for other [advocates]."

The disconnect between how consumers see quality of care and the actual quality measures being used is particularly significant since quality is often the aspect of health care that consumers value the most. Unfortunately, these quality measures are currently too hard for consumers to find, understand, and apply to their own decisions; a problem only exacerbated by the fact that if the measures are found and used they do not necessarily match up with how consumers would evaluate quality. Our panel found, in general, that these problems with quality were a unique opportunity for consumer advocates to help consumers have their voices heard, while also tangibly improving the results of certain models.

In a variety of ways, the panel also highlighted the importance of consumer engagement in health system transformation while recognizing that such engagement was not happening consistently. This was identified as a significant problem since consumer engagement can ensure that new models protect consumers' rights, respond to consumers' needs, and do not put the desires of other stakeholders above those of the people actually using the health care system. In sum, the panel acknowledged that health system transformation requires active consumer engagement to be successful but is currently failing to capture consumer experiences. Medicare Rights can attest to the importance of meaningful consumer engagement in developing new health care models. With funding from the New York State Health Foundation and Community Catalyst, Medicare Rights organized several consumer advocacy organizations to serve as the consumer voice during the development and implementation of the FIDA program in New York.

"People have a lot of access to information, they're getting better at articulating their health goals, and there's a greater level of awareness of the fact that health and wellness matter in people's lives. Yet there seems to be a gap between how the health system sees people and what it is that people really want. The extremely fast pace of health system transformation, combined with changing how primary care practice functions, really risks creating an unbalanced view of how people will access and be engaged in their care. What's new for us is giving people more information and giving them the opportunity to be partners in the health care practice."

Our panel pointed at two examples of how consumer advocacy organizations are working to address the lack of consumer engagement in New York:

First, Medicare Rights and other consumer advocacy organizations created the Duals Advisory Workgroup comprised of providers, insurers, and consumer advocates working with people who have both Medicare and Medicaid. Consumer advocates have used this workgroup to address consumer needs and concerns and then advise government policymakers and insurers on changes that should be made to existing programs. Together with other stakeholders, consumer advocates spot and work to resolve systemic issues and work to improve direct communication between providers, insurers, and consumers.

Second, the Medicare Rights Center convened a workgroup comprised of people enrolled in Medicaid long-term care and their caregivers. This group is active in voicing consumer concerns and suggestions while seeking to increase the influence of consumers on the programs that target their health services and outcomes. While these consumer advocacy efforts are positive examples of how to engage consumers in health system transformation, our panel agreed that policymakers should build consumer engagement into the structure of new models and programs rather than rely on consumer advocacy organizations to organize this engagement, especially without supplying them with adequate resources.

An example of a well-resourced response to consumer engagement and advocacy is New York's Independent Consumer Advocacy Network (ICAN), which was launched in 2014.* ICAN is the state's ombudsman for people who utilize Medicaid-funded long-term services and supports. This state-funded program is operated solely by a network of independent consumer advocacy organizations, which includes Medicare Rights. ICAN—initially created as the ombudsman for the Managed Long Term Care Program and FIDA program—now serves several Medicaid populations throughout New York State. Through participation in the ICAN network, Medicare Rights and other consumer advocacy organizations have the resources necessary to identify systemic issues in health system transformation that are impeding people's access to care and have a direct link to policymakers that can address those problems. ICAN is just one model that Medicare Rights recommends stakeholders replicate in an effort to get to effective and meaningful consumer engagement with health system transformation.*i

Policy Recommendations to Address Challenges and Expand Opportunities of Health System Transformation

Drawing from its policy principles, it the insights of panel interviewees, and its own experience in health system transformation (via ICAN, the Duals Advisory Workgroup and other consumer engagement opportunities), Medicare Rights recommends the following policy actions for government (both state and federal), providers, insurers, and consumer advocacy organizations to make health system transformation work for all New Yorkers:

Ensure clear communication from all parties. Early and ongoing communication between consumer advocacy organizations, federal agencies such as CMS, and state agencies like DOH, as well as providers and insurers, is pivotal to the success of new and emerging models. This communication link is needed to help ensure that models respond to consumer needs in a timely fashion. All parties have an obligation to make this communication occur, but government entities like CMS and DOH, as the developers of most models in New York State, have particularly important roles as conveners and facilitators. That said, consumer groups must

be diligent in securing regular meetings with CMS and DOH in instances where the agencies are not proactively reaching out to consumers.

