Summary of Public Comments and CDC Response

OMB No. 0920-0856

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Public Comment #1

From: usacitizen1 usacitizen1 [mailto:usacitizen1@live.com]
Sent: Saturday, April 07, 2012 2:40 PM
To: OMB-Comments (CDC); deficitreduction@senate.gov; info@taxpayer.net; media@cagw.org; americanvoices@mail.house.gov
Cc: comments@whitehouse.gov; speakerboehner@mail.house.gov; sf.nancy@mail.house.gov; letters@newsweek.com; today@nbc.com
Subject: public comment on fedearl register FW: autism alsomay be preventable by not taking vaccines - you havent done sound research on this - you have done research to protect your back - his agendy is culpable

autism is afffecting one out of 39 kids, our future for america. this is old stuff from l950 where the govt emploeyes with fat cat salaries who do nothing all day want to keep their jobs. this is not necessary at all for america at this time. this is a dead horse. the taxpayers of america do not want to keep supporting this huge bureaucracy and this project is all about their keeping their jobs. the public says downsize. this is a good opportunity to do exactly that. this agency is not needed at all in america.

the public smoking knows what the score is. and they need to do whatever they do by themselves. americans cannot support this huge expensive bureaucracy anymore. we have supported it to the tens of bililions of dollars. enough. is enought. this agency is no help at all, it just costs alot of money and provides jobs to politicians relatives. shut it down. this agency should have been shut down years ago. quitlines are ineffective and too expensive for federal money to continue in this effort. shut down this agency and this project.
jean public

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DEPARTMENT OF HEALTH AND HUMAN SERVICES

Centers for Disease Control and Prevention

[60-Day-12-0856]

CDC Response to Public Comment #1

CDC provided a courtesy reply.

Public Comment #2

(see next page)

June 1, 2012

Sent via email (omb@cdc.gov)

Kimberly S. Lane, MBA
Centers for Disease Control and Prevention (CDC)
Reports Clearance Officer
1600 Clifton Road, MS D-74
Atlanta, GA 30333

Dear Ms. Lane:

On behalf of the North American Quitline Consortium (NAQC), I am submitting comments on the proposed project "National Quitline Data Warehouse (OMB No. 0920-0856, exp. 7/31/2012) – Extension – National Center for Chronic Disease Prevention and Health Promotion, CDC."

A quitline is a health service that offers telephone support – information, counseling, medication and other support – for people who want to quit using tobacco. Quitline services generally include telephone counseling along with a range of services such as: mailed materials, referrals to other cessation services, taped messages or web programs, the provision of nicotine replacement therapies (NRTs) and other medications or assistance in obtaining them, and language- or culturally-appropriate services directed toward specific populations within states. In North America, quitlines exist in all 50 states, the District of Columbia, Puerto Rico and Guam as well as all 10 Canadian provinces, Nunavit and the Yukon; and Mexico. A snapshot of the services available in each state is shown on the map at http://map.naquitline.org.

NAQC is a non-profit professional organization that aims to maximize the access, use and effectiveness of quitlines; provide leadership and a unified voice to promote quitlines; and offer a forum to link those interested in quitline operations. In addition, NAQC serves as a forum for smoking cessation expertise from around the world to discuss guidelines and standards for the best approaches to smoking cessation related to the use of quitline activities. It is comprised of over 400 quitline professionals at state and provincial health departments, quitline service provider organizations, research institutes and national organizations in the United States and Canada. The Consortium enables professionals from these organizations to learn from each other and to improve the quality of quitline services.

NAQC collaborates with CDC on its cessation activities and has provided support for and input on the National Quitline Data Warehouse (NQDW). Two of NAQC's hallmark

products form the basis for CDC's NQDW. These products are the Minimal Data Set for Evaluating Quitlines (MDS), which includes intake and follow-up questions that have been adopted by all government sponsored quitlines in North America and NAQC's Annual Survey of Quitlines. NAQC staff and members have a special expertise in the data elements that CDC proposes to continue collecting and a critical understanding of the processes related to collecting and analyzing such data..

NAQC staff gained input from professionals representing 41 of the State quitlines for this letter. We appreciate the opportunity to comment on the proposed NQDW extension. You have asked for comments on four topics: a) whether the proposed collection of information is necessary for the proper performance of the functions of the agency, including whether the information shall have practical utility; b) the accuracy of the agency's estimate of the burden of the proposed collection of information; c) ways to enhance the quality, utility and clarity of the information to be collected; and d) ways to minimize the burden of the collection of information on respondents, including through the use of automated collection techniques or other forms of information technology. NAQC's comments on each of these topics are predicated on the basis of our members' experiences with the MDS and NAQC's Annual Survey over the past eight years and with the NQDW over the past two years.

