Evaluation

of the
National Guideline Clearinghouse™ (NGC)

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Final Report

Final Contract Report

Evaluation of AHRQ's National Guideline Clearinghouse™ (NGC)

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None of the authors has any affiliations or financial involvement that conflict with the material presented in this report.

Policy Statement

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Preface

A. Project Scope

The purpose of this project was to formally evaluate the Agency for Healthcare Research and Quality's (AHRQ's) National Guideline Clearinghouse™ (NGC).

The purpose of this report is to present the results of a mixed-methods evaluation of the NGC.

B. Organization of Report

This final report for the NGC Evaluation contains five primary sections and an Executive Summary. They are: 1) Background, 2) Methods, 3) General Findings of the Evaluation, 4) Stakeholder-Specific Findings, and 5) Conclusions and Recommendations. These major sections are supplemented by extensive use of appendices. In addition, a separate summary report of the evaluation survey supplements this report.

Section 1 of this report provides background on the NGC Web site, including its initial development, mission, and current activities and trends. This section also describes the purpose of the current evaluation. Section 2 provides detail on the evaluation approach, methodology, and data sources. Section 3 provides a summary of the key findings of the evaluation, including a synthesis of findings from an electronic survey and data collected through key informant interviews and focus group sessions with individuals from key NGC stakeholder groups. Section 4 discusses findings related to specific stakeholder groups. Included in this section are results from each of the stakeholder groups related to NGC's influence and specific uses of the site. This section also presents findings related to NGC processes, influences, and desired enhancements from a group of "guideline developers" who submit their guidelines for inclusion in NGC. Section 5 provides conclusions and general recommendations for AHRQ based on the results of the evaluation.

While this report tries to present the diverse perspectives of the varied stakeholders engaged in this evaluation (through quantitative and qualitative mechanisms), it cannot capture the richness and diversity of all of their comments and contributions. Similarly, while this report presents the key findings of a survey conducted, it cannot capture details on each of the analyses and cross tabulations by key stakeholder group that were conducted. Appendices for this report provide detailed summaries of stakeholder group perspectives, and the results of the comprehensive survey that was conducted as part of this evaluation.

C. Disclaimer

The views, opinions, and content of this publication are those of the authors and do not necessarily reflect the views, opinions, or recommendations of AHRQ or the U.S. Department of Health and Human Services (HHS).

Executive Summary

A.   Purpose of Evaluation

The purpose of this project was to formally evaluate the Agency for Healthcare Research and Quality's (AHRQ's) National Guideline Clearinghouse™ (NGC). The Agency was specifically interested in learning how its multi-million-dollar investment in NGC has shaped healthcare quality and how additional investments can continue to influence that quality. This report presents the results of a mixed-methods evaluation of NGC. Information obtained from this evaluation will inform AHRQ as it considers its next steps and ways to improve the overall usefulness of NGC and to identify areas for refinement and improvement.

The objectives of the NGC evaluation were to gain a better understanding of how NGC:

- Is used by its stakeholders (including AWARENESS of NGC among key stakeholders)
- Supports dissemination of evidence-based clinical practice guidelines and related documents
- Has influenced efforts in guideline development, implementation, and use
- Can be improved

B.   Analytic Methods

Three primary data sources were used to inform the evaluation design: (1) an environmental scan of published and unpublished ("gray") literature on guideline use and dissemination to identify what is known about NGC's influence to date on its various stakeholder groups; (2) a comprehensive analysis of NGC project data (e.g., Annual Project Reports; Annual NGC Customer Satisfaction Surveys); and (3) input from a group of individuals expert in guideline development, evaluation, dissemination, and implementation who formed the evaluation's Participant Evaluation Team (PET).

To achieve the objectives of this project the following data collection approaches were performed:

1) NGC evaluation survey – administered to a convenience sample of both users and non-users of NGC,
2) Focus groups – conducted with guideline developers, medical librarians, informatics specialists, and
3) Key informant interviews – conducted with influential individuals in medical societies, health plans, and quality improvement organizations, as well as medical librarians, researchers, and informatics specialists who produce, use, and disseminate guidelines

For the survey component of the evaluation, three sample frames were employed to reach different mixes of stakeholders, and to include NGC users and non-users. The AHRQ-sponsored

Gov Delivery e-mail accounts subscription base was the main sample frame. In addition, the survey link was sent to subscribers of the American Medical Association (AMA) e-mail services and the America's Health Insurance Plans (AHIP) e-mail list.

Questions in the survey, focus group, and key informant discussion guides were focused on the effectiveness of NGC in areas of dissemination, implementation, and use of evidence-based clinical practice guidelines, and relative to other available guideline sources. For example, measures gathered through the instruments included the level of trust of NGC, the use of NGC relative to other guideline sources, and the influence of NGC on various stakeholder groups. In addition, the instruments were used to measure the use of other guideline resources by non-NGC users.

C.   Key Findings and Potential Opportunities for AHRQ

The evaluation demonstrated that NGC is a well-known and trusted source for clinical guidelines among all stakeholder groups who participated (either through the electronic survey or through focus group sessions or key informant interviews.

Those that used NGC were more satisfied with NGC relative to other guideline sources, had used NGC for a long time, and were likely to recommend it to others. Key findings are summarized below.

Awareness and Use of NGC

Measures of NGC awareness were obtained using a Web-based survey fielded using e-mail subscription lists for AHRQ, AMA, and AHIP.

- **Most survey respondents were aware of NGC (n=7,223; 78%) and the large majority of those who were aware, reported that they use NGC (n=5,828; 81%).**

- **A relatively large proportion of respondents who were not NGC users (75%) reported that they used clinical guidelines frequently or very frequently.**

Use of Other Guideline Sources

- **NGC use was complementary to the use of other guideline sources; survey respondents who used NGC tended to use more alternative sources than those who did not use NGC.**

Based on results from the survey, NGC users were more likely to use six or more sources in addition to NGC (30%) than those unaware of NGC (6%) and non-users who were aware of the NGC (10%). Among stakeholder groups, librarians were more likely to use six or more guideline sources in addition to NGC when searching for guidelines (42%), compared to other stakeholder groups (range: 30% -33%). Of the 17 sources listed, the most popular alternative source used to

locate clinical guidelines was PubMed/Medline (54%).

Data from the qualitative component of this evaluation were consistent with this finding. Most stakeholder groups who participated in focus group sessions or key informant interviews noted that NGC is one of the sources they use to find guidelines, but not the only source. However, many of these participants noted that NGC is often their "first go-to source" for guidelines.

Length and Frequency of NGC Use

- **NGC users tend to have used the site frequently over a long period of time.**

The largest proportion of survey respondents who report using NGC also reported they had been using the site for between two and five years (37.7%). The second most frequent category was newer users of less than two years (32.7%) followed by experienced users of greater than five years (27.7%).   Among stakeholder groups, librarians were the most likely to have used the NGC Web site for more than five years (42%) and were less likely to have used for less than two years (20%). Guideline developers followed librarians at 34% and 26%, respectively.

Almost all NGC users used the site at least once in the past one year (97.1%). A majority accessed the NGC Web site between one and 10 times (65.1%), and a substantial number used the site more than 10 times within the last year (29.6%).

Qualitative data were consistent in many ways with this finding. Most stakeholder groups who participated in focus group sessions or key informant interviews noted that they have been using the NGC "for a very long time." There was wide variability in terms of the frequency of their use ranging from weekly to once or twice a year. Their use was often related to their specific uses of the NGC Web site.

Satisfaction, Trustworthiness, and Appropriateness of Inclusion Criteria

- **NGC users were equally satisfied or more satisfied with the NGC compared to other guideline sources.**

Thirty-eight percent of survey respondents rated NGC as about equal to other sources, while a near majority (47%) of respondents were either slightly or much more satisfied with NGC. Few respondents reported being slightly less satisfied or much less satisfied with NGC (13%).

Among stakeholder groups, librarians and informatics specialists were the most likely to choose "more satisfied" with NGC than with other guideline sources (60% and 58%, respectively). Guideline developers were the most likely to choose "less satisfied" with NGC than with other guideline sources (18%).

Qualitative data were consistent with this finding. There were very few reports from participants of NGC being less useful than other sources. Some notable features of NGC that were commonly

cited by respondents as better through NGC relative to other sources were the diversity and comprehensiveness of the content available on the Web site, the guideline comparison tools (including both guideline syntheses and the dynamic guideline comparison tool), and the fact that it is publicly available. Some features or issues that were commonly cited as problems for NGC when compared to other guideline sources were the currency of the information available, the time that it takes for new content to be posted, and search result sets that contain a lot of irrelevant content. However, even among those participants identifying features of the Web site that they didn't like, most still highly valued the accessibility and comprehensiveness of the resource.

- **NGC was rated as good as or better than other guideline sources in meeting its users' needs.**

Survey respondents reported that NGC did well in fulfilling NGC users' needs across 11 tasks. NGC fulfilled the needs of its users particularly well for the following tasks: finding clinical guidelines, comparing clinical guidelines, developing clinical guidelines and quality measures, professional knowledge building, and supporting clinical decision-making. Therefore, the NGC met its mission in providing a source for individuals interested in finding, comparing, and developing clinical guidelines.

- **The large majority of users found the guidelines on the NGC Web site trustworthy. However, based on qualitative data, some differences in the degree of trust exist among stakeholder groups.**

When NGC users were asked how they would rate the trustworthiness of the guidelines on NGC, three-quarters of users rated the guidelines' trustworthiness as "very good" or "good," with only 1.25% rating it as "poor." Additionally, based on the survey responses, there were no perceived differences in the trustworthiness of guidelines found on NGC among the different stakeholder groups that were targeted in the survey.

Qualitative data were somewhat inconsistent with the findings from the survey. Notably, a number of the participants from the guideline developer and the medical informatician stakeholder groups believed that some of the guidelines included in NGC were, in fact, not trustworthy. Participants from the other stakeholder groups (e.g., medical librarians, measure developers, policymakers) were generally trusting of the content included in NGC and cited that it was a trusted source because it is sponsored by AHRQ.

- **A majority of users believe the NGC inclusion criteria are appropriate. However, based on qualitative data, some differences among stakeholder groups appear to exist, with guideline developers and informaticians being more likely to believe the**

criteria are too loose.

Over 60% of users responded that NGC's guideline inclusion criteria were "appropriate." Only 11.5% said they were either too stringent or too loose. Users who had been using NGC for five years or longer were more likely to say that the inclusion criteria were "loose" (7%) compared with those who had used the site for two to five years (4%) or less than two years (2%). Among stakeholder groups, guideline developers were the user group most likely to rate the NGC inclusion criteria as "too loose" (6.3%). While 6% is low, this might suggest that those who develop guidelines would like more clear standards for what is included in NGC.

Qualitative data were inconsistent with the findings from the survey. Notably, a number of the participants from the guideline developer and the medical informatician stakeholder groups believed that NGC's inclusion criteria are too loose. Participants from the other stakeholder groups (e.g., medical librarians, measure developers, policymakers) were generally in agreement that the criteria were appropriate.

- **The five-year age criterion for guideline inclusion was seen as too long by a large proportion of users in both the quantitative and qualitative findings.**

Compared to responses regarding stringency, respondents were less satisfied with NGC's age criterion. Currently, to be posted on the NGC Web site, a guideline must have been developed, reviewed, or revised within the past five years. Guidelines that do not meet this requirement are either rejected for inclusion or are placed in the NGC Guideline Archive when they become more than five years old. Survey responses regarding the five-year age requirement were bimodal — 43% felt the criterion is "appropriate" and nearly as many (39%) felt that five years is too long. Of those who felt it was too long, the most common recommendation was three years (54% of all responses).

Among stakeholder groups, librarians were the least likely to respond "too long" (37%) and purchasers were the most likely to respond "too long" (49%).

Qualitative data were consistent with the general findings from the survey, with numerous participants in focus group sessions and key informant interviews noting that five years was too long. However, numerous participants from the focus groups also qualified their statements about the age criterion by saying that the appropriate time frame or shelf-life of a guideline is often topic-dependent. Guideline developers also identified the challenges that they face, namely available resources, as the primary challenge they have in keeping their guidelines up to date.

Influence of NGC by Stakeholder Group

NGC has had a significant positive impact on guideline development, implementation, and use across all stakeholder groups. In particular, survey respondents indicated that NGC has to a great

extent, or somewhat, influenced:

- **Guideline developers'** ability to identify guidelines and develop and use quality measures

- **Providers'** ongoing learning efforts, clinical decision-making processes, and identification of guidelines

- **Medical librarians'** ability to meet their clients' needs

- **Medical librarians'** and **researchers'** ability to identify current and high quality guidelines

- **Measure developers'** development of quality measures

- **Policymakers' and purchasers'** ability to identify guidelines and convert clinical information

The above survey findings are generally supported by the comments of stakeholders in focus groups and key informant interviews. A common theme across all stakeholders in qualitative analyses is that NGC is a useful source for identifying evidence-based guidelines. Among guideline developers, NGC has been less influential in terms of advancing guideline development programs (e.g., guideline methodology and reporting). However, there is some support in both the quantitative (particularly for guideline developers who submit their guidelines to NGC) and qualitative data for the idea that NGC's five-year age criterion has had some influence on the frequency with which guideline developers update their guidelines.

Opportunities for AHRQ to Expand NGC's Use and Impact

While the findings of this evaluation suggest that most users rate NGC highly, the findings also point to a number of opportunities for AHRQ to expand the use and impact of this public resource:

Potential for Building on NGC's User Base

- **Respondents not currently using NGC desire more information about it.** Among survey respondents who were unaware of NGC or aware of NGC but do not use NGC (n=3,301), approximately 75% report that they use guidelines occasionally, frequently, or very frequently. In addition, 84% (n=2,649) said they would be interested in learning more about NGC. In addition, although based on a very small sample size, awareness among survey respondents solicited through the AMA newsletters (which target healthcare providers) was lower than that observed in the AHRQ and AHIP sampling frames.

  AHRQ has an opportunity, through heightened marketing, to increase its reach to

individuals interested in learning about and/or using the NGC Web site, particularly among healthcare providers.

Potential for Advancing Knowledge and Awareness about Good Quality and Executable Guidelines Among Organizations that Submit to NGC

- **Based on qualitative data among various NGC stakeholders, namely guideline developers and informaticians, users think that AHRQ can play more of a role in advancing good practices in developing guidelines.** Informaticians suggested that NGC should play more of a role in advancing efforts to improve the executability or implementability of guidelines. Some suggest that NGC could do this by rating that attribute of guidelines. Guideline developers likewise reported that having some measure of a guideline's quality would help to distinguish rigorous guidelines from less rigorous guidelines. Guideline developers also expressed interest in guideline developer conferences and/or methodology workshops.

Potential for Enhancing Guideline Dissemination Activities

- **Thirty-five percent of guideline developers who submit their guidelines to NGC rated NGC's dissemination of their guidelines as neutral or poor.** AHRQ may want to consider researching additional mechanisms that might be used to enhance the dissemination of evidence-based guidelines included in the clearinghouse.

Potential for Enhancing Healthcare Providers' Use of NGC

- **NGC can improve support of providers' use of clinical guidelines and their ability to practice medicine on a day-to-day basis.** Seventy-two percent (72%; n=2,342) of providers stated that having NGC content delivered to them at the point of care would be useful. Sixty-six percent (66%; n=2,270) said they would take advantage of continuing medical education.

Potential to Revisit NGC's Guideline Age Criterion

- **Based on both quantitative (39% of the survey respondents) and qualitative data collected in this evaluation, many NGC users find the five-year age requirement for guideline inclusion to be too long.** This may contribute to difficulties using NGC if a lot of material is outdated compared to available evidence, or if users feel that the content is not trustworthy because of its age.

Potential to Revisit Inclusion Criteria

- **In qualitative data, both guideline developers and informaticians were more likely to say that NGC's inclusion criteria are too loose. In addition, among survey respondents, guideline developers (in particular, those who submit their guidelines for inclusion in NGC) were the most likely to rate the NGC inclusion criteria as "too loose" (6.3%).** While 6% is low, this might suggest that those who develop guidelines would like clearer standards for what is included in NGC.

Potential to Add Significant Value-Add Enhancements to the NGC Web site

- **Potential enhancements to the NGC Web site resonated with a majority of users.** The survey inquired about the value of 12 potential enhancements to NGC. The most popular potential enhancements were subject-specific e-mail alerts and ratings of guidelines' quality or methodological rigor. These were closely followed by offering the ability to search archived guidelines, ability to limit searches of guidelines to information in specific fields, and ability to access archived guidelines.

I.   Background

The mission of the Agency for Healthcare Research and Quality (AHRQ) set out in its authorizing legislation, the *Healthcare Research and Quality Act of 1999*, is to enhance the quality, appropriateness, and effectiveness of health services, and access to such services, through the establishment of a broad base of scientific research and through the promotion of improvements in clinical and health systems practices, including the prevention of diseases and other health conditions. This Act further states that AHRQ shall promote healthcare quality improvement by conducting and supporting:

- Research that develops and presents scientific evidence regarding all aspects of health care;
- The synthesis and dissemination of available scientific evidence for use by patients, consumers, practitioners, providers, purchasers, policymakers, and educators; and
- Initiatives to advance private and public efforts to improve healthcare quality.

As specified in AHRQ's 1999 reauthorizing legislation, Congress eliminated a requirement that the Agency support the development of clinical practice guidelines and created a new requirement that it support the dissemination of others' evidence-based clinical information. The Agency ended its clinical guidelines program in 1996 and in 1997 began the development of the National Guideline Clearinghouse™ (NGC) to meet its new requirement.

A.   Development of NGC

NGC was originally created through a cooperative agreement and collaborative partnership between AHRQ, and the American Medical Association (AMA) and the American Association of Health Plans (AAHP, now known as America's Health Insurance Plans, AHIP). ECRI Institute, a nonprofit health services research organization, was awarded the contract to assist AHRQ in the technical development and ongoing maintenance of NGC and has served as NGC's technical contractor since 1997.

AHRQ, AMA, and AHIP, whose key leaders comprised the NGC Policy Board, and technical support from ECRI Institute, designed and built the foundations of the existing NGC, including the current NGC inclusion criteria and NGC's template of guideline attributes (used to capture and represent content from included guidelines), which have changed little or not at all since NGC's inception.

Consistent with AHRQ's 1999 reauthorizing legislation, NGC continues to serve as a publicly accessible Web-based database of evidence-based clinical practice guidelines meeting a specific set of inclusion criteria. The mission of the NGC is to provide physicians, nurses, and other health professionals, healthcare providers, health plans, integrated delivery systems, purchasers, and others an accessible mechanism for obtaining objective, detailed information on clinical

practice guidelines and to further their dissemination, implementation, and use.

