

September 7, 2021

Submitted via [www.regulations.gov](http://www.regulations.gov)

Mr. Jeffrey M. Zirger  
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Dear Mr. Zirger:

Thank you for the opportunity to comment on FR Docket No. CDC-2021-0058, the National Quitline Data Warehouse (NQDW). As President and CEO of the North American Quitline Consortium (NAQC), my comments represent the perspective of a non-profit organization that is comprised of the 53 states and territories that fund quitlines, the service providers that operate quitlines, researchers and national partners. NAQC began its work in Spring of 2004 as a special program within the American Legacy Foundation. Two years later, with the support of the quitline community, I incorporated NAQC as an Arizona non-profit organization that had developed a business plan, the Minimal Data Set (MDS) which includes intake and follow-up questionnaires, an annual survey, best practices programs, and a board of directors. Some of these accomplishments have been documented in peer-reviewed articles (see references 1-7). Since 2004, NAQC's work has focused on best practices to improve the quality and utilization of quitline services in the U.S. and Canada.

The Federal Register Notice identifies five topics of special interest to OMB:

1. Whether the proposed collection of information is necessary for the proper performance of the functions of the agency;
2. The accuracy of the agency's estimate of the burden of the proposed collection of information, including the validity of the methodology and assumptions used;
3. Ways to enhance the quality, utility and clarity of the information to be collected;
4. How to minimize the burden of the collection of information on those who are to respond; and
5. Assessment of the costs of collecting the information.

NAQC's response to each topic is provided below.

**1. Whether the proposed collection of information is necessary for the proper performance of the functions of the agency**

NAQC would like to begin its response with some context on the Minimal Data Set (MDS) and Annual Survey of Quitlines, fundamental data collection tools that were developed by NAQC and used by CDC to develop the NQDW. As stated on page 3 of the FRN Publication Request for Information Collections, "the MDS was developed collaboratively by quitlines and stakeholders including professional organizations and CDC, to serve as a core set of information" on quitlines. It is concerning that the FRN does not mention the MDS was led by NAQC and that in addition to developing the data set and gaining consensus from state, provincial and territorial quitlines in the U.S. and Canada, we also gained voluntary implementation of the MDS within 6 months of publication by all quitlines. University-based researchers played a key role in

identifying a need for a standard data set that would help identify critical factors for improving the quality and outcomes of quitline services, and in creating the MDS (especially Drs. Sharon Campbell, Shu-Hong Zhu and Debbie Ossip; see references 1-2). The MDS has been adopted as a standard and useful tool by quitlines and networks of quitlines beyond the U.S. and NAQC, in Europe and Asia. NAQC has played an important role in updating the MDS as quitline services evolve, identifying new required and optional questions, and assessing fidelity of quitlines to the questions and response categories over the years. In addition, through its annual survey of quitlines, NAQC has shared aggregate findings from state and territorial quitlines with the quitline community on an annual basis for the past 15 years. The MDS and annual survey provide critical data for NAQC's best practices programs.

In 2010-2011, CDC began using the MDS in response to legislative reporting requirements for new funding streams, as described in the FRN. Through the new funding streams, CDC contributes about 16% of the total national budget for quitline services (states contribute about 84% of the budget with substantial variations in the percentage from state to state). This supplemental federal funding is important for delivery of state quitline services to tobacco users who want to quit.

Since CDC began using the MDS, NAQC has worked with the agency to keep the formal MDS and CDC's reporting requirements for state quitlines aligned as much as possible. As a non-profit organization, NAQC has been able to update the intake and follow-up questionnaires on a shorter timeframe than a federal agency is able to do. For example, NAQC developed standard optional questions on COVID-19 in spring 2020 and about half of the state quitlines were able to add the questions to intake questionnaires by summer 2020. This expedited development (led by NAQC, researchers and a few quitlines) and implementation (by state quitlines) has allowed us to understand the impact of COVID-19 on tobacco users. NAQC also has updated its questions on sexual orientation and gender identity several times in the past decade as experts such as Dr. Scout learn more about the best approach to asking these questions. As a federal agency, CDC has had resources to go beyond a services survey to also collect data on individual clients who utilize quitline services. This data should help advance our knowledge and the field; it is not an activity NAQC has the IT expertise or funding to pursue.

