

SurvivorsFor Solutions

2024 Choices Roadmap



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Overview

Survivors for Solutions' 2024 Choices Roadmap serves to educate the public and patients on both dangerous and pragmatic policies to help them comprehend our nation's biggest healthcare challenges. Understanding the patient experience and how misdirected policies will impact their health journey is critical for anyone making significant policy commitments or legislative decisions.

In a critical year like this one, it's important that the public grasps today's healthcare issues and understands how they impact patients. America's patients grapple with difficult symptoms and challenging medical decisions every day. Whether receiving a serious diagnosis, dealing with disease side effects, or undergoing strenuous treatments, patients have enough challenges, which is why our government mustn't create more barriers to care for them.

As a fundamental rule, any policy that may limit access to treatments, put the government in between patients and their doctors, or risk the research and development of new treatments is a non-starter. America is too prosperous and humane of a nation to foster a healthcare system that either denies or does not welcome the medical advancements that save lives. Patients – both current and future – want to fight their conditions and get back to living. Our healthcare system should afford them all the tools necessary to do so.

Ultimately, hope matters most for patients, and this sentiment should serve as a compass for those navigating healthcare policy. We welcome anyone who chooses to put hope first to sign our patient pledge and commit to patient-centric policies that will protect patients' access to medical innovation.

-Survivors for Solutions

Policy Objectives, Effects & Solutions

What Patients Are Against

Price Controls

- The Inflation Reduction Act (IRA) introduced devastating drug price controls, marking a historic example of government overreach with the potential to completely devastate American medical innovation.
- Price controls destroy incentives for companies to produce lifesaving drugs by limiting the ability for manufacturers to have a return on their investment. In fact, the IRA has already forced companies to reduce R&D spending, and this is just the tip of the iceberg.
- Patients rely on cutting-edge innovation to survive, and price control policies undermine and delay access to much-needed medical technology.
- A patient's doctor should decide the most appropriate medical treatments for their patient; there is no room for the government in the doctor's decision-making when prescribing a treatment plan.
- Unfortunately, the buck doesn't stop with the IRA. Policymakers want to take them further, proposing to double, even triple, the number of drugs negotiated before examining the full impact of the first round of price control changes. The spread of this policy must stop before medical innovation as we know it is destroyed.
- Anyone who considers price controls — not policies that will foster the pursuit of new cures — the most important focus for patients with rare, life-threatening, or chronic illnesses has clearly never been sick.

Pharmacy Benefit Managers (PBMs)

- For decades, drug middlemen have played a crucial role, acting as intermediaries between drug innovators and insurers as well as pharmacies to ensure patients could access prescription medications.
- However, today's Pharmacy Benefit Managers (PBMs) and their large insurer sponsors have exploited the system's opacity to prioritize their profits.
- Negotiated rebates provide massive savings for insurers that should be used to lower the price of drugs under plans. Instead, they are often pocketed by PBMs, leaving patients to pay higher prices at the pharmacy.
- This issue is part of a broader problem: limited transparency and monopolistic control leading to patient harm and higher costs in our healthcare system.
- To ensure patients receive the value they deserve in accessing medications, it is essential to hold PBMs accountable.

Stand Against Government Confiscation of Innovation-Incentivizing Tools

- The protection of patents plays an indispensable role in incentivizing necessary research and development that leads to cutting-edge treatments for patients.
- The government's attempt to confiscate innovation-incentivizing tools, such as patents, is an irresponsible use of policy as it will ultimately lead to fewer new and novel treatments in the pipeline.
- Meddling with medical patents will upend the innovative American medical ecosystem that patients throughout the world rely on for crucial cures and treatments.

Prior Authorization

- Imagine how you would feel if you were a patient treating an illness with a doctor-recommended prescription, and your insurance company decided to effectively override his decision. Insurance companies have weaseled their way into a position to have the final say in medications patients receive—through a process known as prior authorization. This puts people who are more interested in investor health than your health in charge.
- What may have begun as a legitimate effort to curb fraud and abuse is now weaponized to find any penny possible and ultimately prevents patients from obtaining necessary medications in a timely fashion. This merry-go-round of an approval process leaves patients frustrated or worse, and pads "big insurance's" P&L numbers for Wall Street's benefit.
- Prior authorization too often puts patients who are reliant on their doctor-prescribed medications in an even more vulnerable position. The value of a human life should take precedence over an insurance executive's bonus. We need to carefully look at tools like prior authorization that are used to mindlessly deny patients access to lifesaving treatments.

Quality Adjusted Life Years (QALYs)

- Quality Adjusted Life Years (QALY) is a discriminatory drug valuation system used in pricing practices that puts the patients most in need at the back of the line.
- QALYs essentially attempt to put a price on years of human life, giving higher value to a drug that will prolong a patient's life for an extended period. This means an individual with cancer may not get coverage for a drug that would extend their life for only 6 months or a year even though those few months might mean everything to them and their family.