B.   Purpose of Evaluation

Since its public launch in 1999, NGC has been an integral part of the healthcare landscape for numerous stakeholder groups. These stakeholder groups include 1) NGC's intended audience — physicians, nurses, and other health professionals, healthcare providers, health plans, integrated delivery systems, purchasers, and others; 2) guideline developer organizations; 3) quality measure development and implementation organizations; 4) informaticians and/or medical informatics specialists; 5) medical librarians; 6) researchers; and 7) policymakers.

The number of guidelines submitted to, and included in, the clearinghouse has steadily increased since the site launched in 1999, as has the number of users of the Web site. Examples of some of these trends are noted below:

- NGC Web visits have increased more than ten-fold from approximately 70,000 visits per month to more than 700,000 per month in 2009;
- The number of subscribers to the NGC weekly e-mail update service has increased nearly 100-fold;
- NGC's technical contractor has processed, posted, updated, and withdrawn approximately 7,000 guidelines over the first 10 years;
- The number of guidelines represented has grown (2,600 guidelines in 2011; about 250 in July 1999);
- The number of guideline developer organizations that have participated in NGC over the past decade is close to 300 as of 2011, compared with about 50 in July 1999.

Additionally, during the 12 years that NGC has been available, the Internet has evolved to Web 2.0, there has been increased emphasis on evidence-based medicine, and health information technology has developed dramatically. Throughout these developments, key stakeholders have steadily perceived NGC to be an important information source and dissemination vehicle.

As NGC enters its second decade, AHRQ wants to learn when and how it is used and how it can be improved for each of its key stakeholder groups. The Agency is specifically interested in learning how its multi-million-dollar investment in NGC has shaped healthcare quality and how additional investments can continue to influence that quality.

The objectives of the NGC evaluation were to gain a better understanding of how NGC:

- Is used by its stakeholders (including AWARENESS of NGC among targeted stakeholders)
- Supports dissemination of evidence-based clinical practice guidelines and related documents
- Has influenced efforts in guideline development, implementation, and use

- Can be improved

The information collected through this evaluation of NGC will inform AHRQ as it considers its next steps and ways to improve the overall usefulness of the clearinghouse and to identify areas for refinement and improvement.

C.   Questions of Interest

AHRQ contracted with the AFYA/Lewin team to conduct a formal evaluation of NGC and to accomplish the objectives noted above. The AFYA/Lewin team designed an approach to examine NGC's influences across multiple stakeholder groups with respect to guideline development, dissemination, implementation, and use.

As specified in the original solicitation for this project, key questions that AHRQ specifically sought answers to, by key stakeholder group, included the following:

1)   From guideline developers,

- Why organizations do or don't participate in NGC

- From those organizations participating in NGC:

    o   Their expectations regarding NGC's role in dissemination of their organization's practice guidelines and how well NGC has lived up to those expectations

    o   How NGC has influenced their guideline development efforts and whether or not NGC has influenced other quality improvement efforts (e.g., development/use of measures, development/use of guideline implementation tools, integration of guidelines into electronic medical records or clinical decision support), and if so, how and to what extent

    o   (Patterns of) use of AHRQ-supported systematic reviews in the development of their guidelines (see lists of reviews on the AHRQ main Web site and on the Effective Health Care Web site)

2)   From organizations involved in developing and/or implementing healthcare quality measures,

- How NGC has influenced their measure development or measure implementation efforts and how NGC could be more helpful to them

3)   From clinicians and other healthcare providers,

- How NGC has influenced their practice and learning and to what extent

4) <u>From provider organizations,</u>

- How and to what extent NGC has influenced their movement toward and uptake of evidence-based practice across their organization

- Other ways NGC has assisted them in meeting organizational goals (e.g., accreditation, if applicable)

5) <u>From health payer users,</u>

- How and to what extent NGC has influenced their policies and decision-making

6) <u>From informatician users,</u>

- Strengths and weaknesses of existing NGC outputs and specific ideas for improving NGC outputs

- How and to what extent NGC has influenced their efforts to convert (engineer) information in guidelines to knowledge that can be acted upon

- Whether or not NGC should enhance its current indexing efforts through the application of semantic Web standards and/or technologies; if so, the importance of that relative to other ideas for enhancing NGC outputs (e.g., GEM Cutting NGC's content)

7) <u>From medical librarian users,</u>

- How and to what extent NGC has influenced their ability to service their clients' needs regarding evidence-based clinical practice guidelines/evidence-based practice/evidence-based medicine/evidence-based nursing/etc.

- Strengths and weaknesses of existing NGC indexing and search, and specific ideas for improving NGC indexing and search

8) <u>From health services researcher users,</u>

- How and to what extent NGC influences research efforts

- How NGC could be improved to promote and support research

9) <u>From all stakeholders,</u>

- Aspects of NGC that are most valued; those that are least valued

- Importance that NGC be an open and transparent government resource and, if important, how important it is relative to other ideas for enhancing NGC

- Importance that NGC enhance its Web presence through the use of Web 2.0 technologies and, if important, how important it is relative to other ideas for enhancing NGC

In addition, the Agency was also interested in learning:

10) If there are any competing needs across different users that can be clearly identified through this evaluation and how AHRQ can approach them in the context of NGC's missions and priorities

11) How NGC can be positioned to:

- Maximize AHRQ's ongoing investments in research and related activities in quality measurement, health information technology (especially clinical decision support), and comparative effectiveness

- Respond to continuous advances in open government, social media and Web 2.0, and Semantic Web

D.   NGC Stakeholder Groups

For the purpose of this evaluation, NGC's primary stakeholder groups include the following groups of individuals:

1) **NGC's intended audience**: physicians, nurses, and other health professionals and providers
(2) Guideline developers
(3) Quality measure developers
(4) Informaticians
(5) Medical librarians
(6) Researchers
(7) Health plans, health purchasers, policymakers, and others

II.   Methodology

As noted in the previous section, the explicit mission of AHRQ's NGC is:

> "*to provide physicians, nurses, and other health professionals, health care providers, health plans, integrated delivery systems, purchasers and others an accessible mechanism for obtaining objective, detailed information on clinical practice guidelines and to further their dissemination, implementation and use*."

To provide context for this evaluation, AHRQ described its interest in assessing the influences of NGC for three broad areas or domains, across multiple stakeholder groups of the NGC, with respect to specific intended functions associated with NGC use. This framework is illustrated in Figure 1 below.

Figure 1: NGC Stakeholder, Use, and Impact Framework
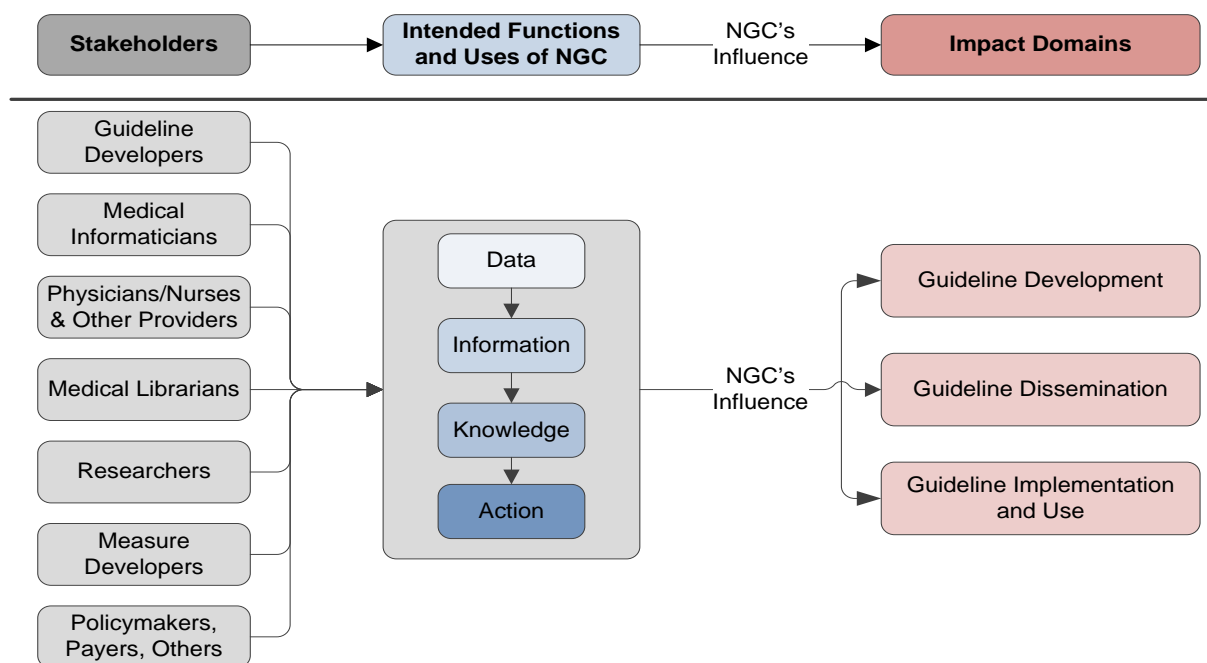
AHRQ recognizes that as a database and information resource, NGC may serve different functions or endpoints for its varied stakeholder groups. AHRQ has described these intended functions (endpoints) and/or intended uses of NGC as points on the continuum of knowledge transfer, or the transfer of research into practice, as indicated in the figure above.

For instance, some NGC stakeholders (e.g., researchers) use NGC for its rich **data**. Others, such as medical librarians, use NGC when looking for **information** or evidence-based guidelines on a particular topic, to support their clients' needs. In this case, NGC provides information that others use.

For others, such as clinicians, NGC serves as a source for information that is used to enhance knowledge. For instance, clinicians may be interested in finding guidelines on a particular topic and from these guidelines the clinician examines the best possible screening, prevention, diagnostic, treatment, management, or rehabilitation alternatives for a given patient (or group of patients). The information obtained from these guidelines is processed into **knowledge.**

And finally, for a number of stakeholders, such as clinicians, policymakers, provider organizations, and guideline development organizations, NGC provides information and knowledge that ultimately drives **action**. Examples include:

- The clinician who uses knowledge gained from information found in NGC to direct patient care decisions
- Guideline development organizations may direct their guideline development activities toward the development of a guideline on a particular topic *(action)* because, after searching NGC and other selected databases or Web sites, it found that no such guidance was currently available
- Policymakers may use the information available in NGC to take specific policy actions

A.   Establishing a Participatory Evaluation Team

To help guide the overall evaluation of NGC, a Participatory Evaluation Team (PET), representing different NGC stakeholder groups was established to advise on the evaluation design and implementation. A roster of PET members appears in Appendix A. The five members of the PET were drawn from the stakeholder groups that are directly affected by the program under review, or are involved in activities related to guideline development, dissemination, and implementation.

The PET for this project had three main roles: to provide feedback, as members of the user community, on the evaluation design; to assist the project team in reaching out to members of stakeholder groups who could serve as focus group participants or key informants; and to provide contextual validity to various components throughout the project.

B.   Evaluation Approach

A logic model based on the Context-Input-Process-Product (CIPP) evaluation framework was used to define the specific research questions that would guide the NGC evaluation. The CIPP model for evaluation is a comprehensive framework for guiding formative and summative evaluations of programs, projects, personnel, products, institutions, and/or systems.

The objectives, inputs, outputs, and outcomes identified in the model were informed by an extensive NGC project documentation review, annual customer satisfaction survey data, discussions with AHRQ, and an environmental scan of literature regarding the use and impact of NGC, across various NGC stakeholder groups. A visual representation of the logic model

developed for the NGC Evaluation is presented in Figure 2, below.

The logic model was used to generate a set of core research questions and outcome measures that could be used to evaluate the impact of the NGC relative to its stated objectives and goals. These are listed in Appendix B. The instruments derived from this model are presented in Appendix C: Survey Questionnaire, Appendix D: Focus Group Discussion Guide, and Appendix E: Key Informant Interview Discussion Guide.

Figure 2: Logic Model Framework
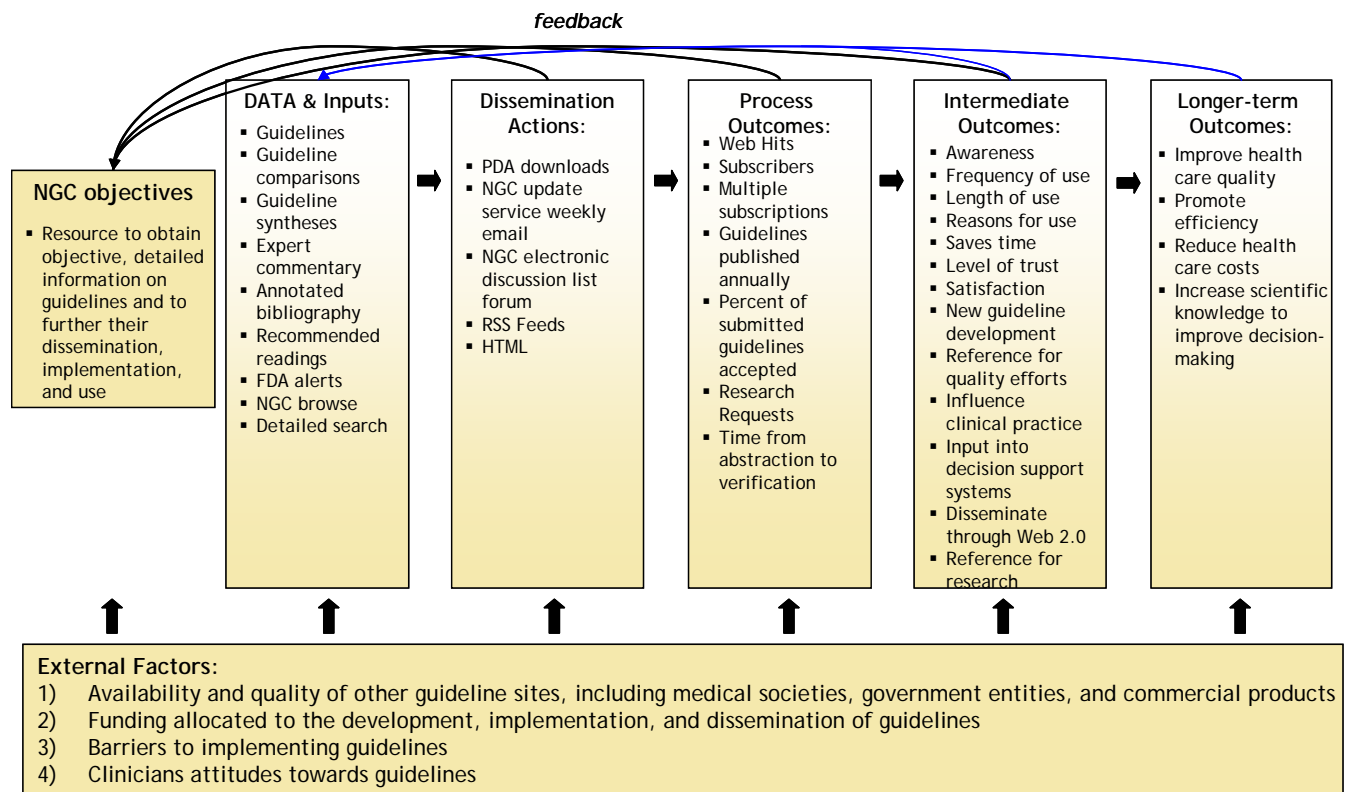
C.   Data Collection and Analyses

To achieve the objectives of this project and address the research questions identified through the CIPP framework, a mixed-methods data collection approach was employed that included:

- **NGC evaluation survey** – administered to a convenience sample of both users and non-users of NGC (see Appendix C for the survey instrument),
- **Focus groups** – conducted with guideline developers, medical librarians, and informatics specialists (see Appendix D for the focus group discussion guide), and
- **Key informant interviews** – conducted with influential individuals in medical societies, health plans, and quality improvement organizations, as well as medical librarians,

researchers, policymakers, informatics specialists, guideline developers, and others who use and disseminate guidelines (see Appendix E for the key informant discussion guide).

Questions in the survey, focus group, and key informant discussion guides focus on the effectiveness of NGC in areas of dissemination, implementation, and use of evidence-based clinical practice guidelines, and its attributes relative to other available guideline sources. For example, measures gathered through the instruments include the level of trust of NGC, the use of NGC relative to other guideline sources, and the influence of NGC on various stakeholder groups.

Instruments for the evaluation were submitted to the Office of Management and Budget (OMB) for clearance and approved on the first submission, on February 28, 2011.

1. Survey

Detailed methodology and the analytical approach of the NGC evaluation survey are described in a separate Survey Summary Report, which supplements this Final Evaluation report, as well as in the materials submitted for OMB clearance. Key points regarding the survey are noted below.

The purpose of the survey component of the overall NGC evaluation was two-fold:

- To obtain feedback from a relatively large number of individuals representing key stakeholders of the NGC initiative, regarding overall awareness of the National Guideline Clearinghouse; and
- For those individuals who described themselves as aware of NGC, to characterize their use of NGC, as well as NGC's influence on their work, organization initiatives, or guideline development efforts, and their suggestions for enhancements

The survey instrument was designed with skip logic and branching to allow questions to be appropriately targeted to subgroups of respondents. This is shown schematically in Figure 3. The survey began with questions to assess the awareness and use of NGC. Respondents who were aware of and unaware of NGC were asked some of the same questions to facilitate a demographic comparison between respondents representing both groups (NGC aware and unaware). Survey questions further segmented respondents based on whether or not they used the NGC Web site. Subsequent modules, containing the majority of the questions, were targeted only to NGC users. After answering a core set of common questions related to NGC use, the trustworthiness of NGC content, and the ability of NGC to fulfill users' needs, respondents were directed to stakeholder-specific modules to facilitate collection of data on stakeholder use and impact of NGC.

Figure 3: NGC Evaluation Survey Branching Framework

Awareness ┄┄┄➤ Section 1
Initiate Survey
NGC
AWARENESS
SCREENER

— Yes — / — No —

NGC Use ┄┄┄➤ Section 2A
(NGC AWARE)
NGC User
SCREENER

Section 2B
(NGC UNAWARE)
Respondent
Characteristics,
Guideline Use → END Survey

NGC vs. other sources
Trustworthiness
NGC inclusion criteria
Enhancements ┄┄┄➤

— Yes — / — No —

Section 3
(NGC USER)
Respondent
Characteristics,
Guideline Use,
NGC use

Section 2B
(NON NGC USER)
Respondent
Characteristics,
Guideline Use → END Survey

Impact/influence ┄┄┄➤

Section 4
Guideline Developer

Section 4
Physician, Nurse, Other Healthcare Professional

Section 4
Medical Librarian

Section 4
Informatics Specialist

Section 4
Researcher

Section 4
Health Plan, Policymaker, Other

Section 4
Measure Developer

END Survey | END Survey | END Survey | END Survey | END Survey | END Survey | END Survey

a)   Survey Methods

The survey instrument was created using SurveyMonkey, a Web-based tool that supports multi-faceted surveys, skip logic, survey branching, and a large number of potential respondents. The survey contained a total of 61 questions that could be asked of respondents. The questions included yes/no and Likert-scaled responses. Skip logic and conditional branching directed respondents to specific questions depending on how they answered earlier questions and/or depending on the stakeholder group they identified with.