Supported with funding from philanthropic organizations, Medicare Rights has a long history of proactively engaging state and federal agencies: as CMS and DOH began the process of developing the FIDA program, it was Medicare Rights that convened a working group of stakeholders from managed care organizations and other advocacy organizations in response. Medicare Rights also sought to be a recognized as a fully-engaged partner with CMS, DOH, and insurers in negotiating the contract that implemented FIDA (known as the three-way contract between CMS, DOH, and insurers). While we were unsuccessful in our quest for a "four-way" contract, the working group Medicare Rights convened began meeting with CMS and DOH representatives, and it is in those discussions that Medicare Rights proposed several consumer protections for FIDA, including an integrated appeals process and an independent ombudsman, which now operates as ICAN.

- Government should convene and facilitate communication among policymakers, providers, the public, and advocacy organizations throughout all model stages, including design, implementation, and monitoring.
- Providers and insurers, who are often the front line of communication with patients, should educate consumers on models that affect them and how these models might change their health care experience.
- Consumer advocacy organizations should proactively advocate for and be accorded a
 seat at the table so that policymakers can include the consumer experience in the
 design, implementation, and monitoring of new health system transformation models.
 Throughout all stages of new models, consumer advocacy organizations should continue
 to reach out to consumers and caregivers with comprehensible and timely information
 on models that empower consumers to make the health care decisions that will serve
 their own interests.

Ensure transparency in policies and results. All parties to health system transformation can benefit when government and insurers are transparent about new policies and data relating to the evaluation and oversight of new models. Among other things, consumers, advocacy organizations, and providers should know what reimbursement rates and rules insurers are operating under and what protections are provided to consumers. The data government collects on the success of models, quality information on providers, and plan compliance is vital for advocacy organizations to understand how the models are working and whether consumer experiences are actually improving. Further, transparency in policies means all parties are operating within the same framework, which allows for greater efficiency when these parties interact, for instance when advocacy organizations serve their watchdog function by weighing in on policies, and when consumers successfully use the health care system and protect their rights.

Government should be transparent in communicating new programs and policies so that
all parties can understand the framework for new models. Additionally, government
should share data gathered on new models, allowing consumers and advocates to use
timely information to make health care decisions and to evaluate the success of models.

- Insurers should release timely, transparent, and easy-to-understand data on enrollment, access to care, volume of care, quality of care, and appeals.
- Providers should stress the importance of data collection with their patients, and allay
 their fears regarding the sharing of personal health information within and between
 health systems. Without patient data, it is difficult for policymakers to determine the
 efficacy of new models and for consumer advocates to make the case for additional
 improvements to health service delivery.
- Consumer advocacy organizations need access to information and should develop relevant expertise in order to distill data down to segments of information that are readily understood by consumers.

Meaningfully engage providers. Problems with the initial rollout of FIDA, introduced in Section III of this report, underscore how important it is for stakeholders to ensure providers are bought into new programs, especially in the model design phase. Despite the demonstration's potential advantages to members, only a few providers were involved in developing FIDA (and some of those involved were only aware of the new demonstration through their involvement in Medicare Rights Center's Duals Advisory Workgroup). As such, a very small number of physicians participated in a FIDA Plan network, promoted FIDA to their patients, or participated in the Interdisciplinary Teams (IDTs) that were a key part of FIDA's person-centered care planning and care coordination. Many providers did not know anything about FIDA, while others with knowledge of the demonstration disagreed with the strict requirements for unpaid provider involvement. In the end, both sets of providers actively discouraged their patients from enrolling, and as a result, many potential FIDA members never heard from their providers about the program, or decided not to join, or dropped out of FIDA after they discovered their doctors were not members of any FIDA Plan networks. The lack of positive provider involvement in FIDA is in large part the underlying reason for the program's low enrollment and serves as an example of why engaging providers at the outset of development is important to the success of new models.

- Government should reach out to and engage providers from the initial development stages of new models and work to facilitate provider buy-in as the model deploys.
- Providers should be active in understanding and helping promote, where appropriate, new models and the promise of health system transformation. Provider input and engagement are vital to the goals of improving the quality and value of health care through health system transformation efforts.
- Consumer advocacy organizations should relay to policymakers the importance of provider engagement and, when necessary, secure funding to conduct provider outreach as provider models are being developed. As mentioned earlier in this report, in response to the lack of provider engagement during FIDA development and implementation, Medicare Rights secured private grant funding to convene its Duals Advisory Workgroup, which afforded physicians the opportunity to assemble best practices for provider engagement and advocate for provider-friendly changes to FIDA policies.

