



Updating the Minimal Data Set for
Quitlines
October 2019

Introduction

NAQC published the original [Minimal Data Set](#) (MDS) in mid-2005 and all quitlines in the U.S. and Canada had adopted it by early 2006. The MDS includes required and optional questions that are asked of callers at intake and seven-month follow-up. The standardized MDS questions create data that is useful for delivery of cessation services, surveillance of quitline callers and evaluation of quitlines. A major strength of the MDS is its ability to evolve over time to reflect new topics and issues of importance to both the quitline and research communities. It is noteworthy that 39 of the 42 questions on CDC's National Quitline Data Warehouse (NQDW) have been adopted from the MDS. In addition, a number of quitline and cessation organizations in North America, Europe and Asia also have adopted the MDS.

By 2018, changes had been made to the MDS, spearheaded by NAQC members and staff. The most notable changes have included the addition of:

- Optional questions on LGBT identity – 2006 with an update in 2016
- Optional questions on Behavioral Health – 2011
- Optional questions on Graphic Health Warnings on Tobacco Packaging – 2012
- Required and optional questions on Electronic Nicotine Delivery Systems (ENDS) – 2015
- Optional and time-limited question on residency in public housing – 2018 through December 2020

NAQC members raised concerns about the amount of time needed at intake to register a tobacco user for quitline services and have asked NAQC to assess whether some intake questions can be removed from the MDS. In response to this feedback and to assess the continued value of the data set, NAQC initiated a review of MDS intake and follow-up questionnaires. The review was conducted from October 2016 to November 2017, and included a robust process of gathering feedback from members, convening a workgroup, and gathering current intake and follow-up questionnaires used by quitlines. In 2017 and 2018 additional work was completed on questions related to LGBT identity and public housing residency. For more information on the methodology of the MDS review please contact NAQC at naqc@naquitline.org.

The goals of the MDS review were to:

- Assess the value of having standardized questions for the quitline community to use at intake and follow-up;
- Assure that current required and optional questions are supported by academic literature and/or quitline community best-practice and that required measures meet the essential data needs of the quitline community; and

- Consider new methods for collecting MDS data that minimize cost and time while delivering reliable data.

This summary is designed to provide NAQC members with a concise view of the final recommendations for changes to the MDS.

Key Findings

Consultations with NAQC's Advisory Council and external subject matter experts, including MDS workgroup discussions, found:

- **Regarding the value of standardized questions:** There is great value in having standardized questions which allow the quitline community to compare experiences across quitlines. However, there is concern about lack of fidelity in adoption of MDS questions. The variability in the wording of individual MDS questions and response options between state quitlines was discussed at length. The lack of fidelity to the wording of questions and response options is of concern.
- **Regarding questions supported by literature and community best-practices:** Overall there is agreement that questions should be supported by literature or community best-practice in the case of emerging issues/topics. Using questions that have been validated by academic literature or community best-practice will further strengthen the data obtained at intake and follow-up.
- **Regarding new methods of collecting data:** There is a need for guidance on how to collect data from quitline callers while moving the callers into services as quickly as possible. For example, using a web-based or text message data collection. This guidance should focus on streamlining intake and possibly on workflow issues and staff training.
- **Regarding outcome evaluation:** Most state quitlines have limited budgets for collecting follow-up data and conducting outcome evaluations. Guidance would be helpful on the frequency of collecting follow-up data, sampling methodologies, and selection of evaluators (i.e., state agency, service provider, or third party).

When members of the MDS workgroup reviewed each individual intake and follow-up question submitted by state and provincial quitlines, they made this unexpected finding:

- Among the 42 state and provincial quitlines that provided an intake questionnaire, the number of questions ranged from 31 to 173, with a median of 62 questions. Among the 39 state and provincial quitlines that provided a follow-up questionnaire, the number of questions ranged from 8 to 107 with a median of 20 questions. These findings indicate that for at least 41 state quitlines the majority of questions included on intake questionnaires are not MDS questions, and for at least 10 state quitlines the majority of questions on

follow-up questionnaires are not MDS questions. In these state quitlines, the majority of questions have been added to address needs of state agencies and other stakeholders. Appendix A provides a listing of non-MDS questions asked at intake and follow-up.