In proposing this project extension, CDC proposes to house data within the NQDW that results from continuing collection of two types of data:

- The online Services Survey (aggregate data collected quarterly using an online data collection system); and
- Individual-level intake data and follow-up data (data from individual callers to the quitline collected on a quarterly basis).

NAQC's comments address all four topics specified by OMB. The comments are organized by the type of data included in the NQDW. Under section I, we have provided comments on individual-level data that is included in NQDW. Under section II, we have provided comments on aggregate survey data that is included in NQDW.

I. Individual Level Intake and Follow-Up Data

The individual-level intake and follow-up data comprise an incredibly rich and powerful data source that will be useful to researchers and practitioners across the nation. It offers a means to better understand smokers: their demographic variables, their levels of addiction, how smokers quit, etc and from this information to improve our methods for helping them quit. As such, it is necessary for the proper performance of CDC's functions related to data collection, analysis of these data and tobacco cessation processes. As mentioned above, these data are derived from intake and follow-up questions that NAQC developed, called the Minimal Data Set (MDS). The MDS has been voluntarily implemented by state quitlines since 2006. Although NAQC had always hoped to be able to create a national database for the MDS, the technical and financial capacity required to build the database is beyond our organization's capacity. Such a database should reside

within a federal agency which has the technical and financial capacity to build, maintain and disseminate findings from the data; we believe CDC is the right agency for this purpose. We are honored to have contributed to the creation of the database and hope to collaborate with CDC as it implements the NQDW and seeks to disseminate and learn from the data.

The following paragraphs address the four topics specified by OMB for inclusion in comments. It is hoped that these responses will provide additional details related to improving the collection of individual-level data and minimizing the burden.

a. Necessity of Individual Level Data in the NQDW for the Proper Performance of the Agency Functions

The individual level data in the NQDW are important and necessary for the agency's functions. Through the NQDW, CDC plans to create a centralized repository for individual level intake and follow-up data from state quitlines, thereby creating a national surveillance system for tobacco cessation quitlines in the U.S. Practical utility will come when the findings are available publicly via the STATE system and when deidentified data sets are available to researchers for further analysis. Since the data have not yet been shared outside of HHS, the practical utility of the NQDW has not yet been demonstrated. It is anticipated that access to these data will allow for an improved understanding of the demographics and cessation efforts of the smoking population across the country. This should encourage the creation of new approaches to addressing tobacco cessation efforts.

b. Accuracy of the Agency's Estimate of the Burden of Collecting Information

The CDC proposal states that the Intake Questionnaire (Appendix E-1) will be administered to an estimated 730,000 callers (approximately 60,833 callers per month) across all states, the District of Columbia, Puerto Rico, and Guam and that the estimated burden for completing the Intake Questionnaire interview is ten minutes. For the portion of callers who contact Quitlines on behalf of other individuals, CDC estimates the burden of intake data collection will be one minute or less, since they will be asked to provide responses only to the first three questions on the Intake Questionnaire. CDC estimates that the burden for reporting follow-up data, which will be collected on about 26,900 callers is seven minutes per response.

Although most quitlines have found the estimates to be fairly accurate, a few have found their actual experience to exceed the estimates. For individual level follow-up data, two quitlines report averages of up to 13 minutes (compared to CDC's estimate of seven minutes).

In addition to the initial time-burden of collecting information from callers, a large burden is experienced in formatting and submitting the data to CDC. This burden is not addressed in the proposal and is actually quite high. For one quitline vendor, the conversion of data and mapping of field names from its system into the format requested by CDC took 60 hours (for service provider and two state clients combined). This was a

one-time effort. Another state quitline reported spending at least 20 hours in a one-time up front planning effort for the data submission. Each quarter, this quitline spends about three hours pulling data for the CDC report. Two single state quitlines reported about three hours for each quarterly submission of data. Two multi-state service providers noted that it takes 30-60 minutes per state to pull the individual-level intake and follow-up data each time they are submitted. A small provider reported spending over 100 hours each quarter preparing the spread sheet for submission to CDC. It should be recognized that the existing technology systems vary significantly among the States and their vendors and these variations account in-part for the large variability in the estimated burden for preparing the reports required by the CDC. The cost of collecting and reporting these data is significant, at a state level and nationally. None of these States or vendors has existing budgets to handle these reporting requirements and this presents a real issue for many States. This is especially true for the follow-up data, as not all states have the financial capacity for ongoing evaluation of the quitline. In order to prevent a decrease in funding for quitline services, CDC should provide funding to states for required reporting.