Meaningfully engage consumers. As emphasized by those on the panel Medicare Rights convened, health system transformation is proceeding largely without crucial input from consumers, the very stakeholders in the position to experience how health system transformation affects access to and quality of care. This means that consumer priorities and experiences must be considered if changes to the health care system are going to be successful. Consumer involvement should be built into the structure of health system transformation and should continue into the implementation and evaluation of programs, with government mandating consumer outreach and meaningful engagement—not tokenism.

- Government should focus on prioritizing those demonstrations that consumers and their advocates identify as most likely to advance their preferences for accessing quality health care and having a positive experience with the health care system. To determine consumers' priorities, government agencies should convene meetings of consumer advisory councils—formal structures for engagement—and should establish consumer advisory panels that focus on specific types of models, such as those that focus on a specific population (e.g. individuals living with diabetes). Government agencies should also require service delivery entities—whether health systems or managed care organizations—to regularly convene their own consumer advisory councils and incorporate consumer input as new models are implemented, adjusted, and improved.
- Insurers should make meaningful consumer participation a hallmark of their products, including soliciting feedback on new models from their plan members.
- Consumer advocacy organizations must continue to ensure that they bring the consumer voice into discussions with government agencies, providers, insurers, and other relevant stakeholders. Consumer advocacy organizations need to be able to provide input on the level of consumer education about new models and consumers' level of satisfaction with the care they are receiving through such models. To do this successfully, consumer advocates need to be able to collect and disseminate compelling examples of consumers' experiences within the health care system. ICAN allows consumer organizations and the state to jointly report on what they hear directly from consumers and track specific trends and outcomes. We must stress that consumer advocacy organizations need additional resources in order to develop the internal processes necessary to collect and share consumer issues, trends, and stories.

Support consumer advocacy organizations. Consumer advocates have and can continue to serve a vital role in empowering beneficiaries and making health reform successful and responsive, but only because they were able to secure funding for this very purpose. Most consumer advocacy organizations lack the access to capital that would allow them to make sizeable investments—in terms of staff time or external expertise—to participate in the development of health system transformation models. In the years leading up to the passage of the ACA, foundation funding made it possible for consumer advocacy organizations to learn about and influence the ACA's impact on the health care system. This funding made it possible for consumer advocates to not only anticipate and respond to unforeseen problems, as well as make the most of opportunities to enhance beneficiary protections and improve health systems, but also build a grassroots consumer base to support and amplify advocacy efforts. But the work on consumer education and navigation, implementation, monitoring, and evaluation continues after grant funding ends and consumer organizations need sustained funding streams to continue their vital work.

Fortunately, consumer advocates in New York have had the opportunity to utilize state funding to fulfill their role of protecting and empowering beneficiaries participating in new health system transformation models; one such example is consumer advocates' role in the ICAN network mentioned earlier. As state and federal agencies developed policies for the soon-to-be-implemented MLTC and FIDA programs, Medicare Rights Center and other consumer advocacy organizations across New York urged DOH to create an independent, consumer-oriented ombudsman program to serve FIDA's enrollees. As a result, several consumer advocacy organizations receive sustained state funding to provide assistance to consumers and provide feedback to CMS, DOH, insurers, and providers on trends, problems, best practices, and successes.xiii Consumer advocates leverage their role as the ombudsman to address individual consumer problems while also identifying and working to change large systemic problems with a vital and expensive area of health care.

Without adequate resources, consumer advocacy organizations would not have been able to rally consumers around the importance of health system transformation in the ACA (or advocate for the creation of various programs and necessary consumer protections), nor would New York's consumer advocates be able to serve as the independent entity tasked with helping low-income New Yorkers enrolled in new managed care programs. From these examples, it is clear that in order to ensure consumer advocacy organizations can represent and protect consumers as policymakers undertake expansive and multifaceted changes to health systems, consumer advocates need opportunities for support.

As noted, philanthropic organizations frequently provide critical early or start-up funding to allow consumer advocates to organize and gain expertise around health system transformation projects. Increasing the robustness and availability of these resources to both individual consumer advocacy organizations and coalitions thereof will be important as the health system continues to transform over the coming decades.

