

Moving Quitline Research Forward: Resources and Tools

Jessie E. Saul, Ph.D.¹, Barbara Zupko, M.A.², Terry Bush, Ph.D.³, Mignonne C. Guy, Ph.D.,⁴ Linda Bailey, J.D., M.H.S.¹, Erik Augustson, Ph.D.⁵

¹North American Quitline Consortium; ²Propel Centre for Population Health Impact; ³Alere Wellbeing; ⁴Mayo Clinic Arizona; ⁵National Cancer Institute

Learner Outcome: Describe, access, and use recently developed tools for researchers and quitlines to engage in quitline-related research.

Background: The North American Quitline Consortium (NAQC) was established in 2004, and serves as the only member organization dedicated to promoting evidence-based quitline services in diverse contexts. NAQC has over 400 individual members representing the 65 publicly funded quitlines in the U.S. and Canada. In an effort to advance research on quitlines, the North American Quitline Consortium recently produced two documents to facilitate collaborations between researchers and quitlines. The first is a Research Agenda for Quitlines, which is designed to provide criteria for developing and managing internally generated research (within the network of quitlines) as well as external requests for network participation, to develop a balanced research portfolio that meets the needs of the various stakeholder groups, and to leverage use of the Minimal Data Set for evaluating quitlines. The second is a Research Guide for Quitlines, which contains information for both researchers (about quitlines) and quitlines (about the research process) to facilitate understanding and collaboration between researchers and quitlines. These and other resources for researchers and students interested in working with quitlines or their data are available at <http://www.naquitline.org/?page=RS>.

Methods: A single workgroup was formed to assist with the development of both products. Workgroup members represented all stakeholder groups for tobacco cessation quitlines, including researchers, evaluators, service providers, administrators/funders, and national partners. The workgroup met monthly by teleconference and webinar. Workgroup members provided feedback on draft documents. NAQC staff incorporated feedback iteratively into successive versions of the document. In addition to workgroup feedback, NAQC staff also obtained feedback on the documents from researchers attending national conferences including the Society for Research on Nicotine and Tobacco (SRNT), the Society for Behavioral Medicine (SBM), and the American Public Health Association (APHA). Finally, NAQC members reviewed near-final documents and their comments were incorporated into the completed versions.

NAQC Strategic Goals

Goal 1: Increase the Use of Quitline Services in North America

- Objective 1: By 2015, each quitline should achieve a (treatment) reach of at least 6% of its total adult tobacco users. (Treatment reach is defined as the proportion of total adult tobacco users receiving evidence-based treatment – either beginning at least one counseling session or receiving medication.)

Goal 2: Increase the capacity of quitline services in North America

- Objective 2: By 2015, on average \$2.19 per capita (\$10.53 per smoker) should be invested in quitline services (both counseling and medications).

Goal 3: Increase the quality and cultural appropriateness of quitlines in North America

- Objective 3a: By 2015, each quitline should have an overall quit rate of at least 30% (as measured by the NAQC standard quit rate calculation).
- Objective 3b: By 2015, each quitline should achieve a reach of 6% in priority populations (American Indian/First Nations, Alaska Native, Asian, Black or African American, Hispanic or Latino, LGBT, Low SES, Native Hawaiian or Other Pacific Islander)

Results

NAQC's Research Agenda for Quitlines

Why develop a research agenda for quitlines?

- Extensive research on quitlines has been done
- Significant gaps still exist
- Need for a tool to help focus our collective efforts, help NAQC prioritize its time and resources

How is the Research Agenda organized?

- Organized by NAQC strategic goals (see shaded box)
- Research questions/areas paired with potential uses of information (see Table 1)

The Research Agenda is available at

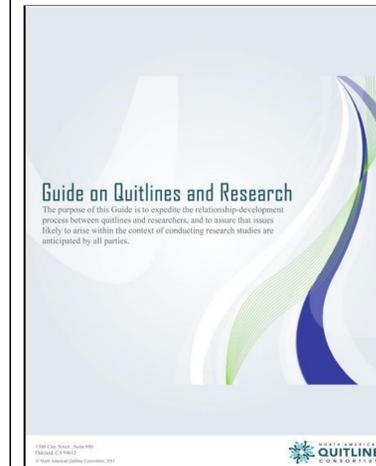
http://www.naquitline.org/resource/resmgr/research/march2012draft_research_agen.pdf. As a whole, it can be used to identify areas of common interest between the quitline community and other individuals and organizations.