Turning now to the question of whether the proposed collection of information is necessary for the proper performance of the functions of the agency, NAQC comments:

- The proposed collection of intake questionnaire electronic data files (4 per year) and the seven-month follow-up electronic data file (1 per year) are necessary.
- The proposed quitline services surveys (2 per year) are not necessary. We suggest that CDC can use the data NAQC collects for this purpose. NAQC would be willing to add questions that CDC has added to its reporting requirements that currently do not appear on NAQC's annual survey and to collect the data twice a year if needed by CDC.

## **2. The accuracy of the agency's estimate of the burden of the proposed collection of information, including the validity of the methodology and assumptions used**

After reviewing the estimated annualized burden hours for collection of information, NAQC believes that the estimates can be improved as follows:

- For the estimates on the burden of the intake questionnaires and seven-month follow-up questionnaires, please include not only the participants and callers to the quitline, but also the quitline staff who ask the questions.
- For the submission of intake questionnaire files, seven-month follow-up questionnaire files and quitline services survey, the estimates seem very low. We would like to clarify whether they include

the time to compile and validate the information. The time allocation seems to only include the time to key-in or create the data file.

- NAQC suggests that CDC should base the estimates on more than a single, very large quitline service provider who serves many states. This provider has more technical capacity than the smaller single-state providers which is likely to underestimate the time needed to submit data files by all quitlines.

### **3. Ways to enhance the quality, utility and clarity of the information to be collected**

NAQC was pleased to see updates to CDC's intake questions which align with changes NAQC has made to the MDS over the past few years (see reference 8). We support these changes which are likely to enhance the quality, utility and clarity of the information collected.

NAQC recommends that on questions related to sexual orientation and gender identity (SOGI), CDC should consider enhancing its questions according to comments submitted by Dr. Scout on behalf of the National LGBT Cancer Network. NAQC plans to begin a process to consider similar updates to SOGI questions in 2021/2022.

NAQC also would like to note that clarification may be needed to the purpose and focus of the question on active-duty military service. Our understanding of VA benefits on tobacco cessation is that they are only available for tobacco users who receive their health care through the VA. If this is true, a more focused question on health care coverage through the VA may enhance the quality of the question and the utility of responses.

In 2019, NAQC removed the MDS question on how a participant heard about the quitline, based on feedback from university-based evaluators. These experts noted that the question does not elicit valid responses.

### **4. How to minimize the burden of the collection of information on those who are to respond**

The required data elements and questionnaires are efficient and minimal. To minimize the burden of data collection, NAQC suggests two alternatives:

- Eliminate the quitline services surveys and rely on NAQC's annual survey for this purpose (see Topic 1, second bullet, for additional information); or
- Reduce the quitline services survey to once a year (and ask quitlines to submit data by quarters or 6-month periods).

### **5. Assessment of the costs of collecting the information**

We did not see documentation related to the costs of collecting the information but would like to comment on such information if it is available. Should NAQC's comment on eliminating the CDC quitline services surveys be adopted, the cost of collecting information would be decreased as NAQC does not use federal funding to collect its annual survey information.

Again, thank you for the opportunity to provide comments. I am available to answer any questions you may have.

Sincerely,



**Linda A. Bailey, JD, MHS**

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cc: Senators Sinema and Kelly, Congressman Stanton

**References**

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7. Leischow SJ, Provan K, Beagles J et al. Mapping Tobacco Quitlines in North America: Signaling Pathways to Improve Treatment. Am J Pub Health. 2012 November; 102(11): 2123-2128.
8. Please see MDS updates here: <https://www.naquitline.org/page/mds>