**Stop the Medicare Experiment!**

**Advocacy Toolkit**

**March/April, 2016**

**Let’s deliver a simple message to Congress:**

**HELP US STOP THE MEDICARE EXPERIMENT!**

At the request of advocates and practices, the Community Oncology Alliance (COA) is offering this toolkit of resources to make getting involved in stopping this misguided Medicare experiment as easy as possible.

**Getting Started is easy:** Just follow the steps below, in order:

1. **Tailor to your specialty**: Throughout this document are areas that need to be tailored to each specialty. Look for [disease] or [specialty] and replace with the right words like cancer or oncologist. Review each sentence to make sure it sounds right or see if you need to tailor it more. ***This is a very important step!***
2. **Key messages**: These messages are suggested ways to help you talk about the experiment in a clear and compelling manner. Review and keep them handy. *Note that these are written for physician or provider use, not necessarily patients.*
3. **Letter to patients**: Customize and distribute this letter to your patients, advocates, and staff. Send it far and wide!
4. **Fact sheet**: Tailor and print out this simple explanation of the experiment. Make it available throughout your practice, waiting rooms, nurse stations, etc.
5. **Contact list**: Create a separate list of staff in U.S. Congressional and Senate offices. Provide it to advocates for easy identification of who to contact in their state or district.
   * **If easier, patients & advocates can call 202-851-2881. The system will patch them through to Congress offices. No need to look up phone numbers or names!**
6. **Phone talking points**: We have developed talking points to help make the most of your calls with Congressional and Senate offices. These are just suggestions for delivering your message clearly and quickly to busy staff.
   * *Note that there are different talking points for patients/advocates and for care providers. Be sure to give the right one out!*
7. **Email to Congress**: We have developed template emails for contacting Congress. These are just suggested language to get you started.
   * Again, make sure you share the right one with patients versus providers.

**Background & Key Messages:**

**The Medicare Experiment**

**The government wants to experiment with how America’s doctors treat [disease], seeking to save money while possibly risking lives.**

* The government, through the Centers for Medicare & Medicaid Services (CMS), is going to conduct an “experiment” to influence the care patients receive, especially seniors covered by Medicare.
* This mandatory experiment was devised solely by the government, without any input from patients, their [specialty], or anyone in the health care community.
* Decisions are being made by bureaucrats hundreds of miles away in Washington, DC, not doctors and their patients.

**The government has decided that it knows how to fight [disease], better than [specialists] in collaboration with patients.**

* Without any evidence, the government is saying that [specialists] are not giving the right treatments to patients with [disease].
* With this experiment, the government will use money and other pressures to influence what [disease] drugs it thinks have the highest “value.”
* Fighting [disease] is not cookie-cutter medicine. Each patient requires a personalized treatment plan that can access all of the available life saving drugs and therapies.
* Every patient responds differently to the cutting-edge, personalized therapies now available to treat [disease].
* [General statement on success of care you provide, e.g. “The ability to personalize treatment has led to unprecedented survival rates for Americans battling cancer.”]
* Bureaucrats dictating treatment decisions in Washington, DC – hundreds of miles away from the treatment room – is a slippery slope to government control of healthcare.

**This experiment is a slap in the face to America’s [disease] patients and their doctors.**

* The government is scaring all [disease] patients into believing that their [specialists] are not acting in their best interests, even though there is no evidence to support that.
  + Imagine patients sitting in a chemotherapy chair right now, receiving treatment, reading about this experiment, and being scared that their [specialist] is not acting in their best interests.
* There is absolutely no evidence that [specialists] prescribe [disease] treatments based on anything but the individual needs of their patients.
* It is shocking and insulting for the government to imply that [specialists] practice medicine based on profits, not healing patients.

**This experiment will backfire, costing patients and taxpayers more for [disease] care, and in the process radically change the U.S. [disease] care system for the worse.**

* Scientific research (published in a peer-reviewed journal) of a similar experiment documented conclusively that it backfired, causing spending on drugs to nearly triple.
  + UnitedHealthcare pilot project, published Sept. 2014 in the Journal of Oncology Practice (vol. 10 no. 5 322-326), <http://jop.ascopubs.org/content/10/5/322.full>
* The government’s experiment will only exacerbate the closure of community [specialist] practices consolidating [disease] care into the more expensive hospital setting.
  + These same hospitals cost patients significantly more for the same care.

**[Specialists] agree the cost of [disease] care needs to be addressed, and have been actively working on efforts to do that. But this experiment is completely misguided – and will do the exact opposite.**

* This mandatory experiment is a blunt, thoughtless approach to addressing all of the complex costs of [disease] care. We need more precise, thoughtful approaches that are developed with the input of doctors and their patients.
* [Specialists] have been on the frontlines, working with insurance companies and the government for years on efforts to address rising [disease] care costs.
* [Specialists] across the country are working on solutions, but it is shocking that the government would propose this experiment without the collaboration or input of [specialty name] providers.