As noted above, the survey was designed to target both non-users and users of NGC. This was done in order to better gauge the overall awareness of NGC among a broader range of health professionals who develop guidelines and use guidelines in their work.

Three sample frames were employed to reach different mixes of stakeholders and to include NGC users and non-users. The AHRQ-sponsored Gov Delivery e-mail accounts subscription base was the main sample frame. In addition, the survey link was sent to subscribers of the American Medical Association (AMA) e-mail services and the America's Health Insurance Plan (AHIP) e-mail list. The AMA and AHIP were chosen not only because their members are important stakeholder groups for the NGC, but these two organizations were also AHRQ's original partnering organizations in the development of NGC.

During the data collection period, potential respondents were contacted via e-mail, reminding them of the opportunity to participate in the evaluation, and the importance of their feedback regarding NGC. The reminder notice was sent via e-mail to the above described subscription lists and provided the hyperlink to access the survey.

Following data collection, survey responses were compiled and assessed formally for data quality to produce a finalized database for statistical analyses. Survey data were downloaded from the SurveyMonkey system into Microsoft Excel. As noted above, the survey asked 61 questions, a number of which were composed of multiple parts, resulting in 184 unique variables for quantitative analysis. In addition, survey responses were recoded and/or collapsed to create 28 new variables for ease of analysis (key variables created are described in detail in the associated Survey Summary report), resulting in a total of 218 variables. Survey data were analyzed using Stata 9.2 for Windows.

Before conducting the primary analyses, several data checks (including an assessment for multiple response bias, and item non-response bias) were performed. Data cleaning measures such as the exclusion of "test" observations, and creating new variables, were also conducted.

Using Stata 9.2, a series of quantitative analyses were performed, including:

- Descriptive analyses: Frequencies (counts) describing the range and distribution of the responses for each question

- Cross-tabs of key questions of interest (e.g., satisfaction with NGC) by respondent characteristics (e.g., stakeholder group). For the cross-tabs, we also calculated the chi-square statistic to test whether the distribution of responses varied by respondent attribute

Interested readers are directed to the Survey Summary Report for additional detail.

2. Focus Groups and Key Informant Interviews

Focus groups and key informant interviews were also conducted to obtain qualitative information that could be used to elaborate on the information gathered from the NGC evaluation survey, and to target specific stakeholder groups.

During the qualitative data collection process, a total of four focus groups and 26 key informant interviews were conducted.

The individual focus groups sessions were stakeholder-specific. There were two guideline developer focus group sessions, one for medical librarians, and one for informatics specialists. Focus group sessions were guided by a Focus Group Discussion Guide (See Appendix D). Key informant interviews were also stakeholder specific, and were used to obtain additional data from the various stakeholder groups targeted in this evaluation. A Key Informant Interview Discussion Guide (See Appendix E) was used to direct individual interviews. A list of the organizations and institutions represented in focus groups and key informant interviews is provided in Appendix F.

Both of the qualitative instruments contained a core set of questions to be asked of all participants across all focus groups and key informant interviews, along with stakeholder-specific questions that were presented to individuals who composed a given stakeholder group. For example, focus groups and interviews conducted with "guideline developers" included the core questions about NGC use, as well as an additional set of questions that pertained to NGC's influence and impact on guideline development, dissemination, and implementation efforts specific to this key stakeholder group.

Two large conferences attended by NGC stakeholders served as the forum for two of the focus groups that were conducted. One conference was the 2010 Guidelines-International-Network (G-I-N) conference, held in Chicago, IL. The other conference was the 2010 American Medical Informatics Association (AMIA) conference, held in Washington, D.C. The other two focus group sessions (one with guideline developers, and one with medical librarians based across the country) were conducted using a conference call/Webinar forum. All key informant interviews were conducted via telephone.

Focus group sessions and key informant interviews were recorded and transcribed to provide complete transcriptions from the sessions. Transcribed data were summarized in text matrices across groups where comparable questions were asked. From these raw data matrices, we identified emerging topics and themes. The qualitative findings supplement the quantitative

findings of the survey. Representative respondent quotes are synthesized into the survey findings in the Results section of this report.

Appendices F-J of this evaluation report provide stakeholder-specific summaries of the qualitative information obtained in this evaluation, by key stakeholder groups.

D.   Evaluation Limitations

As with any survey, the NGC evaluation survey had its limitations. The sample frame of subscribers to the AHRQ, AMA, and AHIP e-mail distribution lists had limitations. First, given that this sample frame was not a random sample of all NGC stakeholders (e.g., physicians, guideline developers), the findings presented here cannot be automatically generalized to the broader NGC stakeholder population. Related to this is the fact that the three e-mail distributions were used to communicate multiple pieces of information to the subscribers, including other surveys. Therefore, the NGC Evaluation survey may have been competing with other surveys that are distributed through the same mechanism. When there are multiple competing surveys, the individuals that respond tend to be those who are much more interested in the topic (e.g., NGC) than is the general population from which they were chosen. Third, although an exact nonresponse rate could not be calculated for reasons specified above, the response rate was low: ~9,400 respondents out of ~290,000 individual contacts (some individuals may have been contacted twice). There were a small number of responses along with a low response rate for AMA and AHIP, in particular. Finally, while we did test the survey skip logic and the general clarity, the survey instrument did not have any pretesting or cognitive testing. However, the survey was assessed by the PET for clarity and completeness. In addition, there was a low item non-response rate even towards the end of the survey, suggesting that the majority of the respondents completed the survey.

There are several limitations of the qualitative data collection approaches used in this evaluation include. First, the qualitative data are based on a significantly smaller number of individuals when compared with the quantitative data. Second, participation was not selected on a random basis. As a result, the feedback collected cannot be assumed to be representative of the opinions of your entire NGC user base.

III. General Findings

The results of the survey component of the evaluation are presented in the subsections that follow. These findings are supplemented with qualitative findings from the key informant interviews and focus group sessions, where appropriate, to offer additional context to the findings of the survey.

A. Characteristics of Survey Participants

Overall, there were 9,389 responses to the survey from April 20, 2011 to June 9, 2011. As shown in Table 1, the large majority of respondents received the survey via the AHRQ e-mail distribution (n=9,289). Only 42 responses were gathered through the AHIP e-mail distribution and 49 responses from the AMA e-mail distribution. The small number of responses from the AHIP and AMA distributions made it difficult to draw any conclusions from these populations in particular.

Table 1: Survey Referral Source

Source	Count
Total	9,389
AHRQ	9,298 (99%)
AHIP	42
AMA	49

Table 2, below, shows the number of survey respondents by the primary modules contained in the survey.

Table 2: Survey Counts by Module

Section/Module	Count
Total	9,389 (100%)
NGC Unaware	2,075 (22.1%)
NGC Aware	7,314 (77.9%)
Non NGC User	1,395 (19.3%)
NGC User	5,828 (80.7%)
Guideline developer	1,076 (18.5%)
Provider	3,271 (56.1%)
Medical librarian	204 (3.5%)
Informatician	292 (5.0%)
Researcher	1,219 (20.9%)
Policymaker	1,219 (20.9%)
Measure developer	351 (6.0%)

1. Occupation Characteristics

Survey respondents were asked to identify the occupational category that best described them. Table 3 presents the frequency distribution of survey responses to this question. Also shown, for comparison purposes, are the results of the most recent NGC Customer Satisfaction Survey (2008). This comparison was performed to allow for an assessment of similarity of the two samples. The data are also presented in Figure 4.

The most frequent respondents to the current evaluation survey were nurses or nurse practitioners (27%), followed by physicians (17%), other (13%), and quality managers (7%). As evidenced in the table below, physicians, nurses, and students were more heavily represented in the 2008 customer satisfaction survey, while the evaluation survey had more responses by researchers, policymakers, and quality managers. This is likely related to the different ways in which the two surveys were fielded, and demonstrates the overlapping but different populations reached by the surveys.

Table 3: Occupational Distribution of Survey Respondents

Occupation	NGC Evaluation Survey 2011 (% of respondents)	NGC Satisfaction Survey 2008 (% of respondents)
Physician	17.0	27.5
Physician assistant	0.5	1.9
Nurse/NP	26.7	30.6
Pharmacist	2.9	7.8
Dentist	0.2	0.5
Other clinician	3.3	3.1
Hospital/health plan admin	1.8	1.5
Healthcare consultant	3.0	1.9
Clinical researcher	4.7	2.4
Epidemiologist/biostatistician	1.5	*
Guideline developer	1.1	2.0
Measure developer	0.3	-
Employer/purchaser	0.6	0.4
Provider	2.7	*
Government policymaker	2.2	0.2
Legal professional	0.5	0.9
Informatics specialist	1.6	2.6
Medical librarian	2.0	*
Medical writer	0.9	1.0
Medical student	0.2	6.2
Nursing student	0.2	7.0
Pharmacy student	0.0	4.6
Other student	0.9	*
Patient/consumer	2.3	*

*Category not captured in the NGC Customer Satisfaction Survey
**The "Other" category in the current NGC evaluation survey captured self-descriptions from respondents who did not select one of the available options. A review of the self-described responses shows that these respondents included individuals who identified with more than one of the available occupational categories, or with occupations not included in the available options.

The latter included individuals who were retired, were educators, were non-government policymakers, were administrators and/or management, and a variety of other categories that were not reflected in the available options.

Figure 4: Occupational Distribution of Survey Respondents
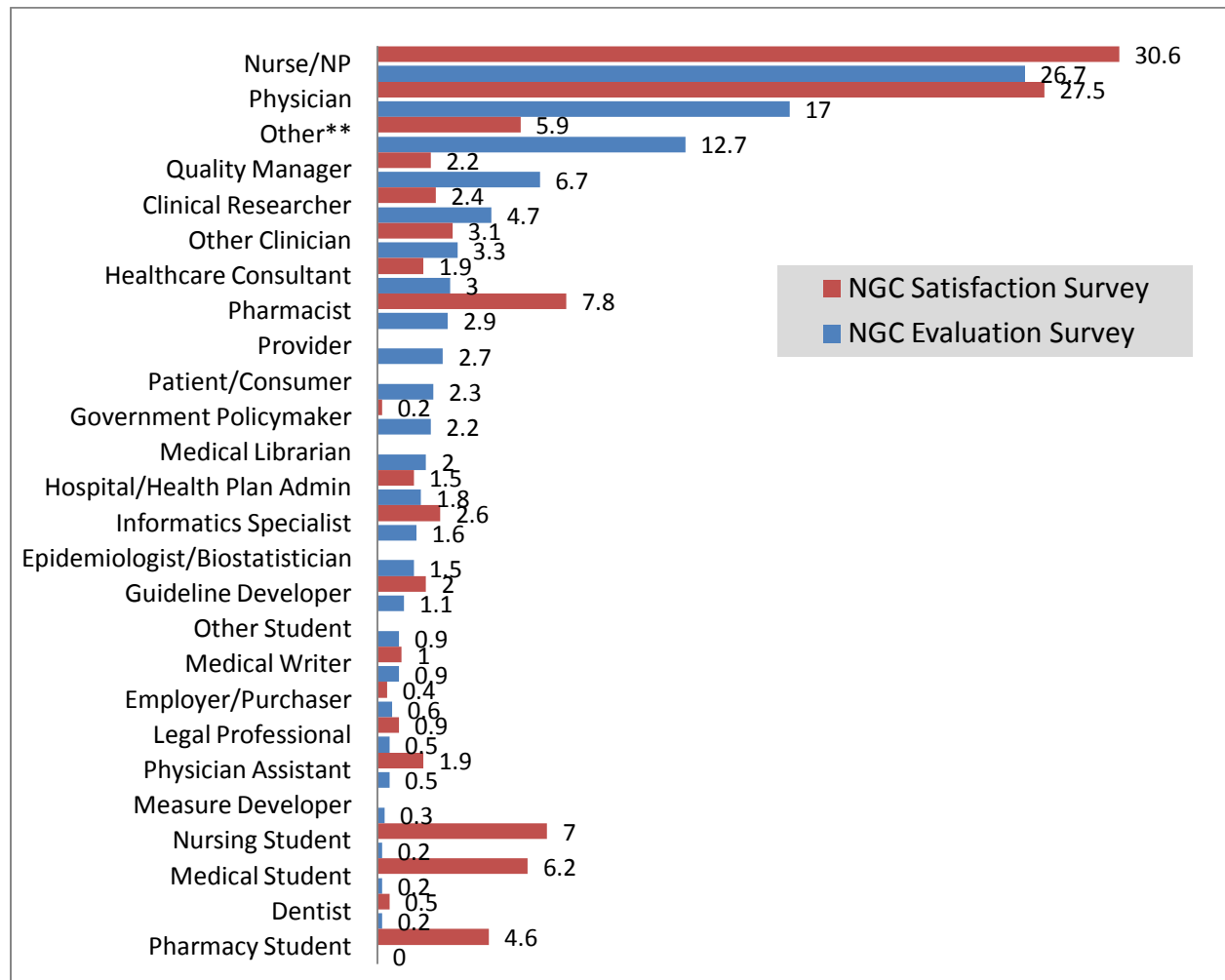
2. Geographical Distribution of Survey Respondents

As shown in Table 4, the large majority (87%) of respondents resided in the United States, with the greatest representation from the Southern region (28%) followed by the Midwest (21%) and Northeast (21%). The response rate for individuals from other countries was very low, topping out at 3.5% for Europe. Again, this finding suggests that the NGC evaluation survey had a somewhat different set of respondents when compared to the 2008 customer satisfaction survey. This is most likely related to the way in which the two surveys were fielded. While the 2008 customer satisfaction survey had a lower percentage of respondents residing in the United States (65%), within the U.S., the distribution across regions was similar for both surveys, as shown in Figure 5.

Table 4: Geographical Distribution of Survey Respondents

Residence	NGC Evaluation Survey 2011 (% of respondents)	NGC Satisfaction Survey 2008 (% of respondents)
United States	87	65
United States Northeast Region	21.4	16.0
United States Midwest Region	21.2	16.6
United States South Region	27.8	19.8
United States West Region	16.8	12.6
Canada	1.4	2.3
Latin America	2.1	6.5
Europe	3.5	11.2
Africa	0.3	1.0
Asia	1.7	9.5
Australia/New Zealand	0.6	1.3
Other	0.9	3.1
Missing	2.2	-

Figure 5: Geographical Distribution of Survey Respondents
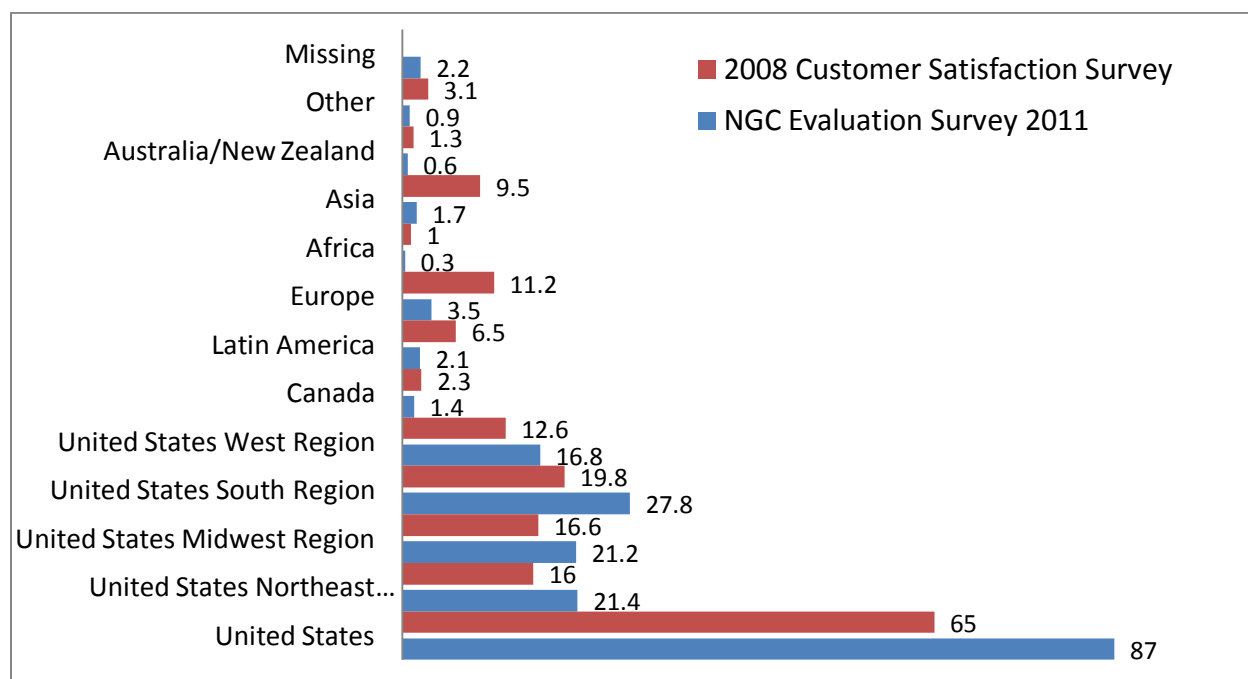
B.   Characteristics of Focus Group and Key Informant Participants

During the qualitative data collection process, a total of four focus groups *(with a total of 29 participants)*, and 26 key informant interviews were conducted. All individuals were aware of NGC and have used the site.

Focus group participants included:

- **Guideline developers** from a variety of national and international guideline developer organizations, *(n=13 in two focus group sessions)*
- **Informatics specialists** who were with medical centers, Federal government agencies, and academic institutions *(n=9 in one focus group session)*
- **Medical librarians** from health service libraries associated with academic institutions, medical centers, and hospitals *(n=7 in one focus group session)*

Key informant participants included:

- **Guideline developers** from a variety of guideline developer organizations *(n=12)*
- **Informatics specialists** who were with the Federal government, a medical center, private industry, and academic institutions; three of these individuals also provide comments about NGC from the perspective of their roles as clinicians; one also provided comments related to his role as an editor *(n=4)*
- **Policymakers/healthcare purchasers/health plans** who were with Federal and State government institutions and private industry, Federal government agencies, and academic institutions *(n=5)*
- **Researcher** at an academic institution *(n=1)*
- **Measure developers** who were with academic institutions and measure development organizations; two also provided input from researcher perspectives *(n=4)*

A list of the organizations and institutions represented in focus groups and key informant interviews is provided in Appendix K.