State and federal governments, through the development and funding of consumer assistance and ombudsman entities that consumer advocacy organizations operate, can help to ensure that consumer advocates have resources to sustain their work in protecting and amplifying the voices of consumers. It is a good sign that CMS has already looked to replicate the ombudsman model on a nationwide scale: the Innovation Center plans to create an Alternative Payment Models Beneficiary Ombudsman to monitor new models and serve as a link to beneficiaries. Further, advocacy organizations should be empowered to solicit opportunities for regular communication with stakeholders involved in health system transformation, including government agencies, providers, and insurers. In short, they need a real seat at the table with actual negotiating clout.

Finally, insurers and providers (who are increasingly taking on financial risks of providing care and other insurer-like roles) should facilitate advocacy organizations' abilities to communicate educational content to, and advocate for, their patients and enrollees. Consumer advocacy organizations are experts at using clear, comprehensible language when communicating to consumers they serve. This is the type of expertise that can help ensure the success of new models: in building trust with consumers by providing accessible information about new programs, consumer advocacy organizations are in a unique position (alongside providers) to secure consumer buy-in as new models launch.

As such, it would serve insurers and providers well to recognize the increased demand placed on advocacy organizations by health system transformation, and provide support to consumer advocacy organizations that measurably protect and educate consumers. This could take the form of purchasing services from consumer organizations in order to create an earned income stream for their work; drafting letters of reference recommending consumer advocacy organizations for private and public grants and contracts; accepting a position on a consumer advocacy organization's board of directors; or providing pro bono advice and expertise.

The various modes of health system transformation have required expanded resources and new roles at CMS, DOH, insurance companies, and health systems. A similar need for additional resources exists at advocacy organizations, which require support to train board members and staff in new skills; to monitor government agencies as they develop components of new models, including oversight structures and payment incentives; and to work in myriad ways to educate and protect consumers.

Conclusion

Although the U.S. health insurance and health care systems currently face uncertainty—as do millions of Americans who rely on these systems for coverage and care—the various models comprising health system transformation are already becoming part of the national health care fabric, and their emphasis on improved care quality and reduced costs will likely remain important nationally and in New York for years to come. With significant experience on the front lines of health system transformation in New York, the Medicare Rights Center and those interviewed for this report have witnessed the challenges and opportunities new models have created. Now, though the future of these initiatives may be unclear, the policy principles and recommendations distilled in this report can serve as a guide for how to ensure that any changes to health care delivery and payment systems benefit and protect consumers and caregivers. As changes like those described in this report unfold, consumer advocacy organizations must play an important role in providing consumer education and protection. Working together, we believe that government, insurers, providers, consumer advocacy organizations, and consumers themselves can build a stronger health care system—one that meets the needs of all people.

Appendix A – Overview of Health System Transformation in New York

Health System Transformation Nationally

In order to contextualize health system transformation in New York, this summary first takes a look at what is happening nationwide.

With Medicare, Medicaid, and the Children's Health Insurance Program (CHIP)

covering over 100 million people, *v the federal government is the single largest health care payer in the country*vi and has the greatest leverage in determining how health care is paid for and delivered.*vii Health system transformation initiatives use the government's power as a payer, along with other financial incentives, to encourage other health care stakeholders to adopt new behaviors.

Passage and implementation of the ACA has led to an intensive period of great experimentation with delivery and payment models. The majority of new programs have been launched by CMMI (also referred to as the Innovation Center), an office created by the ACA to develop and test new payment and delivery models that could reduce costs for the federal government while improving health care outcomes.**

It is expected that the Innovation Center, on its current path, will produce a net savings of \$27 billion between 2016 and 2025^{xix} while also significantly improving health care quality. At the time of this writing, the future of the ACA, the Innovation Center, and many initiatives remains uncertain; the American Health Care Act of 2017 (H.R. 1628), which passed in the House but failed in the Senate, is just one of many expected attempts to change various aspects of the ACA, including the role of the Innovation Center. Even still, the Innovation Center is pursuing dozens of federal projects in the following categories:^{xx}

- Accountable Care
- Best Practices
- Bundled Payments
- Medicare-Medicaid (programs for people who have both Medicare and Medicaid)
- Medicaid and CHIP
- Primary Care
- Promotion of new models (supporting state- and locally-led initiatives through technical assistance and funding)

Health System Transformation in New York

New York is at the forefront of health system transformation, implementing an array of models simultaneously. The state has some of the largest Medicare and Medicaid programs in the country and much to gain if new models can truly reduce costs while improving health outcomes. New York's Medicaid Redesign Team, in particular, has embraced the goals of health system transformation and created its own initiatives to move to a value-based payment system in which Medicaid payments are tied to value, health outcomes, and best practices. Because these programs do not always fall into neat categories and are often interrelated, please refer to the included visual representation of health system transformation in New York to better understand the overall landscape and common goals, in addition to the summary below.