**We need Congress to *HELP US STOP THE MEDICARE EXPERIMENT!***

* We need our elected officials to stand up to CMS for America’s [disease] patients and their providers.
* The Medicare experiment must be stopped before it is too late.
* Please help us reach out to Congress and the Senate and ask them to ***HELP US STOP THE MEDICARE EXPERIMENT!***

**Letter to Patients**

*Customize this draft letter for your practice and distribute it far and wide. Be sure to tailor it to what you want to say about this issue.*

Dear Patients, Advocates, Staff, and Friends:

In recent weeks you may have read about a government experiment to change the way Medicare (the nation’s largest insurer for those 65+) pays for [disease] and other life-saving drugs. What you may not know is that this experiment will radically change the way we fight [disease] in America, including here at [practice name]. We need your help in fighting this experiment!

**What is happening?**

Simply put, the government wants to influence which life-saving [disease] drugs and treatments are made available to patients, all in the interest of trying to save money without consideration of patients’ lives. To do this, the Centers for Medicare & Medicaid Services (or CMS, as it is called), the government agency that runs Medicare, is going to “experiment” – *a word the government uses itself* – on senior patients covered by Medicare.

But this experiment will end up affecting all patients, not just those with [disease]. This includes diseases such as cancer, macular degeneration, hypertension, rheumatoid arthritis, Crohn’s disease, ulcerative colitis, and primary immunodeficiency diseases. [Remove your disease from list, if applicable]

The government thinks it knows how to fight [disease] better than your [specialists] in collaboration with you, the patient. With this experiment, government bureaucrats hundreds of miles away in Washington, DC want to influence what treatments are provided to patients with [disease].

**Why is this a big deal?**

Fighting [disease] is about personalized treatment, not cookie-cutter medicine.

Each patient requires a personalized treatment plan that can access all of the available life saving drugs and therapies. We develop these plans based on careful consideration of the options and what will work best for you!

This experiment will influence the treatments available to patients, regardless of what your doctors think is best. Government bureaucrats should not control how we fight [disease] – that is a slippery slope to government control of healthcare.

**How you can help: Deliver a simple message to Congress**

Speak up now and let Congress know that we need our elected officials to stand up for America’s [disease] patients and their providers, before it is too late.

Your voice matters! As [disease] patients and survivors you will be most affected, and you must be a part of the conversation. Congress needs to hear from YOU. Please speak up!

**Let’s tell Congress: *HELP STOP THE MEDICARE EXPERIMENT CARE!***

Here is how you can help and get involved:

1. Text MEDICARE to 52886 and register as an advocate.
2. Call **202-851-2881** to be automatically patched through to the offices of your Congressmen and Senators. Be sure to do this during working hours.

1. Visit [www.StopCMSExperiment.com](http://www.StopCMSExperiment.com) to send an email, Tweet, post on Facebook and let the world know you oppose this change.

***Thank you for your help in this important battle!*** Please let [NAME IN PRACTICE] know if you have any questions.

[PRACTICE SIGNATURES]

**Medicare Experiment Fact Sheet & Notice**

**Action Alert:**

***Help Us Stop the Medicare Experiment!***

You may have read about a government experiment to change the way Medicare (the nation’s largest insurer for those 65+) pays for health care and other life-saving drugs. What you may not know is that this experiment will radically change the way we provide treatment in America, including here at [Practice name]. We need your help in fighting this experiment!

**The government wants to experiment with how America’s doctors treat [disease], seeking to save money but in the process possibly risking lives.**

Simply put, the government wants to influence which life-saving [disease] drugs and treatments are made available to [disease] patients, all in the interest of trying to save money without consideration of patients’ lives.

To do this, the Centers for Medicare & Medicaid Services (or CMS, as it is called), the government agency that runs Medicare, is going to “experiment” – *a word the government uses itself* – on senior patients covered by Medicare.

But this experiment will end up affecting all patients, not just those with [disease]. This includes diseases such as macular degeneration, hypertension, rheumatoid arthritis, Crohn’s disease, ulcerative colitis, and primary immunodeficiency diseases.

**The government thinks it knows how to fight [disease] better than [specialists] in collaboration with patients.**

With this experiment, government bureaucrats hundreds of miles away in Washington, DC want to influence what treatments are provided to patients with [disease].

Fighting [disease] is about personalized treatment, not cookie-cutter medicine!

Each patient requires a personalized treatment plan that can access all of the available life-saving drugs and therapies, based on careful consideration of the options.

This experiment will influence the treatments available to patients, regardless of what doctors think is best. Government bureaucrats should not control how we fight [disease] – that is a slippery slope to government control of health care.