c. Ways to Enhance the Quality, Utility and Clarity of the Information Collected

The two most important strategies for enhancing the quality, utility and clarity of the information collected for the NQDW are:

i) Developing and implementing a communication plan for exchanging information about the NQDW with interested parties (such as quitline funders, service providers, researchers and national organizations). Through such a plan, CDC could better inform interested parties about its plans for the NQDW and also could engage the parties in a discussion of issues, concerns and opportunities for the NQDW. This step is especially important because the data elements which will populate the NQDW were identified by the interested parties and had been collected by them for five years before CDC established the NQDW. Collaboration and communication with interested parties who have a special expertise and vested interest in the data are essential for enhancing the quality, utility and clarity of the information collected. While collecting information for this letter, NAQC members raised a multitude of issues and concerns about the NQDW that have not yet been addressed. For example, one state raised questions about whether processes will be put in place to ensure that the NQDW data are used appropriately by researchers. Another state raised a concern about balancing state programmatic needs for follow-up data with CDC's reporting requirements for follow-up data. These are topics that should be discussed to enhance the quality, utility and clarity of the information collected; and

ii) Sharing data and findings from the NQDW with interested parties and the broader public. As mentioned above, NAQC supports making findings available to the public via the STATE system, developing and disseminating CDC publications and reports based on analyses of the NQDW, and making

deidentified data sets available to the research community. Such activities will enhance the quality, utility and clarity of the information collected. Recognizing that the dissemination of data is a critical part of this process, we would recommend that interested parties participate early in the process to make this process as seamless as possible and available as early as possible.

It would be helpful to have a timeline and plan for implementing both of these strategies.

d. Ways to Minimize the Burden of Collecting Information on Respondents

CDC has an online system for submission of individual-level intake and follow-up data sets, but several NAQC members have reported that this system has not worked well. Several quitlines have had to re-submit data sets, or burn CDs and mail them in to CDC rather than using the online data submission system. For example, one state reported that it took the statistician nearly three hours to retrieve the individual-level intake and follow-up data, burn it on a CD, and send it to CDC. They had tried to upload the data to the website, but found out later that several files never uploaded. They learned that CDC was having problems with the upload system. Since it wasn't clear when and if the problem would be resolved, the state opted to send the data via CD. We know CDC is aware of these problems and is working to address them. Having a reliable upload procedure for the online data submission system would simplify the process and lessen the burden of data collection.

II. Online Services Survey

The online services survey consists of 61 questions comprising over 400 data elements that describe the services provided by each state quitline, the population that uses the services, the hours of operation, budget levels and utilization. The online services survey is necessary to fully understand the individual-level intake and follow-up data. Together, these data sources describe the quitline services provided across all states and can be used to better understand the factors most important in helping smokers quit. States submit these aggregate data to CDC on a quarterly basis. As mentioned above, the questions used by CDC are a subset of the questions on NAQC's Annual Survey of Quitlines. NAQC has collected these data since 2005 and plans to continue collecting them. We make the data widely available to professionals and the public, and we have shared it with CDC, researchers and others. The data are cited in a number of publications. We believe the proposed CDC Services Survey is duplicative of NAQC's ongoing and more extensive annual survey. NAQC suggests that instead of gaining this data from the States on a quarterly basis, CDC collects the information from NAQC annually.

The following paragraphs address the four topics specified by OMB for inclusion in comments. It is hoped that these responses will provide additional details related to improving the collection of aggregate survey data and minimizing the burden.

a. Necessity of Services Survey Data in the NQDW for the Proper Performance of the Agency Functions

The online services survey provides context for the individual-level data. It describes the services provided by each State quitline, the hours of operation, budget levels and utilization. The online services survey is necessary to fully understand the individual-level intake and follow-up data. Together, these two types of data describe the quitline services provided throughout the states and can be used to better understand the factors most important in helping smokers quit.

Although the information contained in the online services survey is necessary for the proper performance of CDC functions, collecting the data from states may not be necessary; NAQC already collects this information and can easily make the data available to CDC. Sections c and d below provide details on ways to enhance quality and minimize burden on states and other respondents by having CDC collect data for the online services survey from NAQC instead of states.

Although CDC has begun sharing findings from the data it collects within HHS, it has not shared findings with the quitline community or broader public. So, the utility of its services survey data has not yet been demonstrated. NAQC has been sharing its survey data since 2005 and can attest to the high value placed on such data. The data and analyses allow for an improved understanding of the demographics and cessation efforts of the smoking population across the country. This should encourage the creation of new approaches to addressing tobacco cessation efforts.

b. Accuracy of the Agency's Estimate of the Burden of Collecting Information

CDC has estimated that the burden for completing each quarterly online services survey is seven minutes. The actual experience of quitlines shows that seven minutes greatly underestimates the time it takes to complete the 61 questions on the survey.

