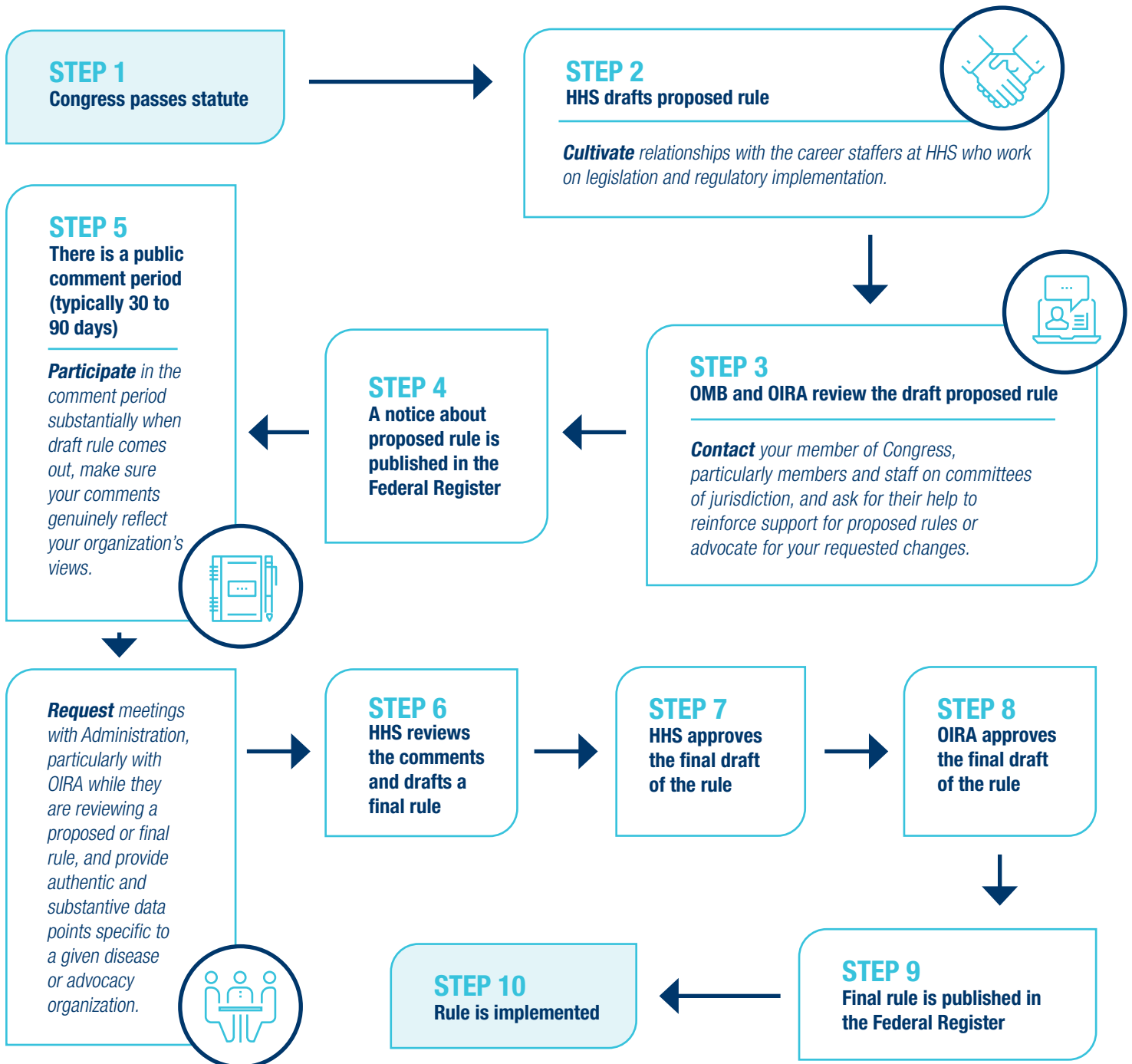


Engaging in the Federal Rulemaking Process

How patient advocacy groups can get involved in the rulemaking process



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Cultivate relationships with career staffers at HHS and CMS who work on legislation and regulatory implementation.

It's important to establish early, long-term relationships with career staffers in HHS or any agency that deals with your constituents. Utilize the office of external affairs to make connections within the agency or check out the agency's website for whom to contact.



Contact your member of Congress and utilize members on committees of jurisdiction.

Your member of Congress or a committee member can be an effective advocate, lobbying for specific legislation and creating pressure before, during, or after the comment period. They want to hear impactful and emotional stories.



Participate in the comment period substantially when draft rule comes out.

Comments are important whether they are in agreement or disagreement with the proposed rule. The quality and volume of comments matter. Provide data and footnotes in the comments. Mobilize state affiliates when appropriate to comment, as well. Your organization can write one letter that multiple people sign onto; however, it is recommended that everyone submit their own organic comments. The comments should never be duplicates. It's okay to have key points, but the more organic the comments look, the better. And remember – if someone doesn't suggest a solution in comments, it's difficult for the agency to do it by themselves.



Request meetings with agency administration specifically about the proposed draft.

When meeting with members of the administration, it is recommended to bring substantive data points and analysis on how proposed changes would impact access. Additionally, keep in mind that when meeting with the Administration (Agency staff), the "pitch" is very different from the usual personal story or narrative that is often meaningful to Hill staff. Companies that could be helpful with data include: Milliman Research and Consulting, Avalere, or The Lewin Group. Meeting with ORIA staff who are reviewing proposed or final rules can add more context to comments that you have submitted to the relevant agency.