**Let’s deliver a simple message to Congress: *HELP STOP THE MEDICARE EXPERIMENT!***

Speak up now and let Congress know that we need our elected officials to stand up for America’s [disease] patients and their providers, before it is too late.

Your voice matters! As [disease] patients and survivors you will be most affected, and you must be a part of the conversation. Congress needs to hear from YOU. Please speak up!

Ask Congress to ***HELP STOP THE MEDICARE EXPERIMENT!***

Here is how you can help and get involved:

1. Text MEDICARE to 52886 and register as an advocate.
2. Call **202-851-2881** to be automatically patched through to the offices of your Congressmen and Senators. Be sure to do this during working hours.

1. Visit [www.StopCMSCuts.com](http://www.StopCMSCuts.com) send an email, Tweet, post on Facebook and let the world know you oppose this change.

***Thank you for your help in this important battle!*** Please let [NAME IN PRACTICE] know if you have any questions.

[PRACTICE SIGNATURES]

**Congressional Contact List**

Attached as a separate file is a staff list for U.S. Congressional and Senate offices. Go through it and identify who is in your state or district.

If you are unsure about who that might be, visit [LOOKUP TOOL] and enter your zip code. This will give you a list of the member offices that should be selected from the list.

With the contact list now focused you can begin making calls and sending emails to staff.

**Note: If easier for your patients and advocates, they can call 202-683-7977.**

**An automatic system will ask for your zip code then patch them through to Congressional offices.**

**No need to print lists, look up phone numbers or names. It’s that easy!**

The automated system is really easy. All you have to do is call 202-683-7977 and follow the instructions which are to enter your zip code. That’s it!

For those practice professionals and advocates able to use the contact sheets and call/email individual offices, we highly recommend this as well. That way you are contacting the specific staff members with the influence to change this misguided experiment.

**Phone Talking Points: For PATIENTS & ADVOCATES**

**Tips and Suggestions:**

* *Print these talking points out and keep them handy during calls.*
* *Remember: This is about your relationship with your doctor!*
* *Make the call personal and professional. Try to include examples of how this experiment will impact you personally. Let them know you are a human being.*
* *Keep it short, clear and direct. Congressional offices get lots of calls. If you want, offer to provide more information in a follow-up email or meeting.*

1. I am a [disease] [patient/survivor/advocate] in [City, State where you live] calling to ask for your help in stopping the Medicare experiment!
2. This Medicare experiment is about the government saying it knows better than my doctor about how my [disease] should be treated and trying to influence my doctor’s selection of life-saving drugs.
3. Receiving a [disease] diagnosis is an extremely life-altering, personal experience. I trust my doctor to work with me to determine the best, personalized course of treatment.
4. The Medicare experiment will put the government in the middle of my health care decisions. What gives them that right!
5. My life is too important to be a test case in a government experiment.
6. Please: we need Congress’ help to ***STOP THE MEDICARE EXPERIMENT!***

**Phone Call Talking Points: For CARE PROVIDERS**

**Tips and Suggestions:**

* *Print these talking points out and keep them handy during calls.*
* *Be sure to tell them who you are and where you are located.*
* *Make the call personal and professional. Try to include examples of how this experiment will impact you personally. Let them know you are a human being.*
* *Keep it short, clear and direct. Congressional offices get lots of calls. If you want, offer to provide more information in a follow-up email or meeting.*

1. I am a [disease] [doctor, nurse, practice administrator] in [City, State where you practice] calling to ask [Representative/Senator Name] for help in stopping the Medicare experiment!
2. This Medicare experiment is a slap in the face to America’s [disease] patients and providers.
3. Without any evidence, CMS is saying that [specialists] are not giving the right treatments to patients with [disease]. It is shocking and insulting to say [specialists] practice medicine based on profits, not healing patients.
4. Fighting [disease] is not cookbook medicine. Every single one of our patients requires a personal treatment plan that can access all of the available life-saving drugs and therapies.
5. And this experiment is not just about patients with [disease]. As the letter from 316 national and state organizations sent to Congress recently points out, this experiment is also about patients with other complex conditions such as cancer, macular degeneration, hypertension, rheumatoid arthritis, Crohn’s disease, ulcerative colitis, and primary immunodeficiency diseases. [Remove your disease area from this list, if applicable]
6. The Medicare experiment would put the government in the middle of the treatment decisions doctors make, in thoughtful discussion with patients and their personalized needs.
7. Worst of all, this experiment will backfire by costing patients and taxpayers more, and in the process radically change the U.S. [disease] care system for the worse.
8. Patient’s lives are too important to be a test case in a government experiment.
9. Please tell [Representative/Senator Name] that we need Congress’ help to ***STOP THE MEDICARE EXPERIMENT!***

**Email to Congress: For PATIENTS & ADVOCATES**

**Tips and Suggestions:**

* *Be sure to tell them who you are and where you live. Include your contact information at the end in case there are follow-up questions.*
* *Make it personal. Try to include examples of how this Medicare experiment will impact you personally. Let them know you are a human being.*
* *Keep it short, clear and direct. Congressional offices are incredibly busy and get lots of mail. If you want, offer to provide more information in a follow-up email or meeting.*

**Draft Email Language:**

Dear [RECIPIENT NAME],

I am writing to express strong opposition to the Medicare experiment. This experiment will radically change the way we fight [disease] in America and must be stopped. I am asking [REPRESENTATIVE TITLE AND NAME] to stand up for [disease] patients and their doctors and HELP US STOP THE MEDICARE EXPERIMENT!