One service provider and state report spending a total of about 80 hours to review the definitions for each question and program the queries (a one-time event). In addition, each quarterly report takes about 45 minutes to fill out per quitline. Two large multi-state service providers report spending between 30 and 75 minutes per state per quarter to pull the data and send to states prior to submission to CDC. The states then review the data (an additional 30 minutes or more of time) and enter it into the online data collection instrument for submission to CDC. For one state, the survey takes about 2.5 hours to complete and submit each quarter. The state attributes the burden in-part to their data systems which change frequently due to changes in operational procedures such as providing vouchers for NRT. It should also be noted that the vendors, in many cases, are asked to provide these data in addition to a myriad of other reports on a routine basis for the States.

As noted in part Ib above, the cost associated with collecting these data is significant. CDC should consider funding reporters for required reporting.

c. Ways to Enhance the Quality, Utility and Clarity of the Information Collected

As described in section Ic above, two important strategies for enhancing the quality, utility and clarity of the information collected for the NQDW are i) developing and implementing a communication plan and ii) sharing data and findings from the NQDW with interested parties and the broader public. As part of the communication plan, CDC should address questions and issues of concern. It may be helpful to work with NAQC and other interested parties in refining some of the definitions and response categories. For example, CDC requires quitlines to report only on "first time callers." It is unclear whether this means a person making a first call to the quitline for this quit attempt, a person making his or her first call to the quitline ever, a person calling the quitline for the first time this year or quarter, or something else entirely. CDC also asks whether quitlines are closed on holidays. The response categories are "yes" and "no". Quitlines would prefer to list holidays on which they are closed. NAQC currently collects this level of detail on its Annual Survey of Quitlines. In addition NAQC gains input from a committee of quitline professionals across the country on each survey question prior to fielding the survey. We believe this is an essential activity for enhancing the quality, utility and clarity of the information collected.

d. Ways to Minimize the Burden of Collecting Information on Respondents

There are a number of ways to minimize the burden of collecting information. First, collect the data on an annual basis instead of quarterly. The vast majority of data elements do not change on a quarterly basis, so annual data collection may be adequate for CDC's needs. If annual data collection is adequate, consider collecting the information from NAQC instead of from each individual quitline. This would prevent duplication of effort and would significantly minimize the burden of data collection in terms of hours, costs and the number of people and states involved.

If CDC decides to collect its own data in lieu of using NAQC's data, it can minimize the burden of collection information by:

- Having the supporting information for each quitline pre-populate on the online survey, with the information from the most recent quarterly submission. Quitlines could then verify this information, make changes as needed, and add in the new number of calls, faxes, etc. rather than having to look up this information from their own records every time they complete the survey.

- Allowing more than one person to access the online survey and enter data. NAQC has done this successfully with its survey and finds that users appreciate this as both the state funder and service provider play a role in data entry. This also would solve another problem that respondents have with the current CDC online services survey. The current online system CDC developed allows only state health department personnel to use the system and submit survey data. In some states, the health department is not the funder of the quitline. This has created challenges for completion of the survey. By allowing multiple users to enter data,

funders outside of the health departments could more easily complete and submit the surveys.

III. Conclusions

CDC is performing an important service for the federal government, States, tobacco control community and the public by establishing the National Quitline Data Warehouse. NAQC applauds CDC's efforts to date. As CDC moves forward, we have identified a number of ways it may improve its efforts. Most important of these are:

For the individual-level intake and follow-up data: Continue to improve the reliability of the online data submission system.

For the online services survey: 1) Collect the information annually instead of quarterly; 2) Collect the data from NAQC instead of from the states to reduce the burden of data collection and to avoid duplicative data collection. If CDC decides to collect data from states, then we also recommend that it makes improvements to its online data collection as described above.

For the NQDW overall: 1) Provide funding for states and other entities who are required to submit data for NQDW; 2) Develop and implement a communication plan for exchanging information and discussing questions and issues of concern with interested parties; and 3) Share data and findings with interested parties and the broader public.

Should you have any questions about these comments, please contact me at 800-398-5489 (ext 706) or via email at LBailey@NAQuitline.org.

Sincerely,

Linda A. Bailey
President and CEO

CDC Response to Public Comment #2

CDC considered the comments provided by the North American Quitline Consortium (NAQC), incorporated changes into the Information Collection Request prepared for OMB review, and provided the following reply to NAQC:

CDC is pleased to receive NAQC's feedback as an organization that represents quitline professionals and national organizations, including CDC, in the United States and Canada. CDC has had a close working relationship with NAQC, and since 2008, NAQC has served as a contractor to CDC with annual funding of approximately $265,000 per year. CDC appreciates the thoughtful comments provided by the North American Quitline Consortium (NAQC) and we have made important and significant revisions to our OMB package based on these comments.