At the completion of its review, the MDS workgroup recommended eliminating 11 MDS questions. Recommended changes were shared with state and provincial quitlines for review and comment. NAQC reviewed all comments and has made final changes as shown:

Type of Question	Original number of required questions	Net change to the number of <u>required</u> questions	Original number of optional questions	Net change to the number of <u>optional</u> questions	Total number of questions as of October 2019
Intake	37 (35 for Canadian quitlines)	-2	32	-2	35 required (33 for Canadian quitlines) 30 optional
Follow-up	27	-21	14	+14	6 required 28 optional

It is worth noting that during the review two questions that were optional intake questions have become required intake questions (see questions RI10a&b and RI16 in the MDS intake questionnaire listed below). The topics of these questions are:

- 1) LGBQ identity; and
- 2) Behavioral health

Updated MDS Intake and Follow-up Questionnaires

Based on the findings of the MDS review, NAQC has updated the MDS intake and follow-up questionnaires and created a new MDS optional question bank document which contains optional questions state quitlines can ask at intake and follow-up.

- [MDS intake questionnaire – October 2019](#)
- [MDS follow-up questionnaire – October 2019](#)

- [MDS optional question bank – October 2019](#)

Next steps

As NAQC staff and members consider next steps, it will be important for:

- NAQC staff and members to continue seeking ways to reduce the length of intake and develop needed guidance on new methods for data collection and outcomes evaluation; and
- Individual state and provincial quitlines to review non-MDS intake questions to ensure that all questions asked at intake and follow-up continue to be relevant to the objectives of the quitline.

Acknowledgements

MDS Review Workgroup

NAQC would like to acknowledge the contribution of the MDS Workgroup in the review and development of recommendations presented in this report. The MDS Workgroup members included: Freeha Bhatti, Sykes; Livia Greenbacker, Public Health Management Corporation; Stephen Gillaspay, Oklahoma Tobacco Helpline; Sandra Hernandez, California Smokers' Helpline; Kevin Horne, Nebraska Department of Health and Human Services; Sharon Lee, Canadian Cancer Society; Jason Lindo, Strategic Research Innovations; Amy Lukowski, National Jewish Health; Robert Vargas, Optum; and Lei Zhang, CDC Office on Smoking and Health. Maria Rudie provided staff leadership for the workgroup.

MDS Review Subject-matter Experts

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NAQC staff

Staff who contributed to this report includes Maria Rudie (project management and writing), Natalia Gromov (layout) and Linda Bailey (editing).

Appendix A: Non-MDS questions asked at intake and follow-up

Topics of non-MDS questions asked at intake

- Pregnancy status
- Employment status
- Diagnosis of chronic condition
- If caller is around other tobacco users at home/work
- If caller is ready to quit
- If caller is currently quit/how long quit
- Income level/household income/# of people supported by income
- Questions about physical disability
- Permission to send email and texts
- Marital status
- Receive services from the Veteran's Administration
- Employer name
- What services the caller is interested in
- If there are children in the home
- If call believes their mental health conditions will interfere with their ability to quit
- Member ID for health insurance/Medicaid
- Price per pack of cigarettes
- If caller has access to computer/internet
- If caller uses Facebook/Twitter, would like to join quitline on Facebook/Twitter
- If the call has been diagnosed with pre-diabetes
- For callers under 18 years: are they currently in school or working
- If caller is a part-time employee/contractor/volunteer
- If the caller is an employee of the state
- If the caller is enrolled in community cessation program
- The caller's preferred name
- What number the caller dialed for services
- If caller has received tobacco coupons/mailings
- The caller's alcohol consumption
- If caller "butts-out" cigarettes
- Questions on previous quit attempts
- If caller has reduced tobacco consumption
- Current use of NRT
- Pets in home
- Type of housing

Topics of non-MDS questions asked at follow-up

- Re-enrollment in quitline services
- Refer a friend
- If quitline met needs/would use again/general program feedback
- Use of cessation medications
- Likelihood to use ENDS in future
- Past 7-day use of tobacco products
- Physical and mental health of quitline participant
- Use of text/email/web programs
- Longest amount of time participant went without tobacco because trying to quit
- Reduction in amount of tobacco used
- Rules on smoking in personal cars and home
- Reason started using ENDS
- Intentions regarding use of ENDS
- Purchase of more NRT than amount supplied
- MDS intake questions on educational attainment and health insurance coverage and age at first use of cigarette
- Living with another smoker
- Awareness of social media ads on quitline
- Participants income level
- Number of people in household
- County of residence
- Reason enrolled in services, services received
- Receipt of NRT
- Demographics data: Age, race, ethnicity, gender
- Awareness of ads about harms of smoking or ads about quitline
- Social support during quit attempt
- Date last smoked
- Number of cigarettes smoked in past 30 days
- If received advice from a health care provider - what type of provider
- Tobacco tax increase
- Confidence/motivation to quit