Table 1: Examples of research questions and potential uses for the information

Examples of research questions	How might we use this information?
Goal 1 (Reach) <ol style="list-style-type: none"> What marketing/communication strategies can improve the reach of quitlines? What is the impact of integration of quitline services with other services with respect to reach? (e.g., web-based interventions, social network technologies, behavioral health services, economic services, etc.) How best to integrate fax referrals into health care systems without increasing the burden on health care providers? 	<ul style="list-style-type: none"> Use trend data over time to show progress or declines in quitline efforts Take lessons learned from effective methods and apply them in other situations. Make the case for integrating quitlines or forming new partnerships
Goal 2 (Capacity/Investment) <ol style="list-style-type: none"> What is the cost effectiveness/cost benefit of various quitline services? How does this vary across population groups (e.g., light vs. heavy smokers)? What is the impact of increasing benefit coverage for quitlines or medications through quitlines? How does health care reform influence this? What is the impact of integrating quitline services with other services on funding levels for quitlines? 	<ul style="list-style-type: none"> Make the case for continued, sustained, consistent, and expanded funding of quitlines to support demand, as well as expanded reimbursement for quitline services. Show the impact of incremental changes in quitline reimbursement. This helps to diversify funding sources for quitlines overall e.g., influencing the outcome of health care reform efforts. Demonstrate the benefit of integration of quitline services. Integration may make quitlines less of an easy target for funding cuts.
Goal 3 (Quality - Effectiveness) <ol style="list-style-type: none"> What are effective and cost-effective models for delivering NRT/medications through quitlines? What is the impact of integration of quitline services with other services? (e.g., web-based technologies, behavioral health services, economic services, etc.) What elements of quitlines are most important for effectiveness and cost-effectiveness? 	<ul style="list-style-type: none"> Target the most expensive programs or protocols to those of greatest need. Make informed decisions about integrating with other services Make decisions about the benefit of adding features/components to quitlines
Goal 3 (Quality – Cultural Appropriateness) <ol style="list-style-type: none"> What is the impact of integration of quitline services with other services (cessation and other) with respect to reach for priority populations? What are effective characteristics of counselor training programs? What are valid measures of cultural appropriateness? How do we determine whether a quitline's services are culturally appropriate or not? What is the relationship between cultural appropriateness and outcomes for priority populations? 	<ul style="list-style-type: none"> Identify partnerships that can be particularly effective at outreach to priority populations. Identify most impactful elements of counselor training or counseling content for different priority populations Develop and adopt measures of cultural appropriateness

The Guide on Quitlines and Research



The purpose of NAQC's Guide on Quitlines and Research is to expedite the relationship-development process between quitlines and researchers, and to assure that issues likely to arise within the context of conducting research studies are anticipated by all parties. To engage in studies with quitlines, researchers, quitline funders and quitline service providers will need to develop both an understanding of the context in which each works as well as working relationships that may anticipate and address issues likely to arise. This Guide is geared towards all parties associated with quitlines such as funders, service providers, and evaluators, as well as researchers who currently work with or are interested in working with quitlines. It aims to educate the quitline community about the research process and practices, and to educate researchers about the complex nature of quitlines. The Guide and related documents are available at <http://www.naquitline.org/resource/resmgr/Research/ResearchGuideMarch2012.pdf>.

Additional resources have been created to serve as companion pieces to this Guide:

- Appendix A** provides a glossary of terms often used by researchers and/or quitlines.
- Appendix B** includes sample text and paragraphs that were gathered from existing quitline data use agreements and contracts. It was developed to provide additional assistance with quitline research.
- A one-page checklist, The Basics for Quitlines: Questions to Ask of Researchers who Request Data**, was developed as a guide for quitlines when they are asked to provide quitline data. The checklist is intended as a guide for initiating and continuing discussions with researchers who are interested in quitline data. This one-page checklist is also included in Section III. (See also Figure 1)

The Research Guide can serve as a starting point for discussion between quitlines and researchers at any point in the research process, but particularly as projects are in the development phase.

Conclusion: Use of these resources and tools will improve the quality of relationships between quitlines and researchers, expand access to quitlines interested in participating in research studies, and enhance the likelihood of success for research studies that may improve current practices and increase rates of tobacco cessation.

Funding for these projects was provided by the National Cancer Institute and NAQC membership dues.

Figure 1: One-page Checklist for Researchers

The Basics for Quitlines: Questions to Ask of Researchers who Request Data	
WHO is requesting the data?	Who are all of the parties involved (identify any subcontractors the research will require as well as vendor, funder, administrative involvement)? Who will have access to the data (include both individuals and organizations)? Who will serve as the key contact person for your organization, for the researchers/organization requesting the data, and for the quitline vendor (if needed)? Who is responsible for funding the data request and/or project?
WHY	Why is the data being requested (include purpose, project summary, and a copy of the proposal)?
WHAT data are they requesting?	What data sets/variables will be shared? Is there a data dictionary, or will one need to be created to be able to appropriately interpret the data sets (this may also factor into cost)? What is the funding commitment needed from the quitline in order to participate in the research project (e.g., staff time, administrative oversight of data sharing, changes needed to regular reports from service provider)? What are the anticipated report deadlines (include in project timeline)? What reports are being requested? What information is necessary to capture to complete these reports? What are the programming and/or software compatibility needs (e.g., version of Excel, Access, SAS, SPSS)? Is data shared electronically or in hard copy?
WHEN	When does the project request begin? When is the data needed? How many data pulls will they need and for how long (one-time, quarterly, annually)? When does the data permission end (include in project timeline)?
WHERE and HOW	Can the researcher produce the IRB-approved protocol to show the research is approved for appropriate Human Subjects and HIPAA protections? Does the data request include data on vulnerable populations such as pregnant women, children, or prisoners and are these individuals included in the IRB approval? Where is the IRB (ethics reviewer) on record? Where will the data be stored? How will the requested variables be pulled from the complete data set? Who will do that work? Will a data dictionary be provided? Who will be responsible for follow-up requests for additional information or clarification? How many quitlines are involved in this data project (consider data compatibility issues)? How will the data be protected? How will caller information privacy be maintained (de-identification of the data set)? How will the data be returned or destroyed at the end of the project? How will data use be monitored (including subcontractors' data use)? How will you be notified of a breach of privacy? How will you be notified of the project's progress and results?