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Advanced American Kidney Health Initiative

Stephanie Silverman
Venn Strategies, United States

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Stephanie Silverman

Government Affairs and Policy Shaping in the US with Case Study: Advancing American Kidney Health Initiative (AAKHI)

I. Intro: Why Kidney Disease?

I have been actively advocating for equitable access to kidney disease treatment, with an emphasis on home dialysis, for over a decade.

As a Foundation board member of the National Association for Advancement of Colored People (NAACP), and a former board member of the American Diabetes Association, I have long been passionate about ensuring that under-resourced populations can access the best available health care modalities. In the United States, where Black Americans are almost four times as likely as white Americans to develop kidney failure[1] and other minorities also suffer disproportionately from kidney failure, and where Black and other minorities are less likely to receive a kidney transplant or home dialysis therapy, we have a lot of work to do.

As executive director of the Alliance for Home Dialysis (AHD), I am proud that we have been successful in driving improved access to home dialysis for all under-resourced communities – through partnerships with the government, clinicians, patients and key stakeholders like the NAACP – but the progress we have made, which shows up as the percentage of incident patients receiving home dialysis almost doubling over ten years,[2] is just the beginning of what we must do as a community.

II. US Health Policy Landscape – End Stage Renal Disease

The most recent US data[3] on kidney disease is from 2020-the first half of 2021, which means that we are seeing the first data that encompasses the majority of the COVID-19 pandemic. The pandemic has been particularly difficult for patients with ESRD, with rates of infection up to 200% higher than Medicare beneficiaries without ESRD and a higher mortality rate as well.[4]

The total number of patients with ESRD in 2020 was 807,920. In 2020, 109,107 patients began in-center hemodialysis, representing 83.9% of patients with incident ESRD. Of those, 12.7% of patients initiated peritoneal dialysis at home and 3.1% received a transplant, and those statistics reflect an important increase over prior years.[5] Home hemodialysis utilization is still very low in the US: in 2020 only 0.3% of incident patients began HHD. As stated above, these numbers are slowly increasing. However, Black and Hispanic patients are still less likely to dialyze at home than white and Asian patients.

Related to the U.S. regulatory “ETC Model,” which was implemented in January 2021, “home dialysis utilization at dialysis initiation was slightly lower in ETC markets, but this difference was not evident after the launch of ETC.”[6]

III. Key Strategy for Shaping Health Policy in the US

Here, I will walk through some of the major strategic questions that should be considered when seeking to change policy in the US.

- a. What is the problem?
 - i. Demonstrate why this is important and ensure that it is actually a problem that the government can and should solve.
- b. Consider how to get buy-in from stakeholders (patients, clinicians, family/caregivers) that the problem is important and needs government solutions.
 - i. Strategies: Meetings/Roundtable discussions in which stakeholders can brainstorm, development of written materials and testimonials that support existence of the problem and need for a solution.
- c. Determine whether there are any natural potential allies in the government.
 - i. Are there any officials with a personal connection to this problem?
 - ii. Does this problem have impact on other areas of health care, such as other disease states, equity as mentioned above, etc.?
- d. Think through and plan how to "sell" the problem to relevant government agencies and policymakers.
- e. Once stakeholders and policymakers are in agreement that the problem needs to be solved, begin to discuss solutions. Ideally, you should have a solution in mind, but will be able to position it so that there is broad agreement and ownership.
- f. Ensure that a small number of policymakers are willing to be the main actors on this issue, but also create "backup," known as political cover, which can be other policymakers who will play supporting roles or quasi-governmental organizations. In the US, this could be MedPAC, for example, which advises Congress about many issues including kidney disease.
- g. Work with your allies to build out a vision with realistic goals, good data, opportunities to provide "care and feeding" for your allies and bring in new stakeholders, and consider a plan to insulate yourself through potential political change, like elections.

IV. Case Study: ETC Model, Under AAKHI (Description, Progress, Future Goals)

On July 10, 2019, President Trump announced the Advancing American Kidney Health Initiative, which included an executive order directing the Department of Health and Human Services to act to increase access to transplant, home dialysis, and more. Specific goals included: 1) Reducing the number of Americans with ESRD by 25% by 2030; 2) Increase the number of patients initiating dialysis in home or receiving a transplant to 80% by 2025; and 3) Double the number of kidneys for transplant by 2030. The ESRD Treatment Choices (ETC) Model, a mandatory payment model aimed at increasing home dialysis and transplant. While kidney disease advocates have worked to increase patient access to therapies and outcomes for many years, it wasn't until HHS Secretary Alex Azar, who had a personal connection to kidney failure, took office and made kidney disease part of his mission.

This value-based payment model was intended to align provider incentives with patient preferences. During the presentation, I will walk through specific elements of the model, including the two payment adjustments. We will also discuss whether the ETC Model aligns with the elements of a successful policy change that were outlined above and talk through some initial data points that have been released on its impact.

- [1] <https://www.niddk.nih.gov/health-information/kidney-disease/race-ethnicity#:~:text=African%20Americans%20are%20almost%20four,failure%20in%20the%20United%20States.>
- [2] <https://usrds-adr.niddk.nih.gov/2022/end-stage-renal-disease/2-home-dialysis>
- [3] <https://usrds-adr.niddk.nih.gov/2022/introduction>
- [4] Note that in the US, all patients diagnosed with ESRD are granted access to Medicare, which is typically reserved for older Americans.
- [5] <https://usrds-adr.niddk.nih.gov/2022/end-stage-renal-disease/1-incidence-prevalence-patient-characteristics-and-treatment-modalities>
- [6] <https://usrds-adr.niddk.nih.gov/2022/end-stage-renal-disease/2-home-dialysis>