

TERMS OF CLEARANCE

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National Guideline Clearinghouse™ (NGC) National Quality Measures Clearinghouse™ (NQMC)

This generic IC is approved consistent with revised supporting statement and revised instruments. Specifically, AHRQ will not provide assurances of confidentiality to respondents since identifying information is being collected as part of the responses. The revised instruments also will make clear why the respondent's email address is being collected but will not be publicly disclosed, and the respondent will be provided a mechanism to submit responses on behalf of him/herself rather than on behalf of an organizational affiliation.

1. P 4: please clarify whether the respondents' email addresses will be posted with their comments on the AHRQ website. The supporting statement says it won't be published. However, the example comment AHRQ included in this package lists the commenter's address (don.casey@atlantichhealth.org). If the email or other address information will be suppressed before the comment becomes public, it would be worth letting the respondents know that on the instrument itself. Otherwise, you may discourage respondents who are wary of having their email address posted on your website.

AHRQ response:

We added a note to the respective response forms indicating that e-mail other addresses will not be published or made publically available. We did not edit the Supporting Statement with respect to this issue as the existing wording addresses this issue. Following is the relevant text:

Responses accepted for publication would be posted to the NGC and/or NQMC Web site(s) along with the submitter's name, current position or occupation, organizational affiliation and disclosed potential conflicts of interest. No other information collected through the Response Submission Form (i.e., email or other address) would be published or made accessible to users of the NGC/NQMC Web sites. A submitter's address is not required and would potentially be used for follow-up correspondences in cases where clarifying information is needed.

2. P4: Please include in the instrument the criteria listed on

page 4 on how you will determine whether a comment gets posted or not.

AHRQ response:

We included the criteria listed on p-4 in the respective response forms.

3. P6: if you are requiring people to provide you their names and you are going to publish their names with their comments, how is AHRQ proposing to provide assurances of confidentiality?

AHRQ response:

Submitters will be requested to provide their names just as in peer-reviewed medical literature. As a FISMA compliant resource, the system controls are in place to protect that data from misuse. The Privacy Policy, as it is currently stated on the NGC website, will be modified to reflect this. We also added clarifying text to the forms.

Note that the name and affiliation fields are marked with an asterisk and the form clearly states that information will be disclosed.

Regarding question # 3 , it seems that since every comment will be associated with someone's name, there is no confidentiality being provided. I think all that means is that the supporting statement should be changed to say that "AHRQ is not providing any assurances of confidentiality" or something to that effect.

Another thought that occurred to me what that people may be hesitant to comment if they have to provide an affiliation. You can imagine several such scenarios:

- a patient wants to comment about how the guidelines do not appropriately reflect what is important to a patient. This person is commenting as an individual. He/she may not be employed (and therefore may not have an affiliation).

- Or perhaps that same patient is employed and therefore does have an affiliation. However, he/she is commenting on behalf of his/her own personal views and not those of the organization he/she belongs to. How does such a patient indicate this?

- Or let's say the patient doesn't indicate this and the organization is then faced with a potentially embarrassing public relations issue or the patient gets reprimanded.

Is there some reason why the affiliation information is critical to this endeavor? If not, I would recommend just not asking for it. If it is critical to the endeavor, can that information be suppressed from public display?

AHRQ response:

We have edited the attached documents to reflect that current position or occupation and organizational affiliation are optional and would be posted when provided. We also replaced the text about assurances of confidentiality on page 6 of the Supporting Statement.