C.   Awareness and Use of the NGC Web site

One of the primary objectives of this evaluation was to determine the current awareness of the NGC Web site among relevant stakeholder groups. This key question was addressed with data from the survey respondents only. A requirement for participation in the focus groups and key informant interviews was that participants were aware of NGC. Thus, no qualitative data are summarized in this subsection.

1.   2001 Evaluation of the NGC Web Site

In 2001, two years after the public launch of the NGC Web site, AHRQ commissioned an independent contractor to conduct an evaluation of NGC. One of the key objectives of this early evaluation was to assess "awareness" and "use" of the Agency's relatively new guideline clearinghouse.

While the methods used to conduct this earlier evaluation were substantially different from those employed for the current evaluation, the results pertaining to NGC awareness and use bear discussion here. The single most important finding of the 2001 evaluation was that most of

the target audience surveyed (70%) was <u>unaware</u> of NGC. As reported in this study, awareness levels also varied greatly across the three provider types surveyed, ranging from a low of about 18% among physicians and 40% among hospitals, to a high of over 78% among health plan respondents.

The authors also noted that of those survey respondents who reported being aware of NGC, the great majority (89.5%) reported also using it, although to a limited degree (i.e., only 16% reported accessing the site more than a total of 10 times). Self-described NGC users in this evaluation were also found to be more likely than non-NGC users to access Internet sources for guideline information.

The authors of the 2001 evaluation note that although interpretation of their findings was limited by a small sample size, they suggest that when individuals become aware of the NGC Web site, that awareness translates into use. The authors suggested that, in addition to a general unawareness of the NGC Web site, resistance by some clinicians to use of the Internet to access clinical guidelines appears to be a barrier in preventing the uptake and use of NGC.

2. Current (2010-11) Evaluation of the NGC Web Site

Unlike the findings of the 2001 evaluation, most (77%) respondents to the current NGC evaluation survey were "aware" of NGC. Consistent with the 2001 evaluation, the large majority (81%) of those who report being aware of NGC also reported using it.

These results are presented in Table 5, below.

Table 5: Awareness and Use of NGC

NGC Awareness and Use	Frequency	Percent
Aware of NGC	7,223	76.9
Use NGC	*5,828*	*80.7*
Aware, do not use	*1,395*	*19.3*
Unaware of NGC	2,075	22.1
Missing	91	0.97
Total	9,389	100

An important note is that the vast majority of survey respondents were directed to the survey from the AHRQ e-mail list. As a result, these individuals are more likely to be more familiar with AHRQ products and programs, such as NGC. Consistent with this potential bias is that respondents who received the survey from the AMA distribution (a much smaller sample) were less likely to be aware of the NGC than those who received the survey via the AHRQ e-mail notice. NGC awareness among respondents from the AHIP e-mail notice (also a small sample) was actually higher than that observed among the AHRQ sample. The relatively small number of responses obtained from the AHIP (n=42) and AMA (n=49) distributions makes it difficult to draw any strong conclusions about awareness and use of NGC from these sample sources.

Awareness among the three survey sampling frames is shown in Figure 6.

Figure 6: Percentage of Respondents who are Aware of NGC by Survey Source
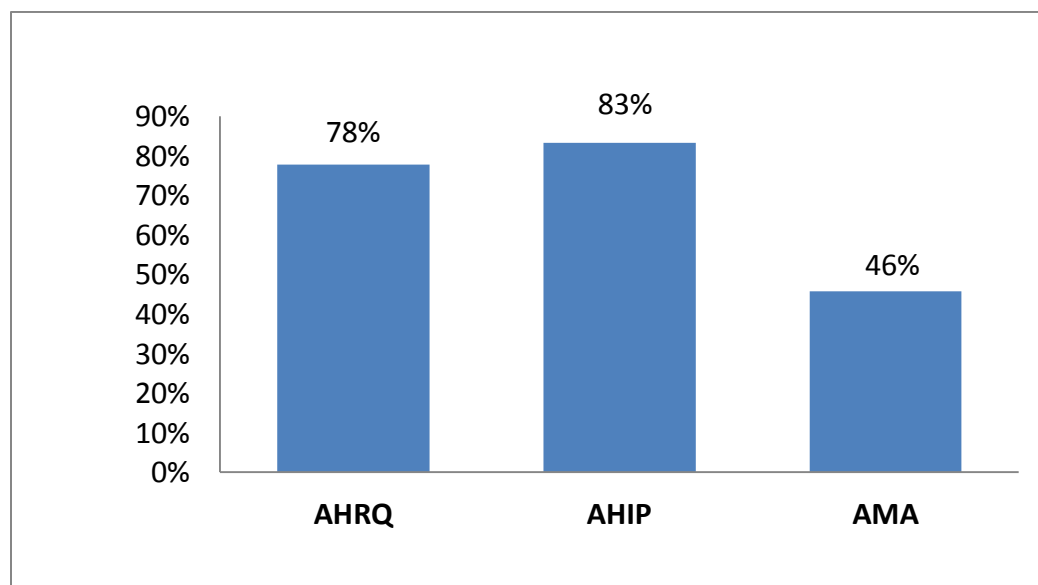
NGC use among those aware of the resource was high. As shown in Table 5 above, 81% of survey respondents who reported being aware of the resource also reported using it. Use was also relatively high among the three sampling frames for those reporting that they are aware of NGC: AHRQ (81%), AHIP (83%), and AMA (73%). This is consistent with the finding in the 2001 evaluation, and consistent with the notion that as members of NGC's target audience become aware of NGC, they are also likely to use the resource.

> ☼ **AHRQ Opportunity**: The findings of this evaluation suggest that there is an opportunity to increase the awareness of NGC, particularly among physicians. This might be accomplished through additional marketing and outreach, or by partnering with medical colleges to incorporate NGC training into medical curricula.

D.   Use of Other Guideline Sources

Data to support an assessment of the "use of other guideline sources" come from the quantitative findings of the NGC evaluation survey, as well as qualitative findings of the focus group sessions and key informant interviews. Survey findings are presented in the next subsection. Qualitative findings, which provide additional context to the survey findings, follow. This pattern will follow where appropriate throughout the remainder of the report.

1. Survey Findings

The NGC evaluation survey asked all respondents to identify the specific sources they used for accessing clinical practice guidelines. For NGC users, the sources were identified as sources other than, or in addition to, NGC. Seventeen different possible sources (one being "other") were

listed, from which the respondent could select "all that apply". As shown in Figure 7, the most popular source for clinical guidelines was PubMed/Medline (54%).

Figure 7: Percentage of Respondents that Have Used the Source to Obtain Clinical Guidelines
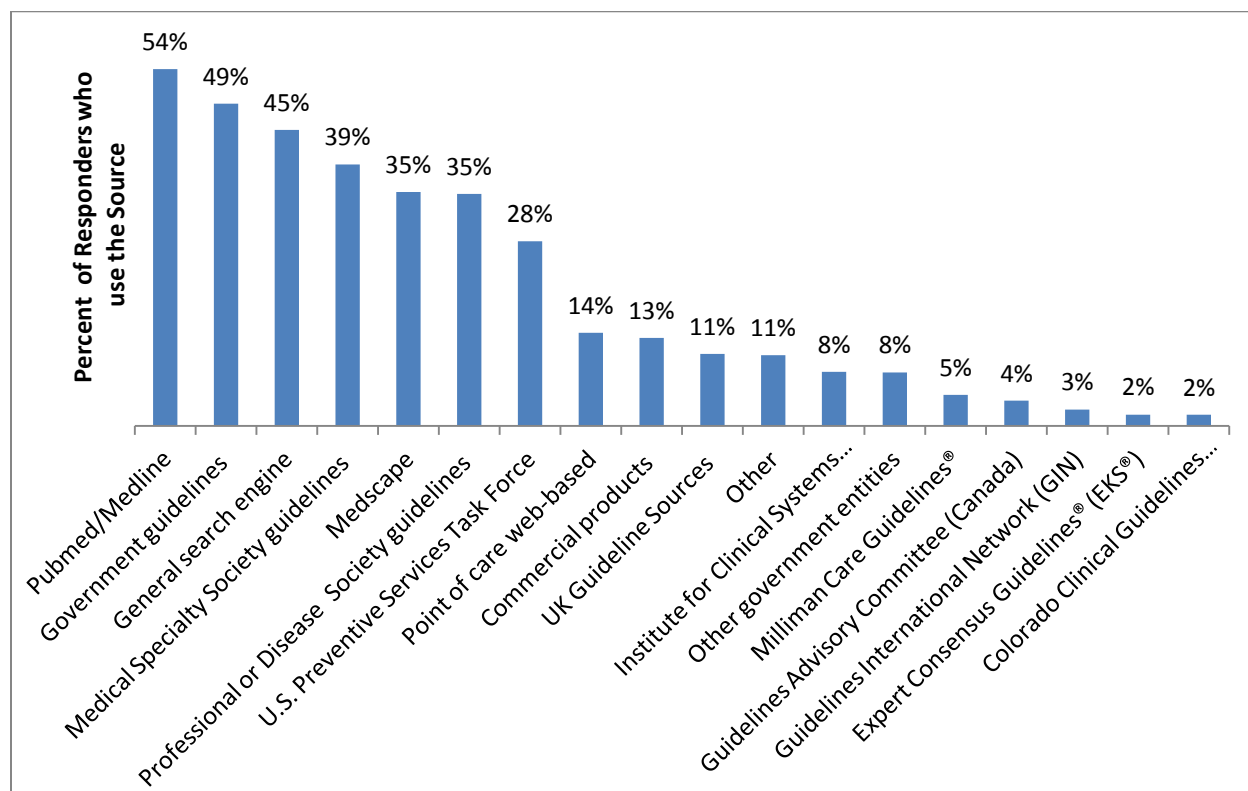
The large majority of respondents (63%) report using more than one source (see Table 6). Forty-two percent of respondents used three to five guideline sources, while only 13% did not use any guideline sources. Over 21% used six or more guideline sources to identify clinical guidelines.

Table 6: Number of Sources Used

Count of Other Sources	Frequency	Percent
0	1,246	13.27
1 to 2	2,187	23.29
3 to 5	3,964	42.22
6 +	1,992	21.22
Total	9,389	100

When we stratified by NGC user (unaware; aware do not use; NGC user), the data showed that NGC use was complementary to the use of other guideline sources (see Figure 8). Respondents who used NGC also tended to use additional sources of guidelines more frequently than those who did not use NGC. Nearly 30% of NGC users used six or more other sources in addition to the NGC (29.6%), while only 6% of those unaware of the NGC, and 10% of non-users who are aware of the NGC used more than six other, non-NGC, sources for guidelines. Also, those that

were unaware of NGC and non-users that were aware were much more likely to not use any sources (29.2% and 19.93%, respectively) than NCG users (4.65%). These figures suggest that NGC users tend to consult more sources than non-users.

Figure 8: Number of non-NGC Guideline Sources Used, by Respondents' Use and Awareness of NGC
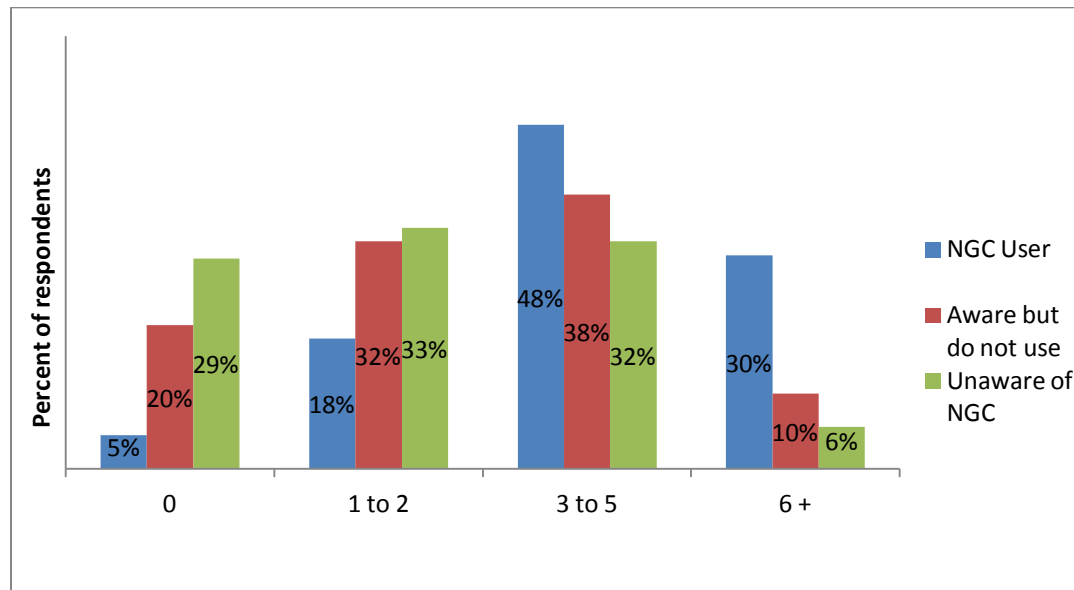
2. Qualitative Findings

In both the focus group setting and the key informant interviews, participants were asked about other sources of guidelines that they use. Many of the interviewees and focus group participants cited numerous other sources that they use when they have a need for guidelines. Responses included some of the following resources:

- PubMed
- Medical societies, guideline publishing organizations, and/or guideline developer Web sites directly
- U.S. Preventive Task Force
- CDC community guide
- NIH consensus statements
- International Databases (e.g., NICE, New Zealand group, Australian group, Scottish group)
- Cochrane Review
- GIN library
- ACP PIER
- DyneMed

- MD Consult

A common statement from respondents about their use of other resources was that even though they use other sources, they usually go to NGC first. They are generally pleased with the breadth and comprehensiveness of the information in the NGC database.

Many of the various stakeholders generally noted that most of them use it as the first go-to resource to find clinical practice guidelines. Guideline developers use it when they are considering developing a guideline to see if there are other guidelines available on a topic of interest. Some use NGC specifically to look for guidelines that contain reviews of evidence to support their own guideline development. Others look to make sure that there is no duplication of effort, or to identify potential collaborations. Other stakeholders also report use of it as a first stop, simply to find out if there is a guideline on a specific topic.

Excerpts from individual interviews and/or focus groups about NGC use relative to other guideline sources are listed below.

- *"I would consider National Guidelines as the gold standard outside of the specific organizations that are developing the guidelines in the first place."*

- *"NGC is first go-to source, but it's only one of many sources that we go to. We have good confidence and want to always use NGC. But we want to be comprehensive, so sometimes we need to expand into other ways to make sure that we're trying to cover everything we can."*

- *"NGC has a larger [selection]. When I go to SIGN it's just looking at SIGN, so if I want more of a variety, I'll go to NGC."*

- *"NGC is very comprehensive, user-friendly. It compares well, probably a little bit better than PubMed, because PubMed's more focusing on the citations, whereas NGC, you can locate the guideline by issue, by association, by author."*

- *"The NGC is just listing the abstracts or you have a lot of criteria. You're [NGC] not the end source of these guidelines. You're a resource that can guide me to whether I want to look further at the sources – whoever's produced the guidelines – and I think it's important for me and others I work with to remember that. So we have to go to the association or society or whatever organization it was that actually produced them if we want to cite it or if we want to use it or converse with the authors or whatever. If I go straight to another company or organization, I just get their guidelines straight from them, the full thing. But you [NGC] have a more representative – a broader array of topics than I'm often going to find with some of the other companies."*

- *"It depends. It's hard when you're actually going to, for example, the American Diabetes Association, their paper might be 2- or 300 pages long, trying to pull out the information that we're really looking for, you may have to really dig. Whereas, using the NGC template, they probably have those things listed right there. They're the important things in their template. The NGC saves us time as long as it's been updated on their Web site."*

- *"We're aware of many of the different sources you can use. But the benefit of the AHRQ resource is that it kind of spans across the entire breadth of guidelines that are developed. ...NGC is one of the first sources though..."*

- *"It's just sort of a first place to go when you're not sure if there's something in existence."*

E.   Satisfaction with NGC Compared to other Guideline Sources

1. Survey Findings

When asked to rate their satisfaction with NGC compared to the other guideline resources respondents used, NGC users were generally at least equally satisfied with NGC compared to other guideline sources, or more satisfied. As shown in Figure 9, about a third (33.7%) of users rated NGC as about equal to other sources, while a near majority (42%) was either "slightly" or "much more satisfied" with NGC. Few respondents reported being slightly less satisfied (10%) or much less satisfied with NGC (3.4%).

Figure 9: Satisfaction with NGC Compared to Other Guideline Sources

	Much less satisfied	Slightly less satisfied	About equal	Slightly more satisfied	Much more satisfied	No Response
Percent	3.40%	10.00%	33.70%	22.70%	19.50%	10.70%
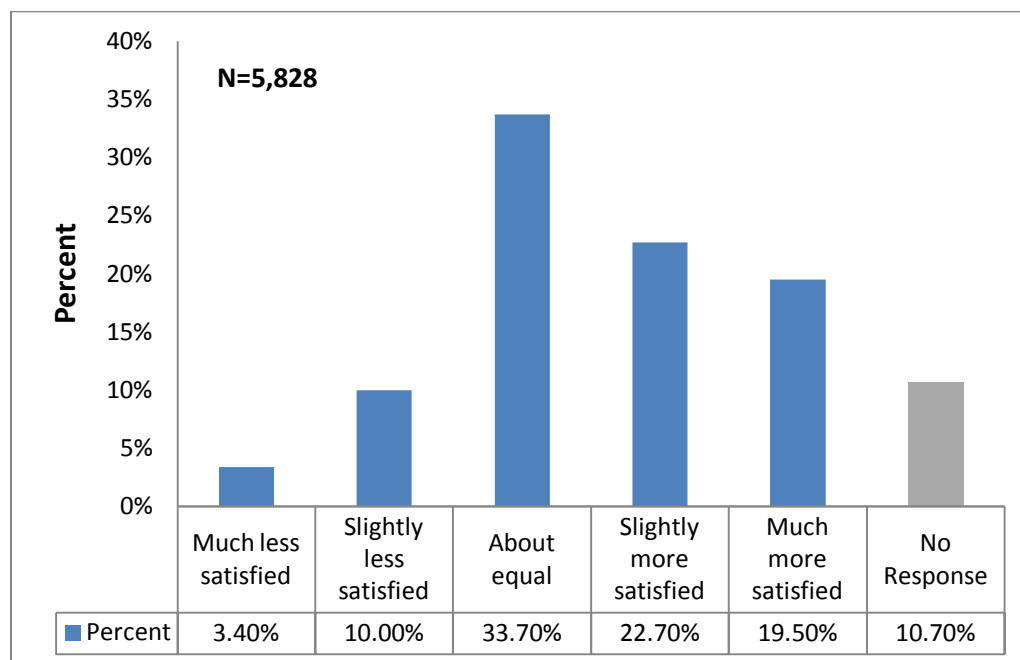
When responses to this question were cross-tabulated with "length of use of the NGC Web site" users' satisfaction with the NGC compared to other guideline sources was found to be positively correlated with length of NGC use. Not surprisingly, users who had been using the NGC for the longest time rated the site most highly compared to other guideline sources. See Figure 10, below.

