



## **Sharing your Story with Policymakers: Frequently Asked Questions on Government Requests for Public Input**

Submitting a written comment is an effective way to share the unique experiences, needs, and challenges of the PSP, CBD and MSA communities with policymakers. This FAQ explains why Requests for Information (RFI) and public comments matter, how to prepare a focused and privacy-conscious response, and how to submit it.

### **What is the difference between a RFI and a public comment?**

An RFI is a tool that government agencies may use to gather information, feedback, and lived experiences from the public on a specific topic. The information collected can help agencies better understand an issue and inform future policy decisions, programs, or recommendations.

Public comment broadly refers to feedback that individuals or organizations submit to a government agency in response to a request for public input. Depending on the opportunity, comments may address a proposed policy or rule, an agency initiative, or another issue under consideration.

In practice, both provide opportunities for individuals and organizations to share their experiences, perspectives and recommendations with government decision-makers. RFIs are generally structured around specific questions and defined topic areas, while other opportunities for public comments may be more open-ended. Always follow the instructions for the specific opportunity when preparing and submitting your response.

### **Why is submitting a response or comment important?**

Public input can help policymakers understand the needs and priorities of the PSP, CBD, and MSA communities and inform their decision-making. Hearing directly from people impacted by these diseases, including people living with PSP, CBD, or MSA and their care partners, can help ensure their experiences are represented when relevant policies, programs, and recommendations are considered.

### **What should I say in my response or comment?**

Whether you are responding to an RFI or a call for public comment, your response is an opportunity to share your perspective and highlight what you want policymakers to understand. Some tips for structuring your response:

- **Introduce yourself.** Briefly share your name, where you live, and your connection to PSP, CBD, or MSA.
- **Share your experience.** You might:
  - Describe your personal experience relevant to the topic.
  - Identify an unmet need or challenge.
  - Explain how an issue affects people living with PSP, CBD or MSA and their care partners.

- o Recommend an action the policymakers should consider.
- **Be specific.** Concrete examples can help illustrate why an issue matters and what could be improved.

As you write, consider:

- What unique perspective can I contribute as a member of the PSP, CBD and MSA community?
- How does this issue uniquely affect people living with PSP, CBD and MSA?
- What change would make the greatest difference in addressing this challenge?
- What is the most important thing I want the reader to know after reading my comment/response?

### **Are there specific considerations when responding to an RFI?**

- Each RFI identifies specific topic and questions for which the agency is seeking input. Read the instructions carefully and keep your responses relevant to those topics.
- You generally do not need to answer every question in an RFI. Focus on one or two areas where your experiences or perspective can make the greatest contribution.

### **What are general guidelines should I consider, including privacy?**

Requirements vary by agency and opportunity, so always review the specific instructions before submitting your response. In general:

- Comments may become a part of the public record and may be posted publicly.
- Include only information you are comfortable sharing publicly.
- Avoid sensitive personal, confidential, copyrighted, or proprietary information.
- Do not include detailed personally identifiable information about other individuals.
- When possible, use links to publicly available information instead of attachments.
- Avoid submitting duplicate comments for the same opportunity.
- Keep your comments respectful, constructive, and focused on the issue.

### **Is there a word or page limit?**

Typically, there may be a word limit. This may especially be the case if you are submitting your response via a website and not emailing a document. Review the instructions for the specific opportunity before writing and submitting your response.

### **How do I submit my comment or response?**

Submission methods vary. You may be asked to submit your response through an online form, by email, or through another designated government website. Each announcement should provide the submission method, deadline, and any formatting or other requirements. Always follow the instructions provided by the issuing agency and submit your response by the stated deadline.