Accountable Care Organizations

There are 27 Medicare ACOs throughout New York State; these organizations were formed when different health care providers operating in the same geographic area agreed to be held accountable for the quality and cost of care for the ACO's patients.** ACOs function as part of the Medicare Shared Savings Program (MSSP); created by the ACA, MSSP is a funding mechanism that gives an ACO the opportunity to keep some of the money they are saving CMS—if the ACO can reduce the cost of care and meet certain quality requirements** The MSSP program is ongoing, with each of the 27 ACOs in New York having selected one of three tracks corresponding to different levels of risk related to how they share in losses and savings.** For example, Montefiore Pioneer ACO participates in the Pioneer ACO Model, meaning it is responsible for a significantly larger population and, as a result, takes on higher levels of risk.** Provider participants in this model can also elect to participate in population-based payment

models, meaning CMS reimburses the ACO a set amount based upon the total patient population. In the first three years of the model, the Montefiore Pioneer ACO was one of the most successful ACOs in New York and one of the most successful Pioneer ACOs in the country, as reflected by its sharing in larger amounts of savings and improved quality scores, though the ACO did not earn shared savings in 2015. **XXXIIII*

On a much smaller scale, the Rogosin Kidney Care Alliance participates in the Comprehensive End Stage Renal Disease (ESRD) Care Model.*** The Alliance is an ESRD Seamless Care Organization serving approximately 400 dialysis patients at two kidney centers in New York City.** While this model serves significantly fewer New York residents than other accountable care models, it still has the potential for high impact, since ESRD beneficiaries, though only 1.2% of the Medicare population, account for 6.3% of Medicare's costs.***

Bundled Payments

In New York, both Medicare and Medicaid demonstrations are developing and testing bundled payment models. All bundled payment models reimburse providers based on the expected costs for a clinically-defined episode of care, though they differ in the providers involved, the conditions or treatments for which payments are provided, and how different quality measures affect reimbursement amounts.

Due to changes in leadership at the Department of Health and Human Services, which houses CMS, the future of bundled payments, like many other health system transformation models, remains unclear: CMS has delayed the implementation of its CJR model from July 1 to October 1, 2017 and is weighing the option of delaying until January 1, 2018 the implementation of the Cardiac Rehabilitation Incentive Payment Model.**

Medicare-Medicaid

New York has elected to target a subset of its population of residents who are dually eligible for both Medicare and Medicaid through the Fully Integrated Duals Advantage (FIDA) demonstration.**

This demonstration has led to the creation of private FIDA insurance plans, which provide combined, comprehensive Medicare and Medicaid benefits for dually eligible beneficiaries with long-term services and supports needs. FIDA plans are required to provide additional benefits (e.g. hearing, vision and dental care) to members, as well as an integrated appeals process designed to better protect plan members.**

The plans are also encouraged to engage an interdisciplinary team comprised of plan representatives and the member's health care providers in order to better coordinate member care and develop a person-centered care plan tailored to each member's needs.**

While the FIDA program is small, currently serving

just over 5,000 members,^{xl} it may grow now that the demonstration has been extended through 2019 and is set to expand to other parts of the state.^{xli}

Primary Care

New York is reshaping primary care through a variety of initiatives, including a Medicare demonstration called the Comprehensive Primary Care (CPC) Initiative. *\(^{\mathbb{I}\ii}\) This model attempts to redesign primary care practices by increasing access, engaging patients and family members in decision-making, coordinating care, focusing on chronic and preventive care, and allowing for risk-stratified care management. Participating provider networks receive monthly non-visit-based care management fees and the opportunity to share in any Medicare net savings. There are currently more than 60 New York provider networks participating in the CPC Initiative and more set to participate in CPC+. *\(^{\mathbb{I}\iii}\)