Figure 10: Satisfaction with NGC Compared to Other Guideline Sources by Length of NGC Use
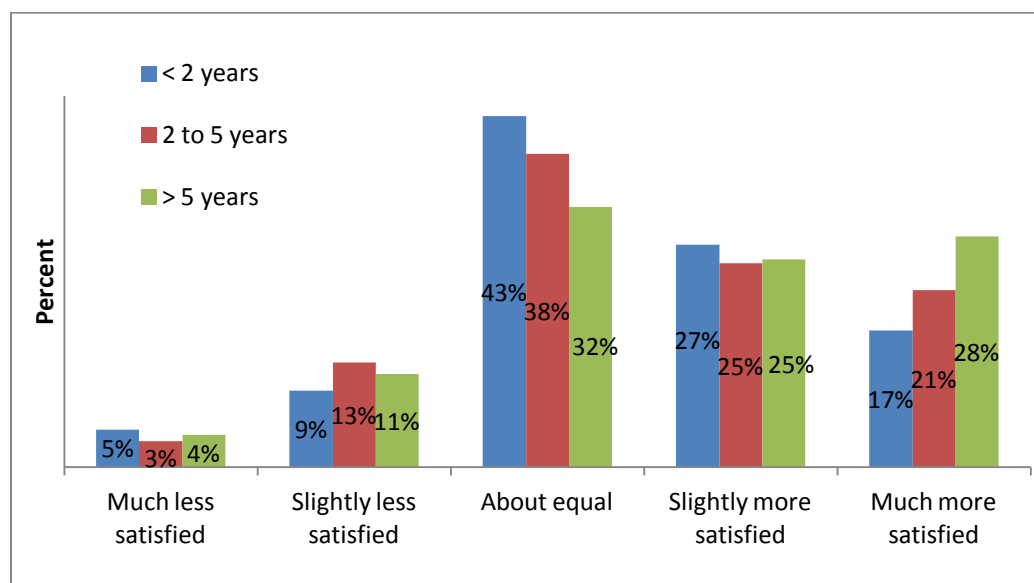
2. Qualitative Findings

Data collected from key informant interviews and focus group sessions adds context to the above findings. For instance, participants in qualitative assessments report that the NGC interface is easy to use. NGC offers an effective aggregation tool for finding guidelines with a guideline grouping system. It also has an effective comparison tool. Participants also highlighted the fact that NGC is a free resource. This enables many different audiences to access the guidelines and tools without subscriptions. The respondents indicated this was important for teaching, as students and faculty can always access NGC.

Excerpts from key informant interviews and/or focus group sessions regarding relative satisfaction are noted below:

- *"I like that NGC sort of aggregates all of these [guidelines], and the new change in the interface has made it so much easier for me to use and for the people I work with to use. I like the comparison feature because that saves me a lot of time."*

- *"Well, in my opinion, it's a nice comprehensive resource. There are a few good features that we tend to highlight to people, in terms of browsing the guideline syntheses, the ability to browse by an organization, in terms of accessing our guidelines quickly and easily. And, honestly, the bottom line, from an educational standpoint, particularly with our undergrads, our meta and undergrads and our residents and fellows, is the fact that it's free."*

- *"I find that, especially the new interface for the NGC is much easier to use in my experience than the NICE guideline site where I just feel like I'm going down one gopher hole after another and I'm not entirely sure that I've gotten everything that I need to…I like the guideline comparison feature, personally, because of the structured abstracts. It's a lot easier to see and compare*

across multiple guidelines on one screen."

- *"Compared to a lot of the other sources we're looking at are sort of like, say the Web site of an organization that produces systematic reviews or technology assessment reports, and they're sort of limited, and it might be harder to search and it's more browsing than searching and it's only content from one provider. So, compared to those things, having a guideline clearinghouse and interface, you know, I think it's one of the better ones and easier ones to search compared to some of these other things."*

Some focus group participants and key informants also discussed features of other guideline resources that made them more appealing relative to NGC. Some reported that "other resources" have more current or recently published guidelines. This was especially true of PubMed and medical society Web sites, which respondents report have the most current information about clinical practice guidelines. Respondents also indicated that other available resources [e.g. commercial products like DyneMed] are in some cases easier to use in terms of browsing by topic or specifying search terms. It was noted that some other sources of guidelines have a better organization or that it is easier to examine the evidence ratings than when using NGC.

Excerpts from the key informant interviews and/or focus group sessions relating to appealing aspects of other guideline resources are below:

- *"ACP PIER and DyneMed... have things like the evidence rating system..."*
- *"Our clinicians, our med students, they all like DyneMed a lot because of the interface, global interface, to the point where they'll use that more than other resources that may be potentially as good, simply because it's easy for them to access."*
- *"I will say that many of these resources are much more user-friendly. You know, the evidence ratings or grading is consistent across resources, whereas it may not be, depending on the guidelines that you are looking at in NGC."*
- *"So many of our clinicians tend to like some of these other resources. They are a bit easier to use on a hand-held, which is, I think, for guideline-type use, that's really important – to have access."*
- *"It's easier for me to find something that is more current by going to PubMed because I can tell it the date that I'm interested in, and I'm just more familiar with the interface of PubMed."*
- *"The decision factor for me on whether I'm going to search for guidelines in NGC is how current I'm being told the guideline is. If I'm told that it has come out in the last three to five months, I tend <u>not</u> to go to guidelines.gov first because my experience is there's a lag time before those new guidelines show up in NGC. And, I've never been sure why... I suspect it's because of the kind of review and editorial process that goes on, which is very valuable, but I wish that were faster."*

> ☼ **AHRQ Opportunity:** Major enhancements to the site may increase the use of and relative
> satisfaction with NGC compared to other resources. These include providing more timely access
> to new and updated guidelines included in the database; providing information about the quality of
> the guidelines included in NGC using a uniform system; and enhancing the presentation of content
> for clinicians and other healthcare providers who are interested in using the resource at the point of
> care.

F.   NGC Trustworthiness and Appropriateness of the NGC Inclusion Criteria

More than 10 years following the development of the NGC Web site, guideline development
approaches and user expectations regarding transparency and rigor have evolved. In addition to
the users' overall assessment of NGC and uses of NGC, this evaluation attempted to obtain
information about the trustworthiness of existing content available through the site, and about the
appropriateness of specific qualifications that guidelines must meet in order to be posted and
disseminated via the NGC Web site. The evaluation further attempted to gather views from key
stakeholders on AHRQ's role in striking a balance between serving as a central repository for all
clinical practice guidelines and including only those guidelines that meet high standards for
methodological rigor, credibility, and trustworthiness.

1. Survey Findings

The first question asked survey respondents to assess the trustworthiness of the guidelines
included in the repository. Options ranged from "very good" to "very poor," and included a
"don't know" option.

The second set of questions pertained to NGC's inclusion criteria. Survey respondents were
asked to rate the appropriateness of NGC's inclusion criteria, with the options available being:
stringent, appropriate, or loose. A related question asked survey respondents to rate the
appropriateness of NGC's five-year guideline age criterion, which states that a guideline must
have been developed, revised, or reviewed within the past five years in order to be included.
Options for this question included:

- Too long (should be reduced to 4 years)
- Too long (should be reduced to 3 years)
- Too long (should be reduced to 2 years)
- Appropriate
- Too short (should be lengthened)

Trustworthiness of Guidelines Included in NGC: NGC users were asked:

 "How would you rate the trustworthiness of the guidelines included in NGC?"

As shown in Figure 11, the large majority of users found the guidelines on the NGC Web site
trustworthy. When NGC users were asked "*How would you rate the trustworthiness of the*

guidelines included in NGC?" three-quarters of the respondents rated the guidelines'
trustworthiness as "very good" or "good," with only 1.25% rating it as "poor" or "very poor ."

Figure 11: Trustworthiness of Guidelines Included in NGC

Percent	Very poor	Poor	Acceptable	Good	Very good	Don't know	No Response
Percent	0.30%	0.90%	9.60%	16.00%	59.10%	3.30%	10.80%
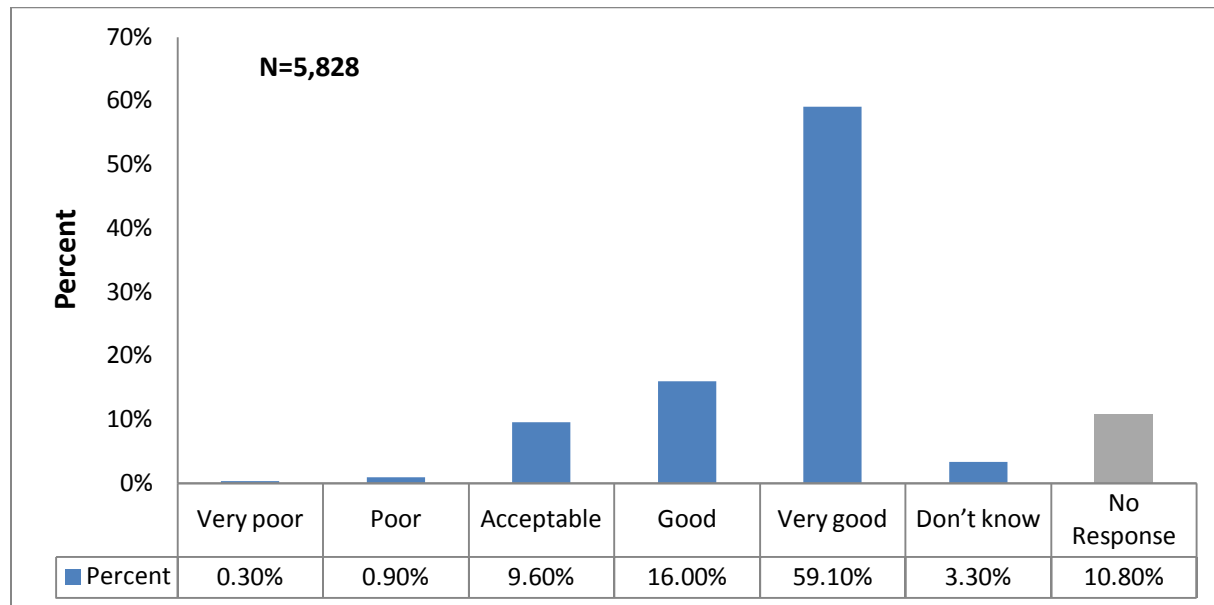
Ratings for trustworthiness were also cross-tabulated by the key stakeholder groups targeted in
the evaluation to determine if there were differences in opinion by different groups. The
distribution was fairly uniform throughout the categories, without noticeable outliers.

Related to trustworthiness, when respondents were asked how likely they were to recommend the
NGC Web site to colleagues, over 80% said either "*definitely"* (42.3%), "*very likely"* (26.2%),
or "probably" (12.4%). Six percent responded "possibly," with less than 2% saying "probably
not" or "definitely not" (0.2%). Less than 1% said they didn't know and about 10% did not
answer this question.

Appropriateness of NGC Inclusion Criteria: NGC users were asked:

 "*How would you rate NGC's guideline inclusion criteria?"*

Over 60% (62.6%) of survey respondents stated that NGC's guideline inclusion criteria were
"appropriate." Approximately 8% (7.7%) said they were too stringent and even fewer (3.8%)
said they were too loose. Note, however, that about a quarter of respondents did not know
(14.8%) or skipped this question (11.1%). This is shown in Figure 12, below.

Figure 12: Assessment of the Appropriateness of NGC's Inclusion Criteria

	Stringent	Appropriate	Loose	Don't know	No response
Percent	7.7%	62.6%	3.8%	14.8%	11.1%

N=5,828
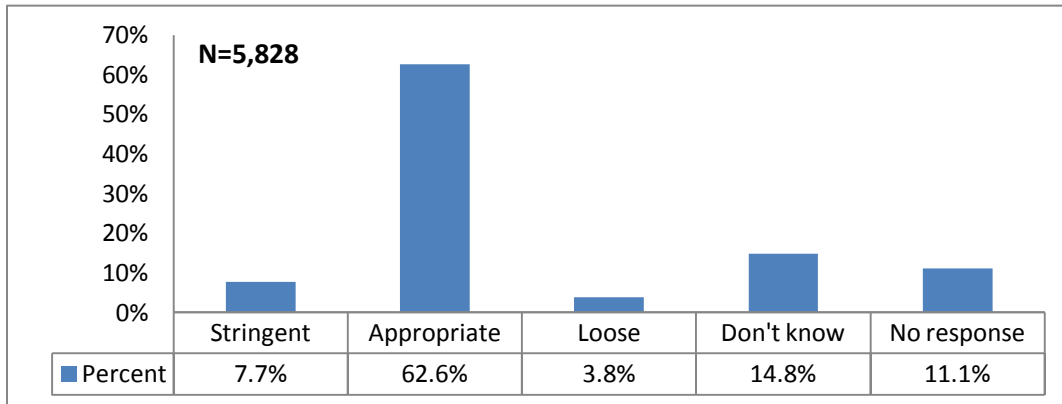
When responses to this question were cross-tabulated by the users' "length of time using the NGC Web site," users who had been using the NGC for five years or longer were more likely to say that the inclusion criteria were "loose" (7%) compared with those who had used the site for two to five years (4%), or less than two years (2%). As expected, those who had used the site for less than two years were more likely to say "don't know" (20%). These findings are presented in Figure 13, below.

Figure 13: Rating of NGC Inclusion Criteria Appropriateness by Length of NGC Use

Legend: < 2 years, 2 to 5 years, > 5 years

	Stringent	Appropriate	Loose	Don't Know
< 2 years	8%	69%	2%	20%
2 to 5 years	8%	72%	4%	15%
> 5 years	10%	69%	7%	15%

Y-axis: Percent of Respondents
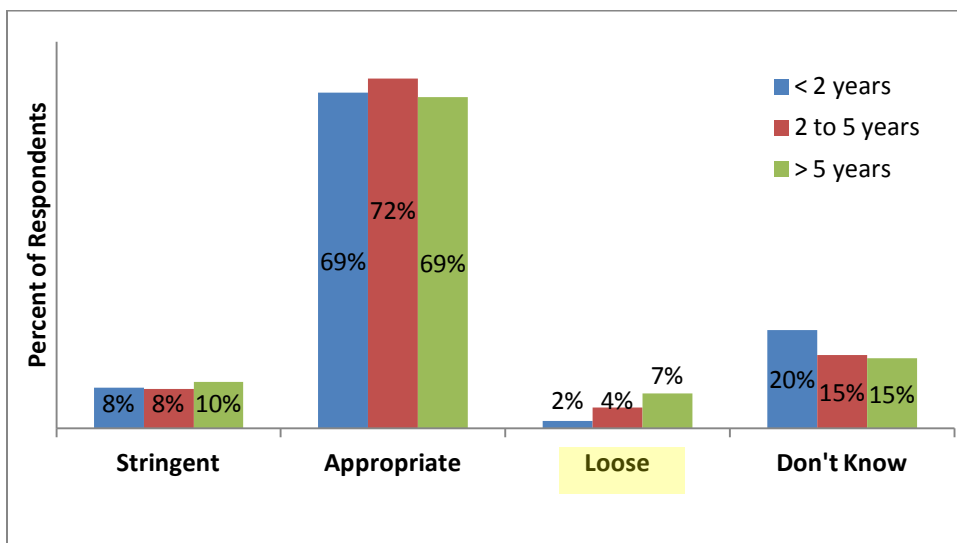
An interesting finding emerged when responses to the appropriateness of the NGC inclusion criteria were cross-tabulated by users' satisfaction with NGC relative to other guideline sources. The data show that respondents who are less satisfied with NGC than with other guideline sources are more likely to say that NGC inclusion criteria are loose (13.2% compared to 3.2% and 2.3%). It may be that their dissatisfaction with NGC relates to their belief that the inclusion

criteria are too loose.

The data were cross-tabulated by the key stakeholder groups targeted in the evaluation to see if there were differences by key stakeholder group. As with the trustworthiness cross-tabulation, the distribution of responses was fairly uniform throughout the categories, with the exception that guideline developers were slightly more likely to say that the inclusion criteria are too loose, and medical librarians were more likely to say they didn't know. This is shown in Figure 14, below.

Figure 14: Appropriateness of NGC Inclusion Criteria by Stakeholder Group
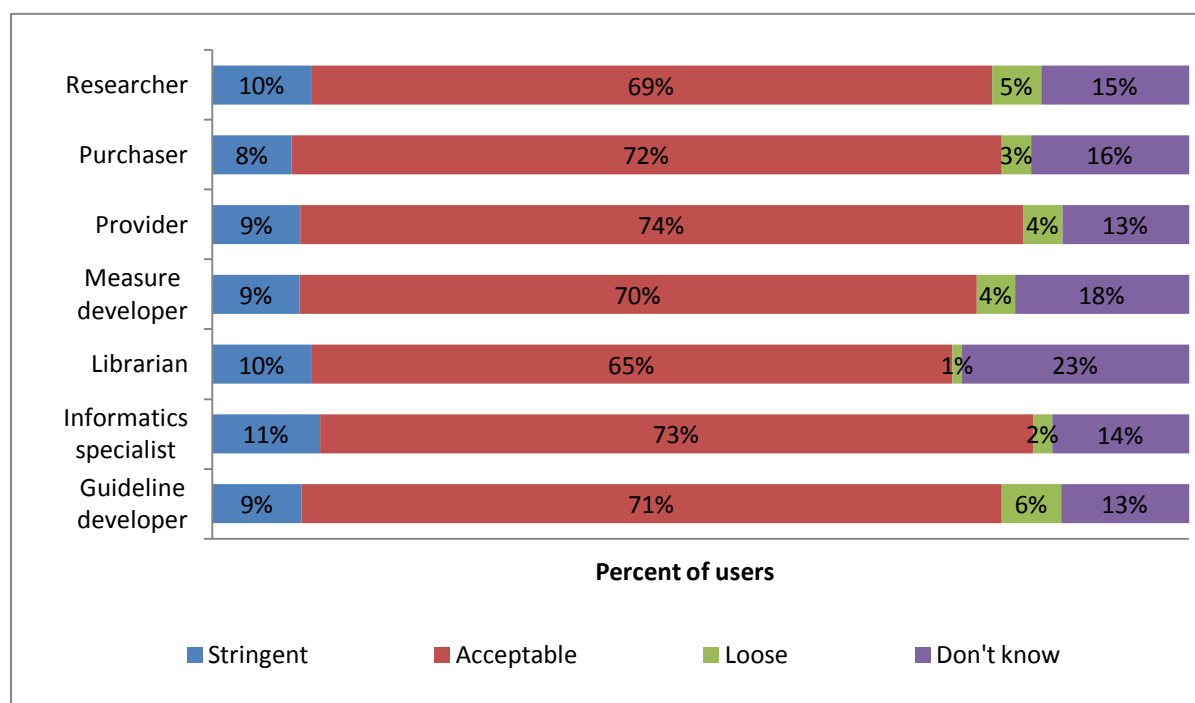
NGC's Age Criterion: NGC users were asked:

 "NGC's current inclusion criteria require that guidelines included on the Web site have been reviewed, revised, or developed within the last five years. How would you rate this timeframe?"