- This also means that drugs that treat rare or life-threatening diseases will not receive the attention, research, or funding required to bring these medications to pharmacy shelves.
- This cost-effectiveness analysis is used by insurers and payers to inform medical treatment coverage decisions. Insurers and payers give preferential treatment to healthier patients at the expense of those who have more difficult-to-treat or advanced conditions, such as patients living with rare illnesses, chronic conditions, or life-altering disabilities.
- Any efforts to import this discriminatory rating practice will keep drugs away from patients most in need. Lawmakers must pass federal legislation to outlaw biased and discriminatory valuation systems that hinder the treatment of our nation's most vulnerable patients and have no place in our healthcare system.
- We do not have to estimate the negative impacts of these types of policies. They have already been implemented abroad, where they result in restricted access. Efforts to mimic them domestically should be a nonstarter.

Prescription Drug Affordability Board (PDAB)

- Prescription Drug Affordability Boards (PDABs) are another vehicle for inserting government bureaucrats into the drug pricing system. State lawmakers across the country are proposing the boards, believing they would help them manipulate drug prices without knowing the full costs of such a proposal. These boards are not there to help people get access to life-saving medication but to determine whether it should even be an option.
- Many big insurance executives sit on these boards, giving them powerful oversight over drug pricing, where they are likely to sway decisions in their favor. Of particular concern are their efforts to use these boards to kill longstanding protections for patients with pre-existing conditions. If a drug is too expensive to treat someone with a serious illness, this board may be able to determine it fails the affordability test.
- These boards add layers of regulation to an ecosystem that currently provides us with a pipeline of discovery, adding unnecessary risk to the hope millions are praying for.

What Patients Are For

Supporting Innovation

- Access to medical innovation is a crucial and often lifesaving part of a patient's story. Drugs and treatments are known prescriptions for improving health outcomes – not policies that restrict access.
- Drug R&D ventures lead to more treatment and care options for chronic illnesses and diseases. Having multiple options to choose from is critical for patients in case their first prescribed dose is not the best option. This is why the development pipeline must be nourished to ensure future cures and medications come to fruition.
- Policymakers should incentivize the development of these breakthrough treatments if they want to improve health outcomes in America and lower overall healthcare costs.

Addressing the IRA's "Pill Penalty"

- Whether overhauling the entire drug negotiation program or incrementally fixing the most dangerous provisions of the law, the IRA must be torn down before it devastates US medical innovation as we know it.
- Bipartisan legislation in Congress proposes to protect small-molecule drugs from Washington bureaucrats who want to shorten the patent protection period necessary to incentivize their innovation. Small-molecule drugs are especially critical for patients fighting cancer or rare illnesses who often have no other option to fight their aggressive diseases. Risking their development was cruel and one of the worst ingredients in the IRA's innovation poison pill.

Removing Treatment Denial Measures

- Big insurers utilize a number of tools to deny patients with chronic illnesses and rare disease coverage, arguing their treatments are too expensive or their lives are less meaningful due to the seriousness of their health condition.
- This is not how a healthcare system should treat patients. It's time to refocus the system on helping patients access any and all treatments and medications they need to survive their illness and live more productive lives.

Purposeful and Responsible Application of Artificial Intelligence (AI)

- The opportunity for tackling complex illness, solving the unsolvable, and advancing medical innovation has never been greater. Artificial intelligence is a powerful tool that requires responsible thinking, not cowering risk aversion.
- AI and advancements in quantum computing can mean unfathomable progress in combating the world's most difficult health challenges. Allowing the passion of patient advocates, disease-centered foundations, and all medical researchers to harness the entirety of the world's knowledge to be deployed on behalf of patients and survivors.
- While AI in healthcare is the Wild West, we can envision a few opportunities for the technology to help patients. For example, AI could reduce administrative burdens for clinicians, including note-taking. AI could also help forecast someone's risk of disease, which could lead to earlier diagnosis or, at least, more patients visiting their doctor.
- It's important to get ahead of this technology and begin to regulate it but also use it to our advantage. Just like the invention of the wheel, we should see it as a tool that will enable humans to largely better our lives; in ways that are impossible to imagine today but made possible with purposeful and responsible application.
- We don't necessarily need the implementation of harsh regulations governing AI, but rather "guard rails" that allow the technology to flourish without too much risk. The potential benefits for doctors and patients are too important to let doomsayers stop this vital innovation.