Medicaid and CHIP

Perhaps more than any other state, New York has embraced the goals of health system transformation through its Medicaid program. Since 2011, the state has actively restructured Medicaid through the previously mentioned Medicaid Redesign Team, which incorporates some of CMS's and the Innovation Center's health system transformation initiatives into its policy changes. *Iiv* The main focus of New York's efforts is its goal of moving 80-90% of all managed Medicaid payments from fee-for-service to Value Based Payments (VBP) by 2020. The state is working to meet this goal with a variety of projects, including:*IV

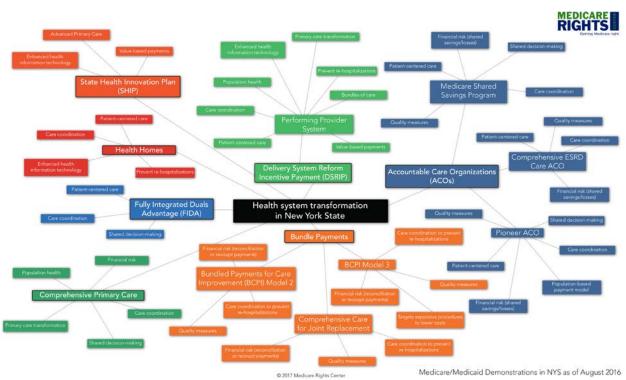
- Total Care for the General Population (TCGP): The TCGP model requires and incentivizes state contractors, such as hospitals, to take responsibility for the total care of a particular population by involving other community stakeholders, such as communitybased organizations. This model integrates population health, xlvi care coordination, referral patterns, and discharge management.
- Integrated Primary Care (IPC): The goal of IPC is to reduce "downstream" costs (such as avoidable emergency room visits or hospital readmissions) through better care coordination, easier access to primary care, and an emphasis on population, physical, and behavioral health. If providers reduce costs in these areas, they are entitled to a share of the savings they created.

The state's VBP efforts are mostly aligned with the Delivery System Reform Incentive Payment (DSRIP) program, the largest part of an \$8 billion agreement with CMS to restructure health care delivery and payments. *Ivii DSRIP currently supports 25 different Performing Provider Systems (PPSs), which are networks of clinical delivery sites, other health care providers, and community-based organizations tasked with coordinating care delivery. *Iviii To support state programs, CMS provides financial and technical support to New York through the State Health Innovation Plan (SHIP), *Iix which also funds innovations in primary care through the Advanced Primary Care (APC) Model. I

On a smaller level, New York is implementing a program to target a specific subset of its Medicaid population: the Health and Recovery Plan (HARP) model, which aims to increase access to behavioral health services for people with serious mental illness or substance abuse disorders. HARP funds and oversees private managed care plans through which Medicaid enrollees can access their health benefits, including behavioral health services, while reducing

costs by eliminating avoidable hospitalizations. Plans participating in HARP need to meet certain quality and performance standards created specifically to measure behavioral health outcomes, as well as to provide person-centered care plans and advanced care management.

New York also targets a subset of the Medicaid population through Health Homes. Health Homes are not a physical place but a set of care coordination services, provider networks, and communication policies designed to ensure that patients can access the services they need without duplication. More than 100 participating Health Homes across the state currently offer care management services whereby all of a patient's providers and caregivers communicate regularly. Iiii



Appendix B – Map of Health System Transformation in New York

View pdf of map.

Appendix C – Policy Principles

In light of the new challenges created by the payment and system delivery changes discussed above, the Medicare Rights Center developed a set of nine core, consumer-oriented principles meant to guide the development, implementation, and evaluation of new models and systems. These principles are a general framework that government, insurers, providers, and consumer advocacy organizations can use to shape health system transformation and help ensure that it meets real needs.

1. All care models should build upon the positive outcomes of current care models while ensuring consumers have affordable access to health coverage.

- 2. All care models should leverage the meaningful engagement of consumers, their caregivers, and their advocates in all aspects of design, implementation, and evaluation.
- 3. All care models should promote health equity for all and address social determinants of health.
- 4. All care models should include consumer protections that are developed in partnership with them, their caregivers, and their advocates and are designed to enhance quality of care and promote health care access and equity.
- 5. All care models should be coordinated and person-centered.
- 6. All care models should be evaluated using measures of performance that are actionable, coordinated, and clearly explained to consumers and their caregivers.
- 7. All care models should leverage the meaningful engagement of providers in development and implementation in order to ensure buy-in and clear communication with members of the provider community.
- 8. All care models should promote better engagement by incorporating accessible and supportive health information technology for consumers and caregivers.
- 9. All care models should make financial incentives transparent to consumers, caregivers, and their advocates, and those incentives should promote quality without reducing choice or access to care.