Compared to responses regarding stringency of NGC's inclusion criteria, survey respondents were less satisfied with NGC's age criterion. Currently, to be posted on the NGC Web site, a guideline must have been developed, reviewed, or revised within the past five years. Guidelines that do not meet this requirement are either rejected for inclusion or are placed in the NGC Guideline Archive when they become more than five years old. In looking at the responses of survey respondents, a bimodal distribution in responses emerges. Approximately 43% of users said that the five-year age requirement is "appropriate," but it fell short of a majority. Nearly as many respondents (39%) said that five years is too long. Of these individuals, 54% stated that it

should be reduced to three years, and 38% stated it should be reduced to two years. A very small percentage (1.6%) said that five years is too short. These results are presented in Figure 15, below.

Figure 15: Rating of NGC's Guideline Age Requirement
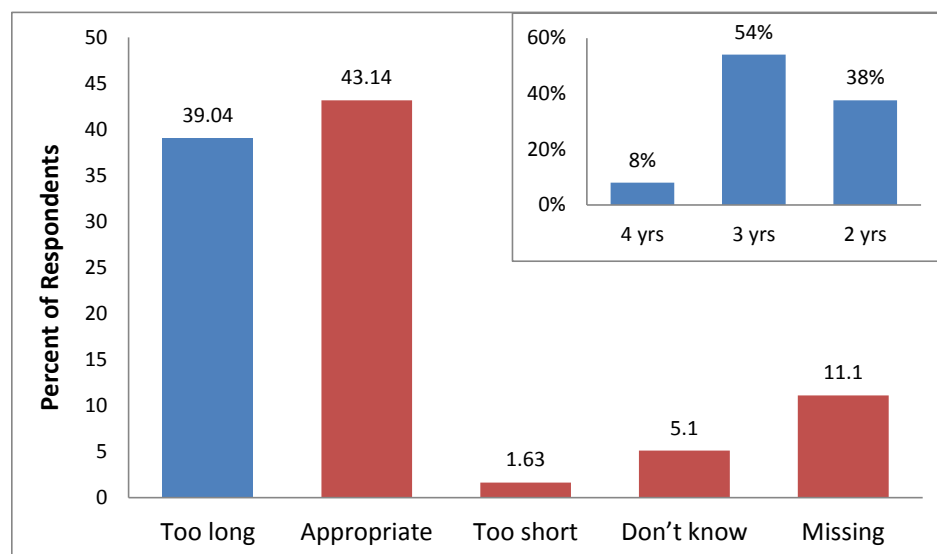
The data regarding the guideline age criterion were cross-tabulated by the key stakeholder groups targeted in the evaluation to see if there were differences by key stakeholder group. As with trustworthiness and the appropriateness of the inclusion criteria, the distribution of responses was fairly uniform throughout the categories, with nearly equal numbers in each group saying that five years is appropriate or that it is too long. The one exception is that medical librarians are a little more likely to choose "appropriate" (53.2%) and a little less likely to select "too long" (37.4%), relative to the other stakeholder groups.

2. Qualitative Findings

Data collected from key informant interviews and focus group sessions adds context to the above findings regarding trustworthiness, appropriateness of the NGC inclusion criteria, and the guideline age criterion. Some key differences were observed in both the focus group sessions and the key informant interviews, the most notable of which were that there were more obvious differences in opinions regarding trustworthiness and the appropriateness of NGC's inclusion criteria across the different stakeholder groups. For instance, guideline developers and informaticians were much more likely to say that NGC's inclusion criteria are too loose, when compared with the other key stakeholder groups. Similarly, guideline developers and informaticians were less trusting of some of the guidelines included in NGC.

Excerpts from key informant interviews and/or focus group sessions regarding relative trustworthiness of guidelines included in NGC are noted below by the key stakeholder groups:

Guideline Developers/Informaticians

- *"I trust that what's there is what was in the guideline. Whether I trust the recommendations – that would go beyond what the NGC provides in terms of information, at least for our purposes. So, I do believe that it's probably accurate, but our group has to do stuff with what we find from the NGC to then start making decisions with whether we will use what we have found or not."*

- *I believe they're abstracted correctly, but as far as quality, I'm not sure. I've seen some guidelines that we've found where I think the abstract prepared by NGC is larger than the actual guideline. It turns out to be some two-page document that was done by some very small group that really isn't even a guideline. Yet, it appears on NGC with a big five-page PDF file making it look really official, but when you get it, it's like: Oh my gosh, how did this end up on there at all."*

- *"It's only going to be as trustworthy as the source is..."*

Medical Librarians, Measure Developers, Policymakers/Purchasers, and Researchers

- *"When there's a large government perhaps even remotely affiliated with it, like the U.S. government, I feel more comfortable with it...it's a publicly available source.... And then I think finally the fact that where these things come from, and a variety of other attributes of these things are very clearly identified. That's really important to me."*

- *"Very much"* – in response to a question about whether they trust the information available in NGC.

- *"YES – I would say [they are trustworthy] because it points to where the information is coming from and it's cited, and we know that it is pretty current and it tells when it was last updated."*

- *"One of the things that we always talk about when we're instructing on EBM (evidence-based medicine) and use of EBM, particularly in a clinical setting, is the importance of doing some of your own evaluation. And so, while a lot of guidelines, being secondary literature sources, do a lot of evaluation for us, we are always looking at the different organizations that are producing them and having a good understanding of the criteria for how they are included in NGC. So, I think we as librarians stay on top of that and, for that reason, we can tell our clinicians that don't necessarily have the time to devote to some of that that they can trust the information that is provided in NGC."*

- *"They seem to be authoritative, and you can tell who said what when."*

- *"Well, I'll preface this by saying we don't ever make any clinical decisions based on what we find in here, so our level of trust doesn't have to be that high. We use it for different purposes. We aren't even passing on information to anybody who's going to be affecting clinical care for it. But, of course we trust it because it's from the Agency for Healthcare Quality and Research."*

- *"We had processes that allowed us to evaluate evidence, and we had processes that allowed us to*

actually evaluate the evidence that had gone into policy... And the stuff when it came through or was associated with NGC when I was getting my briefings, there was not concerns raised about the quality or the utility or relevance of the evidence."

- *"I would say we would trust it."*

- *"Because it's something that's sponsored by the U.S. government, or, you know, like in the case of NICE, you know, NICE guidelines are developed out of the UK, but because of the fact that it's associated with the U.S. Federal government you have – that, by itself gives you some comfort, I guess, that the material that you're gathering from it is credible."*

- *"I would say that I trust it, but I would say that I would rarely make a decision based only – I would probably go to the original source, as opposed to trying to make a decision on the basis of the information that's purely on the NGC Web site. But that may be because I am doing things more for research purposes."*

The same pattern of results is also seen in responses to the question about the appropriateness of the guidelines included in NGC.

Excerpts from key informant interviews and/or focus group sessions regarding the appropriateness of guidelines included in NGC are noted below by the key stakeholder groups:

Guideline Developer /Informaticians

- *"...the quality of the criteria was good when NGC started out but it has gotten more complicated..."*

- *"...If the goal is to be 'all inclusive,' then the criteria are fine. [But]....there needs to be some other ways to separate the wheat from the chaff."*

- *"They could raise the bar."*

- *"I agree. I think that it could raise the bar..."*

- *"I'd say too loose.... I think there's a belief that: A) NGC creates these guidelines...and then, B) there's also a belief that NGC somehow has a very rigorous process for only allowing certain guidelines in, or certain types of very high quality guidelines, or that it's an endorsement of these guidelines. And it isn't."*

- *"Too loose. As long as we call ourselves an organization and fill out the right forms, we can be a guideline on NGC.... I think NGC still basically takes all comers and doesn't really pay attention to the quality."*

- *"NGC could be more rigorous in identifying preferred guidelines, or even best guidelines. Or do the first pass at the knowledge abstraction – identify those key concepts or highly agreed upon fundamental core concept statements from across guidelines."*

Medical Librarians, Measure Developers, Policymakers/Purchasers, and Researchers

- *"I think the inclusion criteria are appropriate."*

- *"I would actually think it sounds about right, except for the five years…"*

- *"I thought they looked appropriate, and I would just say that they need continued, to be relooked at on an ongoing basis, because our view of what constitutes evidence-based medicine will change over time. And so, right now, I mean, I think they're reasonable criteria."*

- *"I think that that's very appropriate."*

Consistent with the survey findings, an even stronger theme among participants in the focus group sessions and key informant interviews was that the age criterion for inclusion of guidelines on the NGC Web site is too long. Also noted in many of the comments was the qualifier that different fields change at different paces, and that five years may be appropriate for some guidelines, but that less than five years is probably more appropriate for other topics.

Excerpts from key informant interviews and/or focus group sessions regarding the five-year age criterion for guidelines included in NGC are noted below by the key stakeholder groups.

Guideline Developers/Informaticians

- *"I think it [NGC's inclusion criteria] sounds about right, except for the five years. … Things are changing pretty rapidly right now, and I know NQF is using a three-year time to evaluate their endorsed measures, so making that a little more frequent might be a good idea."*

- *"It is maybe a long period of time. We are required to update our guidelines at a minimum every two years. Although sometimes five years is probably reasonable."*

- *"[Our organization] revisits all of [our] guidelines every three years. That has proven to be beneficial, because that's just the right amount of time to capture any new data but allow the original publication of the guideline to be vetted in all the appropriate places."*

- *"I guess I would say they are subject to being out of date with a five-year window. We update all of our guidelines every year. And we're getting a lot of client feedback that they want some of them updated more frequently. And these are particularly in new technologies, new medications, things like that. We will be going to at least a twice-yearly, and perhaps four-times-a-year update in those particular areas. Now, other areas probably don't change as frequently, but I think five years is really quite a long time."*

Measure Developers, Policymakers/Purchasers, and Researchers

- *"It depends on the topic. And it depends on the guideline developer. You know, some guidelines are good for 20 years. Others, you know, should be reviewed every year and updated."*

- *"Five years is a long time, but the problem is, it's situation dependent…. five is I think on the long side, but I don't have any magic number. I think it's, as I said, depends on if there is a big transformation in a new technology. One just has to be aware of that and then it requires a sooner relook, so. Five is OK as a backstop, I guess."*

- *"Has anybody done a systematic review of guidelines and have they said that sort of the sell-by date for a guideline is five years, and then it's stale on the shelf? And are there criteria by which certain guidelines are more likely to change than others? I mean, for example, is a cancer guideline more likely to be superseded than a cardiology guideline, or a sexually transmitted disease guideline? Or are screening guidelines more or less likely to become obsolete versus a treatment guideline or something else, or a pediatric guideline versus a geriatric guideline? I mean, I don't know that anybody's systematically studied it, so five seems to be a reasonable, seat-of-the-pants, arbitrary number."*

Guideline developers discussed the five-year criterion from a different perspective. While many noted that five years is probably too long, a number of individuals discussed the problems that they (and their organizations) face in keeping them up to date. Key among the issues identified were the resources that are required to update and revise guidelines. Excerpts from a couple of guideline developers are presented below.

- *"I actually think that the five-year thing is difficult, because we do have a guideline that is older than that, and we have not had the resources to update it. So, I'm not sure about five years, in a field where the research is not necessarily changing rapidly."*

- *"The area we bump up against most often is the five-year longevity deadline, revising, because we're not unlike a lot of other companies. We have very limited staff; we're a public agency on top of that, so we can't just hire more resources to keep these updated. And if you're really going to do something evidence-based, I don't think anyone except those who are involved with it really understand how lengthy that process is. The process to figure out what the evidence is and what it says and whether its valid and useful is a very difficult, lengthy process. We're lucky if we can do two guidelines a year. And because topics are always coming up, and you want to build a library of them yourself, we could spend all our time doing nothing but revising guidelines. And never doing any new ones. And we can't keep them on the guideline clearinghouse, because we exceed the five years. And it's a challenge."*

☀ **AHRQ Opportunity:** Findings from the evaluation suggest that AHRQ may increase the value and use of NGC if it revisits the current criteria for inclusion as well as the five year age criterion.

IV.   Stakeholder-Specific Findings—Impact, Influence, and Other Key Findings

The objective of this component of the evaluation was to examine differences among NGC's key stakeholder groups in terms of their uses of the NGC Web site, and the impact and/or influences the NGC Web site has had.

A variety of data sources inform this section of the evaluation. First, as described in the Evaluation Approach section of this report, the NGC evaluation survey included specific modules for different stakeholder groups, with specifically tailored questions. The modules were accessed by survey respondents who self-selected one or more of the following seven stakeholder roles when using the NGC Web site:

- Guideline developer
- Physician, nurse, other healthcare provider/students
- Medical librarian
- Informatics specialist
- Researcher
- Measure developer
- Healthcare purchaser, policymaker, quality improvement specialist, other

A second source of data for this component of the evaluation comes from stakeholder-specific focus groups, and key informant interviews with individuals from the above noted key stakeholder groups. Four focus groups were conducted. Two were conducted with "guideline developers," one with "medical librarians," and one with "medical informatics specialists." Twenty-six key informant interviews were conducted with individuals that corresponded to the following key stakeholder groups:

- Guideline developer   (12 interviews)
- Informatics specialist (4 interviews)
- Researcher (1 interview)
- Measure developer (4 interviews)
- Healthcare purchaser, policymaker, quality improvement specialist, other (5 interviews)

Note: A number of the individuals participating in both focus groups and key informant interviews provided perspectives as clinicians, in addition to members of the above stakeholder groups, as a number of the individuals were also practicing physicians. Others provided comments from a researcher perspective as well, given their varied roles and uses of NGC.

The findings from both of these sources of information are presented in the subsections that

follow.

A. Guideline Developers

Data sources for this section come from the NGC evaluation survey, as well as from focus group sessions and key informant interviews with individuals representing 20 guideline developer organizations.

A total of 1,076 survey respondents completed the "guideline developer" module of the survey. In addition, individuals completing this module of the survey were asked whether they or their organization submit their guidelines for inclusion in NGC. A total of 199 indicated that they (or their organization) submit guidelines to NGC.

The section presents the findings on: 1) the influence of NGC on guideline developer activities; 2) experiences of guideline developers who submit their guidelines to NGC; and 3) key differences between guideline developers who submit their guidelines to NGC and those who do not.

1. NGC's Influence and Impact for Guideline Developers

a) *Survey Findings*

NGC evaluation survey respondents were asked to what degree NGC has influenced various elements of their organization's guideline development activities. These attributes included:

- Guideline topic selection
- Guideline development methodology
- How your organization documents or reports its guidelines
- How frequently your organization updates its guidelines
- Collaboration with other guideline developers
- Your approach to identifying guidelines
- Development of quality measures
- Use of quality measures
- Development of implementation tools
- Use of implementation tools
- Integration of your organization's guideline into electronic medical records
- Integration of your organization's guidelines into clinical decision support systems
- Other

Guideline developers could respond based on a Likert scale which ranged from "not at all" to "to a great extent." ("Don't know" was also an option.)

Responses to this series of questions are presented in Figure 16, below. The responses were mixed across the 12 components. As expected, the component that received the largest

proportion (61%) of responses for "to a great extent" or "somewhat" was guideline developers' approach to identifying guidelines. This was followed by "guideline development methodology" and "development of quality measures," with 52% of guideline developers reporting that NGC influenced these activities "to a great extent" or "somewhat." On the other end of the spectrum, 45% of guideline developers said that NGC influenced their collaboration with other guideline developers "very little" or "not at all."

Figure 16: NGC's Influence for Guideline Developers

	Don't Know/Missing	Very Little/Not At All	Somewhat	To a Great Extent
Your approach to identifying guidelines	19%	20%	40%	21%
Org's guideline development methodology	19%	29%	39%	13%
Development of quality measures	28%	21%	38%	14%
Use of quality measures	28%	23%	35%	14%
How org documents or reports guidelines	21%	33%	36%	10%
Org's guideline topic selection	19%	38%	32%	11%
Development of implementation tools	29%	30%	31%	10%
How frequently your org updates its guidelines	20%	40%	28%	12%
Use of implementation tools	30%	31%	29%	10%
Org's collaboration with other guideline developers	21%	45%	26%	8%
Integration of your org's guidelines into CDSS?	32%	36%	25%	8%
Integration of your org's guidelines into EMRs?	32%	42%	20%	6%

Percent of guideline developers

b)   Qualitative Findings

Data were collected from two focus group sessions and interviews with 12 key informants regarding the influences that NGC has had for them and/or their organization. Participants were asked:

"How, if at all, does NGC influence your organization's guideline development program?"