Fighting [disease] is about personalized treatment, not cookie-cutter medicine! Each patient requires a personalized treatment plan that can access all of the available lifesaving drugs and therapies. Medicare’s experiment would put government bureaucrats in the middle of [disease] treatment decisions, undermining the careful decisions made by patients and their doctors.

Worse yet, this experiment will end up affecting all patients, not just those with [disease]. This includes diseases such as cancer, macular degeneration, hypertension, rheumatoid arthritis, Crohn’s disease, ulcerative colitis, and primary immunodeficiency diseases. (Read more in a letter from 316 advocacy organizations to Congress: <http://bit.ly/1SW0HHs)>. [Remove your disease area from this list, if applicable]

The lives of [disease] patients are too important for this experiment. Please tell [REPRESENTATIVE TITLE AND NAME] to do whatever it takes to stop the CMS Medicare experiment!

Thank you,

[NAME, ADDRESS]

**Email to Congress: For CARE PROVIDERS**

**Tips and Suggestions:**

* *Be sure to tell them who you are and where your practice is located. Include your contact information at the end in case there are follow-up questions.*
* *Make it personal. Try to include examples of how this Medicare experiment will impact you personally. Let them know you are a human being.*
* *Keep it short, clear and direct. Congressional offices are incredibly busy and get lots of mail. If you want, offer to provide more information in a follow-up email or meeting.*

**Draft Email Language:**

**Subject line**:

Please, Help Us Stop the Medicare Experiment

**Email:**

Dear [Name of Recipient],

As a [disease] care provider in [City, State] I am writing to express strong opposition to the recently announced CMS Medicare Part B Drug Payment experiment. This proposed experiment will significantly impact the care our patients receive and devastate the [disease] care system in this country. **The Medicare experiment must be stopped and I am asking for [Congressman/Senator’s name] help.**

First and foremost, the CMS experiment is an intrusion on the close relationship we have with patients and our clinical decision making. It totally fails to understand the complex, personal nature of [disease] care available to patients today. Fighting [disease] is about personalized treatment, not cookie-cutter medicine. We cannot legislate treatments in such a bureaucratic manner.

**This experiment is a slap in the face to America’s [disease] patients and providers.** Without any evidence, the government is saying that [specialists] are practicing medicine based on profits, not healing patients. Now, our elderly patients receiving chemotherapy are scared that we are not acting in their best interests. Is that the message you intended to send about America’s [disease] doctors? It is shocking and insulting that CMS would say such a thing.

And it’s not just [disease] care. As the letter from 316 national and state organizations sent to Congress a week ago (<http://bit.ly/1SW0HHs>) notes out, it is also complex conditions such as [disease], macular degeneration, hypertension, rheumatoid arthritis, Crohn’s disease, ulcerative colitis, and primary immunodeficiency diseases. [Remove your disease area from this list]

[Specialists] are in full agreement that the costs of [disease] care need to be addressed. And we have been actively working on efforts to do that, including close collaboration with CMS on reform initiatives. I might add that all government reforms proposed to date were developed in the open and with significant physician and patient input, unlike this experiment.

**This experiment will backfire, costing patients and taxpayers more for [disease] care, and in the process radically change the U.S. [disease] care system.** In fact, it ignores the numerous other factors such as [insert reason if applicable, or cut this sentence out] that are driving [disease] care costs up. If allowed to go through it could lead to the closure of community practices, reduce patient choice, and drive [disease] care into the more expensive hospital setting.

**Scientific research – published in a peer-reviewed journal – of a similar experiment documented conclusively that it backfired, causing spending on drugs to nearly triple** (see UnitedHealthcare pilot project, published Sept. 2014 in the Journal of Oncology Practice, vol. 10 no. 5 322-326). This experiment has no basis in evidence, which should be the first step in any change of this magnitude to our nation’s health care system.

I respectfully ask that your office please **TELL CMS TO STOP THE PROPOSED MEDICARE PART B DRUG PAYMENT EXPERIMENT!** Tell them to work with [Specialty name] to develop new ways to ensure high-quality, high-value [disease] care. Please help us to stop this experiment before it is too late.

Sincerely,

[Full name, practice name, address]