Appendix D – Expert Panel Participants

Hany Abdelaal Deborah Bachrach Pam Brier Audrey Chun Tara Cortes Lisa David Trilby de Jung Valerie Grey Kathryn Haslanger Karen Ignagni llene Margolin Rachel Miller Kirstin Mooney Karen Nelson Carol Raphael Lynn Richmond Kathleen Shure Rick Surpin Bruce Vladeck Mark Wagar Patricia Wang

Dennis Whalen

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- ⁱ In this report, "health system transformation" is used as an umbrella term to describe an often interconnected array of local, state, and federal programs designed to change how health care is paid for and delivered. More specifically, these initiatives are tied together by their goals of improving the quality and value of health care services. By using this term, Medicare Rights does not mean to imply that these programs will certainly transform health care, only that this is the goal that ties them together.
- ii See Appendices A and B for an overview of health system transformation in New York.
- iii Throughout this report, the term "consumer" is used as a stand-in term for people who interact with the health care system in some way, such as a patient seeking care, a Medicare beneficiary, or a Medicaid recipient. Admittedly, there are problems with using terminology that could put undue focus on the transactional aspect of health care and could imply false analogies, for instance between a person using the health care system and a person buying a tangible product from a department store. This report acknowledges those problems but for ease of argument will use "consumer" as shorthand to describe people using the health care system.
- ^{iv} A focus of this report is on consumer advocacy organizations, which is an inclusive term encompassing a wide range of entities, from direct service community-based organizations working at the local level to national consumer advocates, like Medicare Rights, that provide not only direct services but also seek to reform Medicare-related systems across the country.
- ^v The ACA established a new financial alignment demonstration that allowed states to integrate Medicare and Medicaid services for individuals dually eligible for both programs. The demonstration currently being implemented in New York is the Fully Integrated Duals Advantage (FIDA) program.
- vi This conclusion is bolstered by a series of Robert Wood Johnson Foundation (RWJF) focus groups conducted in 2011 and aimed at determining how much members of the public wanted to know about health care delivery and payment system reform (http://www.rwjf.org/en/library/research/2011/04/talking-about-health-care-payment-reform-with-u-s--consumers.html). Study participants were generally not interested in learning about changes to how their providers would be reimbursed for their care, and most did not understand how their providers were currently paid. Participants also expressed strong feelings against hearing anything about programs that linked value with their health care; some participants even became angry when told that programs were going to change how they received health care in order to achieve a better value. According to the RWJF report, these patients became upset because they did not know how provider reimbursement worked, and linking any sort of payment to their health outcomes made them uncomfortable.
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- ix Concannon, Friedberg, Hwang, Wiitala. "Engaging Consumers in the Quality Measurement Enterprise." *Rand Corporation*, (2017), available at: http://www.rand.org/pubs/research_reports/RR1760.html.
- ^x General information on ICANN available at: http://icannys.org/.
- xi Medicare Rights participates in other programs that can also serve as models. For instance, Medicare Rights provides training, technical assistance, and promotional activities in support of the State Health Insurance Assistance Program (SHIP) and 54 SHIP projects nationally, which use the platform to help beneficiaries navigate Medicare and Medicaid questions. (See https://www.medicarerights.org/pdf/fy-16-annual-report-summary.pdf). Medicare Rights also works with a network of organizations as Community Health Advocates (CHA) that use financing from New York's state budget to help consumers find and navigate health coverage or access low-cost or free care. (See http://www.cssny.org/programs/entry/community-health-advocates).
- xii See Appendix C for the policy principles.
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- xv Id. "On its 50th anniversary, more than 55 million Americans covered by Medicare." (July 2015), available at: https://www.cms.gov/Newsroom/MediaReleaseDatabase/Press-releases/2015-Press-releases-items/2015-07-28.html. xvi In 2014, the federal government paid approximately 28% of all health care expenditures. Id. "National Health Expenditures 2015 Highlights." (2015), available at: https://www.cms.gov/research-statistics-data-and-systems/statistics-trends-and-reports/nationalhealthexpenddata/downloads/highlights.pdf.

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xxv General information on the Medicare Shared Savings Program available at:

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https://innovation.cms.gov/initiatives/Pioneer-ACO-Model/index.html https://innovation.cms.gov/initiatives/Next-Generation-ACO-Model/index.html.

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