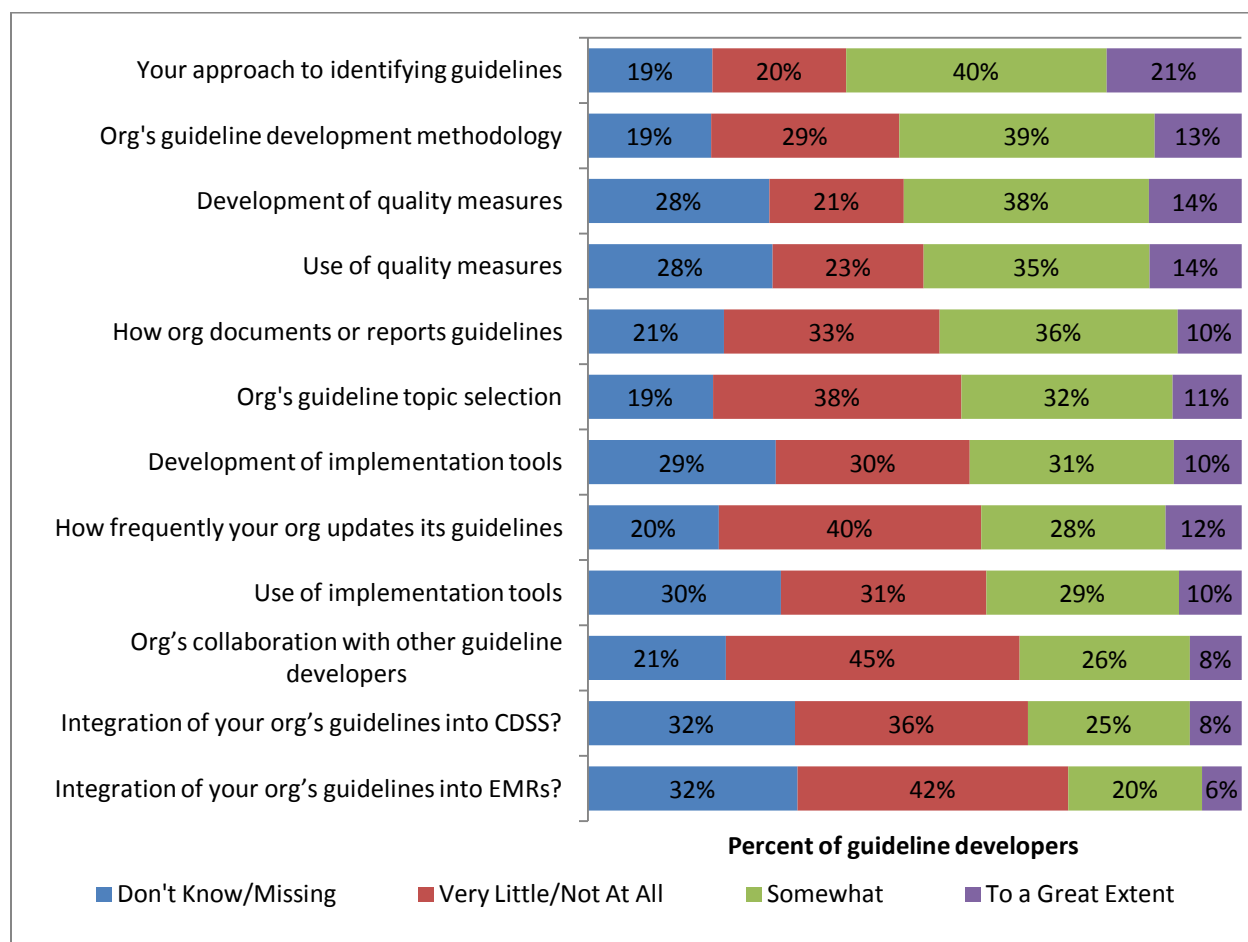The following probes were suggested as areas in which NGC may have had an influence: guideline topic selection, guideline development methodology, how organizations document or report their guidelines, how frequently they update their guidelines, collaboration with other

guideline developers, or in other ways.

Overall, the answer to this question was that NGC has not had much of an influence. The only influence from NGC was perhaps putting pressure on organizations to keep their information current on the NGC site. Some developers noted that NGC may have had an impact in the early days of its existence, or for guideline developers who are new to guideline development, given that it provides a lot of information and access to other guidelines. However, for most of the participants, NGC was not identified as an influential force for their respective guideline development approaches or programs. However, NGC was identified as a primary go-to source for information on guidelines that are available on a given topic. Many developers noted that they use it as an input to their guideline development activities, either as a source for evidence to support their guideline development, or as a tool to identify potential collaborators, or to ensure that the topic area under consideration hasn't already been addressed by another group.

A few excerpts from guideline developers in response to this question are presented below.

- *"No. We take our evidence reporting from the USPSTF. And now we're moving to the GRADE system for recommendations. Ours have always had algorithms, which a lot of the ones on NGC do not."*

- *"Early on, it might have been a first level to start. But for our organization, no."*

- *"No, not really. The program was started as a member-driven program; therefore, we really take what our members say to further develop how our guidelines are formatted and structure, and the methodology behind them. We really don't look at outside sources. We're trying to make sure that we focus internally first. We often ask other associations to co-sponsor guidelines. So we collaborate on them and see what works for them and we share our ideas with them. And we use the GRADE system."*

- *"Not particularly. I wouldn't say that I am doing business differently because of NGC. I try to make sure that in writing a guideline I'm addressing the criteria I know I'm going to have to submit to you. But even that is not that difficult."*

- *"Whether or not it affects the quality of our guidelines, I'd probably say that it doesn't have that much impact. We're always trying to improve our quality, but we are typically looking at other guidelines in the community. We more or less would get that from a specific guideline developer that's doing things in a really great way and we would try to model things after them and not necessarily NGC."*

- *"I don't believe so, simply because, when you're talking about the stakeholders in that particular area of influence – decisions – NGC doesn't really come to mind. So I don't think that they would influence…"*

- *"I couldn't say that it's had an [influence] – I couldn't point to a particular example of something that has been cause-effect. You know what I mean? Like, this is what NGC was doing,*

and so we did this in response."

There were, however, a few individuals who remarked on ways that NGC has had an influence. Some of these comments are noted below.

- *"The five-year thing is sort of pressure."*

- *"I would only say it's influenced us from the standpoint of the resource information it provides. So when we're going to do the next guideline, it influences us in terms of often being able to get a better basis of knowledge to start with. We know what's out there, how many others have guidelines in this area, whether our plan for ours is going to be similar or different. It gives us a snapshot of what's in the landscape."*

- *"As a benchmark for how frequently our organization's guidelines should be updated. NGC has also influenced at least the minimum requirements, which we do anyway, but just that it's a specific process, it's documented. But I think we also look to other groups as well, like IOM and some other published statements. We look at a range of people's recommendation on what – the method that should be used and the methods of reporting. But definitely, we want to make sure we meet whatever NGC says so that ours get on the NGC. We may look at the [NGC] summary to make sure the information is there. It does flag a few things, so it has some influence, maybe we're not as clear about how we actually came up with the recommendation. So it highlights things we could do better."*

- *"The availability of the guidelines will have an influence, because obviously that's one source that someone can go to and see all these different guidelines from different associations. And that might have an influence as to if they decide to develop a guideline on another topic or, you know, how they would like to – I don't know – update their current information."*

> ☼ **AHRQ Opportunity:** Evidence from the evaluation suggests that NGC has had some influence on guideline developer activities. For instance, NGC's guideline age criterion has influenced to some degree, the frequency with which guideline developers update their guidelines. AHRQ has an opportunity to increase knowledge among guideline developers about how to create and report trustworthy guidelines. This might be accomplished through guideline development training sessions or conferences.

2. Use of Other Research Tools

a) Survey Findings

AHRQ is also interested in whether or not NGC stakeholders use other AHRQ products. One question in this module asked guideline developers:

"Does your organization use any of the following AHRQ-sponsored products to inform its guideline development activities?"

Respondents were instructed to select all of the available options that applied. As shown in

Figure 17, the most commonly used products include: systematic evidence reviews (49%), comparative effectiveness reviews (31%), and technology assessments (22%). Those less commonly used include DEcIDE and CERT project reports (3%-4%).

While 49% of respondents report using systematic evidence reviews prepared by AHRQ in their guideline development activities, only 31% and 22% of respondents reported using other comparable reports (i.e., comparative effectiveness reviews and technology assessments, respectively).

Figure 17: Percentage of Guideline Developers that Use Other AHRQ-sponsored Products in Guideline Development
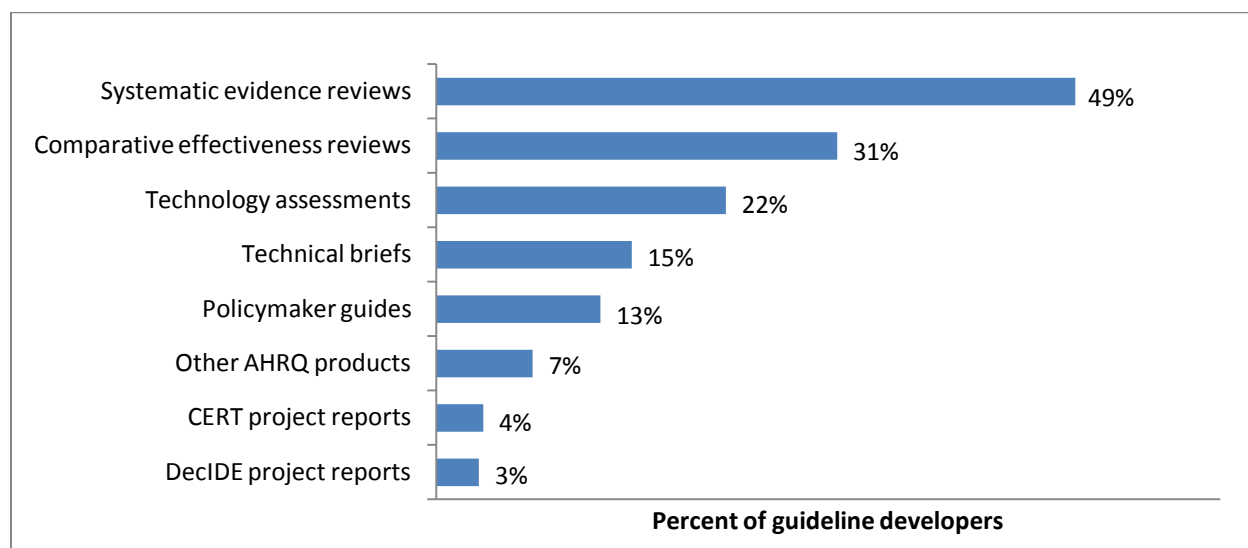
b)   *Qualitative Findings – Use of Other AHRQ Products among Guideline Developers*
The findings from the survey presented above are consistent with comments from the focus group sessions and key informant interviews with guideline developers. Participants were asked:

To the best of your knowledge, does your organization use other AHRQ-sponsored products to inform its guideline development activities?

Several of the respondents reported using other AHRQ products. Others reported that they did not, or that they didn't know. A few excerpts from the respondents' discussions on whether or not they or their organizations use other AHRQ products are presented below:

- *"It depends on what the topic is. There have been times that we've looked at those [comparative effectiveness, evidence-based practice centers, systematic evidence reviews]."*
- *"Yes, we use the systematic evidence review and other technologies and find them extremely valuable. We'd like to see a lot more of that."*
- *"Yes, we always look to AHRQ. I love all the methods guides." [Re: systematic evidence reviews]: "I don't think the topics that they have done have branched over into our area yet.*

We're in sleep medicine, it doesn't seem to reach sometimes the national agenda as far as getting some of that work done. But their methodology-related documents have been influential."

- *"Possibly. It depends on what the topic is. There have been times that we've looked at those....[But] We haven't, at this point, submitted any [requests for specific topics]."*
- *"Not that I'm aware of."*
- *"We would use them if they had anything in any of the topic areas that we address, but to date that hasn't been the case."*

☼ **AHRQ Opportunity:** While nearly 50% of guideline developer respondents note the use of some AHRQ products when developing guidelines, a fair number do not. This presents another opportunity for AHRQ to try and build on stakeholder interest in and use of its other products by guideline developers who develop evidence-based guidelines.

3. Guideline Developer Experience with NGC (Submitters Only)

a) Survey Findings

Among the NGC survey respondents who described themselves as guideline developers (n=1,076), only 19% (n=199) said that they or their organization actually submit guidelines to NGC. This section presents the results of data obtained from guideline developers who participate in NGC.

Guideline Developer Experience with NGC Processes: Guideline developers were asked:

In your experience, how would you rate each of the following components of the NGC process?

The components covered included:

- NGC's submission process
- Providing copyright
- NGC's preparation of the NGC summary and abstraction of your organization's guidelines
- NGC's verification process (per each guideline summary and/or annually)
- NGC's dissemination of your organization's guidelines
- NGC's response to Food and Drug Administration (FDA) warnings

A large proportion of respondents to this section of the survey reported "don't know" to most of these questions (ranging from 24% to 42%). However, for those respondents who could evaluate these processes (excluding the "don't know" responses and the non-responses), the majority of guideline submitters rated these processes as "good" or "excellent," as summarized in Table 7, below. Of interest, guideline developers rated NGC's response to FDA warnings the most favorably, followed by NGC's verification process.

Table 7: NGC Submitters' Experience with NGC

Component	Proportion of Submitters who Rated the Component		
	"Excellent" or "Good"	Neutral	"Fair" or "Poor"
Submission process	68.6% (n=83)	14.9% (n=18)	16.5% (n=20)
Providing copyright	58.6% (n=58)	28.3% (n=28)	13.1% (n=13)
NGC's preparation of guideline summary and abstract	66.9% (n=89)	20.3% (n=27)	12.8% (n=17)
Verification process	71.1% (n=86)	17.4% (n=21)	11.6% (n=14)
NGC's dissemination of their guidelines	64.5% (n=89)	21.0% (n=29)	15.1% (n=20)
Response to FDA warnings	73.6% (n=78)	15.1% (n=16)	11.3% (n=12)

Another key finding worthy of elaboration here is the fact that only 64.5% of participating guideline developers rated NGC's dissemination of their guidelines as "excellent" or "good." Approximately 35% were either neutral in their opinion or said that NGC's dissemination of their guidelines was "fair" or "poor." This is shown in Figure 18, below.

Figure 18: Guideline Developer Perceptions about NGC's Dissemination of their Guidelines
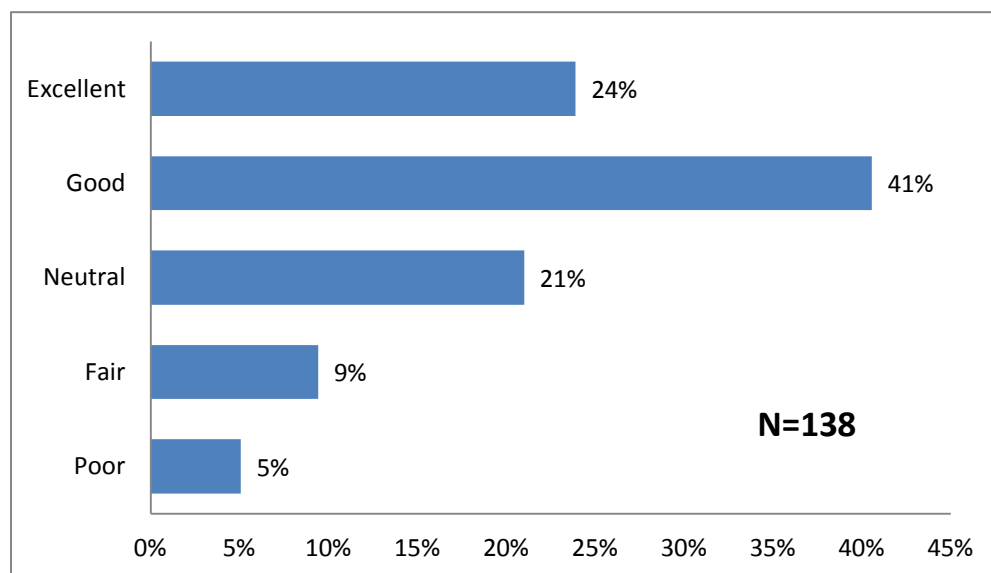
☀ **AHRQ Opportunity:** With nearly 35% of guideline developers being less than satisfied with NGC's dissemination of their organization's guidelines, AHRQ has an opportunity to identify additional ways to enhance the dissemination of guidelines.

Guideline Developer Use of Guideline Summary Usage Reports: Guideline developers were asked:

How do you or your organization use NGC's Annual Summary usage reports?

Response options for this question were:

- As an indirect measure of the dissemination of your organization's guidelines?
- Research/agenda priority setting?
- Budget justification
- Don't know
- This information is not used at all

The majority of those who submit guidelines (69.2% when excluding those who "don't know") report using the annual summary usage reports as an indirect measure of the dissemination of their guidelines. This was confirmed in the qualitative interviews and focus group sessions.

b)   *Qualitative Findings   Guideline Developer Experience with NGC (Submitters Only)*

Guideline Developer Experience with NGC Processes

Similar to the survey question, focus group participants and key informants were asked how they would rate the following components of the NGC process.

- NGC's submission process
- Providing copyright
- NGC's preparation of the NGC summary and abstraction of your organization's guidelines
- NGC's verification process (per each guideline summary and/or annually)
- NGC's dissemination of your organization's guidelines
- NGC's response to FDA warnings

Overall, participants rated each of these processes as excellent. One of the individual interviewees had problems with the submission process. The problem with the process was that the participant felt the same information was being asked for multiple times. Also, the length of time from submission to actually going live on the NGC site was seen as another problem; a number noted that they would like for the public to have access to their guidelines more quickly than they do now because of the time it takes to process their guidelines for inclusion.

A few excerpts from guideline developers who participate in NGC are presented below.

- *"Very good. I let them know that we have a new guideline and then they do the summary."*

- *"Really simple and easy. Not anything would really improve the process."*

- *"It's been great. [NGC] sends me the e-mail and says we need this and this from you. And it's very clear what [they] need."*

- *"I think the process is good."*

- *"I love the annual verification report. It highlights if we just didn't know, just a reminder, these [guidelines] are the ones that need updating."*

- *"I always found it very easy to submit. I also like the fact that if we've published a guideline and haven't submitted it to NGC, they sort of find it on their own and they contact me and ask to put in on NGC."*

- *"Difficult. The process is very tedious and very lengthy. It took months and months to get something published. I'd send them the guideline and they'd say OK, and I'd have to wait a month or something for them to come back and say now complete our form with how it meets this criteria. I already knew what criteria it needed to meet, so why don't I just send you that from the beginning and we're not waiting two months for you to turn it around. Some of the criteria I find a little confusing. I'm not sure what the difference is between one or the other. And it seems to be very nuanced. In that way, I find it tedious. It'   60 different criteria or something that I have to answer. It's complicated to take what's already been a lot of work on the guideline and then distill it into answering each of your questions. What disturbs me is once I've sent everything, I'm waiting six months to a year for something to show up. And by that time, we've lost a year of the age process."*

- *"I haven't had any issues with NGC. Our guidelines are not copyright, so we don't have that issue. I guess the length of time with the NGC process is a little bothersome. When it seems to take several months before something I sent them actually was done and final and put on the Web site. People can go to our Web site and find the guideline pretty much right away after it was approved."*

Regarding dissemination, one of the participating developers noted that having their guidelines disseminated through NGC was a way for them to make sure that they meet the IOM criteria for accessibility, since their guidelines are not otherwise available. For another hospital-based guideline developer, having their guidelines posted in NGC is a very important tool for disseminating their guidelines as they have no other mechanism for disseminating them. The NGC summary is also considered a publication by their institution and helps to recruit individuals to participate in the panels to develop the guidelines [serving as an incentive].