Policy GPA Scale

Rubric for policy objectives

	3	2	1
Innovation & Future Cures Development	Expected to reduce research investments and the development of new treatments	Unclear of impacts; more review and oversight are needed	Ensures treatment innovation can thrive; protects current and future R&D
Treatment Choice	Reduces the number of treatment choices and the likelihood of new options	Unclear of impacts; more review and oversight are needed	Allows for the availability of numerous drugs and therapies for health conditions
Patient-Doctor Relationship	Doctors will have fewer treatments to prescribe, and patients will have restricted treatment courses	Unclear of impacts; more review and oversight are needed	Ensures patients and their doctors are able to make the most appropriate decision for healthcare

Score

Price Controls

- Innovation & Future Cures Development - 3
- Treatment Choice - 3
- Patient-Doctor Relationship - 3
- Final Score: 9

Prior Authorization

- Innovation & Future Cures Development - 2
- Treatment Choice - 3
- Patient-Doctor Relationship - 3
- Final Score: 8

Quality Adjusted Life Years (QALYs)

- Innovation & Future Cures Development - 2
- Treatment Choice - 3
- Patient-Doctor Relationship - 3
- Final Score: 8

Pharmacy Benefit Managers (PBMs)

- Innovation & Future Cures Development - 2
- Treatment Choice - 3
- Patient-Doctor Relationship - 3
- Final Score: 8

Prescription Drug Affordability Boards (PDABs)

- Innovation & Future Cures Development -3
- Treatment Choice - 3
- Patient-Doctor Relationship - 3
- Final Score: 9

Patient Pledge

About the Patient Pledge

Healthcare is a pillar of many policymakers' political agendas. However, their objectives are either misguided or misaligned with the policies that would actually benefit patients, particularly for our sickest. It's time that our politicians commit to patient-centric principles and solutions that:

- Always dignify and put the patient first.
- Preserve and protect patient hope for the discovery of life-saving treatments.
- Keeping hope for the patients – present and future – as our aim.

Take the Pledge

Below are ten key guidelines to help navigate policymakers into making meaningful policy commitments and decisions.

1. Ensure patients always have a seat at the table.
2. Keep and incentivize an ongoing pipeline of medical breakthroughs.
3. Champion the unique conditions that exist in America that incubate the scientific and investment risk that advances all of us.
4. Return to the spirit which fueled 40 years of bipartisan cooperation and again unite in support of unleashing American leadership in the development of, and access to, breakthrough cures and treatments.
5. Remember that this is about finding better care for our fellow citizens, not just administering more efficient "sick care."
6. Never forget that the most expensive prescription is the one that disrupts America's ecosystem of medical breakthroughs, subjecting patients to a life in a taxpayer-funded hospital bed: hopeless, undignified, and cast off as subsidized yet worthless refuse.
7. Take aim at the bad actors who exploit our generous commitments to caring for health with exploitative prices and unjustified gouging. We do this by expanding transparency, vigorous enforcement of law and enlistment of all invested stakeholders, and better federal and state stewardship of patient and taxpayer dollars.

8. Know that history has never shown that government price controls have ever worked. We must avoid the seemingly simple imposition of centralized economic control. Knowing the results have almost always been tragic, with unintended consequences that produce the exact opposite of what was hoped.

9. Always ask, "does this result in more cured and healthier patients or no?" We will oppose anything that doesn't.

10. Expose hard truths like the recent enactment of the Inflation Reduction Act of 2022 (IRA). Under its seemingly innocuous title, it includes provisions that are already disincentivizing investments in biopharmaceutical research and development and making the development of cures less likely. We plan to vigorously call out these dangerous policy flaws and seek to reform, revise, or repeal these policies.

I, _____, pledge to the American patient that I am committed to protecting their hope and access to cures.

Signature

Date

Please return the signed pledge to Survivors for Solutions by emailing cz@survivorsforsolutions.org.

Get Involved

Sample Social Media

Price Controls

- #Rx price controls disincentivize critical medical innovation. Politicians must prioritize #patients by protecting America's innovation pipeline that delivers vital treatments and cures. #PatientPledge
- The implementation of #Rx price controls would destroy #patient hope for future cures. This overreach would take a sledgehammer to America's innovation ecosystem that brings vital medications to pharmacy shelves. #PatientPledge

Intellectual Property

- The US patent system protects the research and development that delivers #patients life-saving cures and treatments. Those living with rare, chronic, or life-threatening diseases rely on #IP rights to incentivize the creation of new medications. #PatientPledge
- Property rights are a cornerstone of the US economy. Politicians must work to protect the #IP that allows innovators to take the risks that deliver cutting-edge medical advancements to patients in need. #PatientPledge

Protecting Hope and Cures

- Patients suffering from rare, chronic, or life-threatening diseases rely on the hope for a brighter future that medical innovation provides. Policymakers must endeavor to protect the research and development that brings vital new treatments and cures to patients in need. #PatientPledge
- Politicians and policymakers must protect America's medical innovation ecosystem to promote the development of new cures that foster hope for #patients most in need. #PatientPledge

Make the #PatientPledge

- Make the #PatientPledge to commit to standing up for survivors of rare, chronic, and life-threatening diseases. Fostering the #Rx research and development that delivers much-needed treatments and cures to #patients should be policymakers' top priority. #PatientPledge
- Make the #PatientPledge to support #patients in need across the world. Those in power must do what is right and protect the flourishing innovation pipeline that brings treatments, cures, and hope to all those suffering from chronic, rare, and life-threatening diseases and their loved ones. #PatientPledge