Another noteworthy finding from the "qualitative findings" was that essentially everyone agreed that NGC's response to FDA alerts is good, and that this is a useful source of information that NGC provides. One individual doesn't like the way NGC places a notice on the relevant guidelines because she thought that, for their guidelines that are pediatric, the notices aren't generally relevant. But all others like this service or note that it is useful.

A number of individuals also noted that while they get information about FDA alerts from NGC, they also get it from other sources, or that they themselves track this information. However, an important point made is that NGC actually takes actions with the information and identifies how

the information affects specific guidelines. One person noted that they like that NGC actually places an FDA notice in the NGC summary of the relevant guideline so that the information is readily available to anyone (e.g., clinicians) who is using the information provided through NGC. Some relevant comments are noted below.

- *"Yes, it has been useful. The physicians and myself are signed up to get alerts from various places. But NGC is always right there, sending us something and to let us know we found something on your guideline that refers to that drug, or whatever it was. And also the fact that they put something on the actual guideline, even though it's not a guideline that we've just recently updated, whatever is helpful to make sure the physicians out there treating patients have the most current information, that's great."*

- *"Yes. We've encountered it a few times, and I find it very helpful just to see a brief summary of what's happening. We track FDA and other drug announcements. But it [NGC] is very helpful. Because sometimes you just know that something has happened to that particular drug, but then we can't really relate it to a guideline. So it is very good to see that this specific guideline has been affected and this is what's happening."*

Guideline Developer Use of Guideline Summary Usage Reports

Guideline developers were also asked to discuss how they use NGC's annual summary usage reports.

The following probes were suggested as possible uses of the summary usage reports: indirect measure of guideline dissemination through NGC, budget justification, or research priority setting.

In response to this question, a number of the participants stated that they didn't recall getting the information, or they thought they had gotten it once or twice, but not every year. Others, who recalled getting the information, said that it has been very useful. One organization said that it was very important to budget allocations to their program. Others said that it is nice to know, but not used in any way as a basis for decision making within their program.

A few excerpts from guideline developers are presented below:

- *"Yes. We use that information with our work groups, especially when revising documents. It gives us a sense of how often these things are being accessed."*

- *"...the other big thing they send us is the page views   the number of hits. And I've used that many times as a tool to try to capture which ones are the most important ones, which ones have the most impact. If we have to prioritize, which ones really need to be worked on because people are really paying attention and reading them. When we have to make decisions about where the resources need to go, and to prioritize if we have to make a choice, you know these ones [with the biggest number of hits,] we definitely have to update these, and the other once maybe can wait a year. I'm also adding the charts over time, so I can see year to year what's changing and that*

maybe gets at dissemination. Are certain topics, why aren't they being used? Are they not interested in that or maybe they don't know about it? Or is it just sort of a niche area that not too many people in general work in or something like that."

- *"We really appreciate the monthly counts of page views. Because it's very hard for us to evaluate the impact of a guideline. Has it changed practice, are we getting diagnoses made earlier and more accurately, is treatment happening more quickly, we don't always know. So in the absence of more meaningful quality measures, it is helpful to us to see how often others are at least looking at them. And we have received correspondence directly from people who say, I saw your guidelines on NGC and I have a few questions. So it has been a good vehicle for receiving communication from other people. Our advisory group is very interested in how the guidelines are being used. And I give them a report of how many page views there have been. We don't use it for topic or priority setting or budget justification because it is a retrospective piece of data."*

- *"It's outstanding. We were so excited last year, I couldn't believe the increase in looking at our guidelines from the previous year. We don't use the usage figures in any other way, other than just more of a nice to know. We do compare from one year to the next because there was just such an increase in hits and stuff. So it's exciting for us."*

4. Comparison of Guideline Developers who Submit Guidelines to NGC and Those who Do NOT Submit Guidelines to NGC

Only 19% of users who identified themselves as guideline developers actually submitted guidelines to NGC (as an individual or through their organization). In order to determine if there may be something in the data to suggest why organizations do not submit their guidelines to NGC, we conducted several comparisons between the "submitters" and "non-submitters" for the following NGC-related topics:
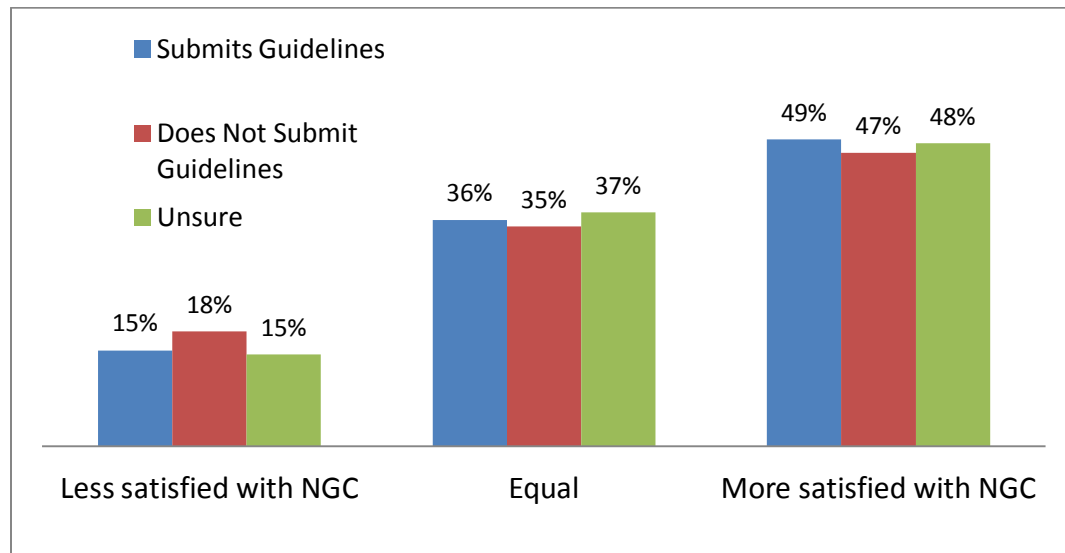
- Satisfaction with NGC compared to other sources
- Appropriateness of NGC's inclusion criteria
- Trustworthiness of the guidelines included in NGC
- NGC's influence on 12 activities related to their guideline development programs

The comparison found that differences in satisfaction with NGC were insignificant; however, those who submit guidelines were more likely to rate the NGC inclusion criteria as "loose" and the NGC guideline trustworthiness as "poor." These findings do not shed light on why guideline developers do not submit to NGC, but they do raise some questions about how these two groups rate the quality of content contained in NGC. Each of these comparisons is described below.

Satisfaction with NGC Compared to Other Sources

As shown in Figure 19, the responses across all three groups regarding their satisfaction with NGC compared to other resources is pretty uniform among all three groups (i.e., submit to NGC, do not submit to NGC, and don't know) (p-value=0.698).

Figure 19: Satisfaction with NGC Compared to Other Guideline Source by Guideline Submission Status

NGC Inclusion Criteria

Unlike satisfaction with NGC compared to other sources, the difference in the rating of the appropriateness of the NGC inclusion criteria by guideline submission status was statistically significant (p-value<0.0001) (see Figure 20). Guideline developers who submit guidelines to NGC were the least likely to say that the NGC inclusion criteria are appropriate (61% vs. 73%). In addition, those who do submit guidelines were more likely to say that the criteria are too loose (14% vs. 5%).

Figure 20: Rating of NGC Inclusion Criteria by Guideline Submission Status
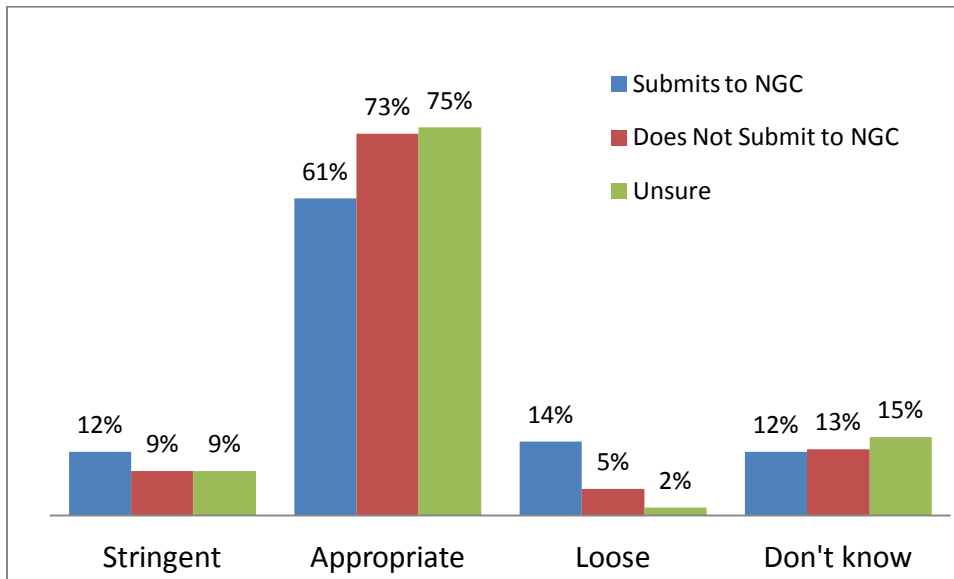
Trustworthiness of Guidelines on NGC

The large majority of all guideline developers rate the trustworthiness of the guidelines on the NGC as good (refer to Figure 21). However, statistically significant differences were present between those who submitted and those who did not submit. Guideline developers who submit were less likely than those who do not submit to rate the guideline trustworthiness as good (73% vs. 84%) and were more likely to rate it as poor (6% vs. 1%).

Figure 21: Rating of NGC Guidelines' Trustworthiness by Guideline Submission Status
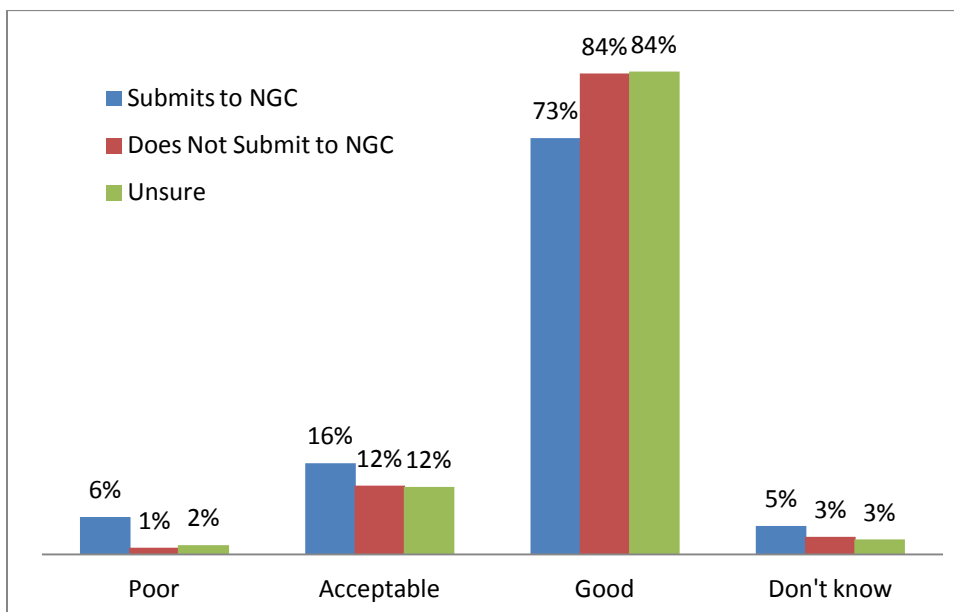
NGC's Influences on Guideline Developer Activities

The section examines influences of NGC for guideline developer groups who submit guidelines to NGC compared to those who do not, as well as those individuals who did not know if they submitted their guidelines to NGC. The relative influence of NGC for each of the following activities was examined:

- Guideline topic selection
- Guideline development methodology
- How your organization documents or reports its guidelines
- How frequently your organization updates its guidelines
- Collaboration with other guideline developers
- Your approach to identifying guidelines
- Development of quality measures
- Use of quality measures
- Development of implementation tools
- Use of implementation tools
- Integration of your organization's guidelines into electronic medical records
- Integration of your organization's guidelines into clinical decision support systems
- Other

The differences among the three groups were statistically significant for all 12 activities. Comparisons for each of the 12 activities can be found in the Survey Results Appendix (beginning on page 62).

In general, with a couple of exceptions, NGC has had a greater influence on guideline developers' activities if they do NOT submit guidelines when compared to those who do submit guidelines.

Specifically, those groups who report that they do NOT submit guidelines to NGC were more likely to report "to a great extent" or "somewhat" with regard to NGC's influence, for the following activities:

- Guideline topic selection
- Identifying guidelines
- Development of quality measures
- Use of quality measures
- Development of implementation tools
- Use of implementation tools
- Integration of your organization's guidelines into electronic medical records

On the other hand, guideline developers who reported that they do submit to NGC indicated a greater influence from NGC than those who do not submit, for the following activities:

- Guideline updating frequency
- How organizations document or report their guidelines

This is an interesting finding. The two activities for which NGC has had a great influence among guideline developers who submit their guidelines to NGC are activities directly related to whether or not their guidelines will be accepted for inclusion in the clearinghouse. Namely, the age of the guideline, and whether or not the guideline clearly supplies all of the methodology details required to meet the NGC inclusion criteria. Some evidence from the qualitative findings is consistent with this finding. For instance, some of the guideline developers who participated in the focus groups and key informant interviews noted that NGC's guideline age criterion is a factor in how frequently they update their guidelines. However, there was less support from the qualitative findings that guideline developers have been influenced in any significant way by NGC in how they document or report their guidelines.

B.   Healthcare Providers (Physicians, Nurses, and other Healthcare Providers)

Healthcare providers (composed of physicians, nurses, other healthcare providers, and students to a lesser degree) made up the largest stakeholder-specific subgroup, with 3,271 survey respondents. Non-response rates to these questions were low (typically 4% or lower).

### 1. NGC's Influence and Impact   Healthcare Providers

a)   Survey Findings

The "healthcare provider" module of the survey included a series of questions to assess NGC's influence on guideline-related activities relevant for health providers. Specifically, NGC influence among health providers was assessed for the following activities:

- Clinical decision-making processes
- Ongoing learning efforts
- Individual implementation of guidelines
- Organization implementation of guidelines
- Identifying guidelines

Providers responded using a Likert scale for the extent of NGC's influence, with options ranging from "not at all" to "to a great extent." ("Don't know" was also an option.) The results (see Figure 22) show that NGC has had a strong influence on each of these activities.

Figure 22: NGC Influence on Health Providers' Activities
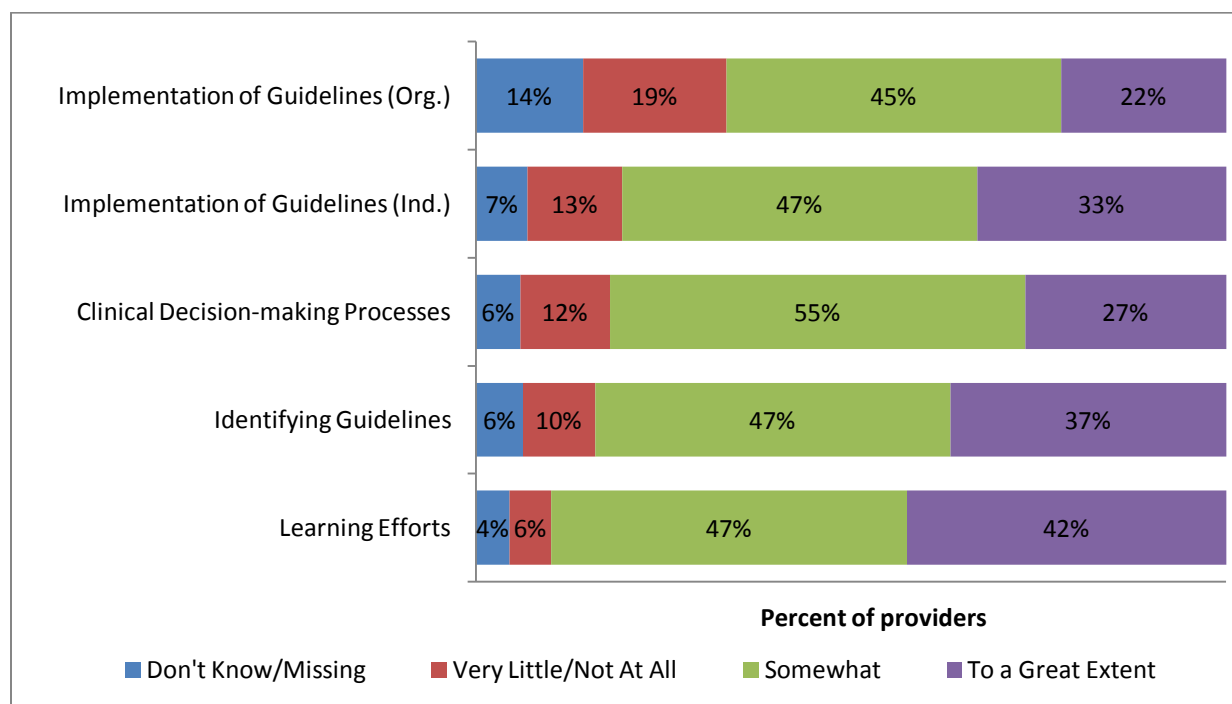
2. Desired Enhancements to NGC   Health Providers

a)   Survey Findings

The "health provider" module also asked provider respondents about their potential use of specific NGC features or enhancement. In general, most of the providers said that the potential enhancements identified in the survey would be highly utilized. In summary:

- **Do you or your organization utilize clinical decision support tools at the point of care**? Seventy-two percent (72%) of providers stated that having NGC content delivered to them at the point of care would be useful.
- **If continuing medical education were available through NGC would you take advantage of it**? Sixty-six percent (66%) said they would take advantage of continuing medical education.
- **Is there a need to broaden the scope and type of guidelines (e.g., credentialing, privileging, ethical, procedural, training) included in NGC**? Similar to influence, providers who responded via the AHRQ e-mail distribution were more likely than those who responded via the AMA or AHIP distribution to respond favorably to these questions.

C.   Informaticians

Data sources for this section come from the NGC evaluation survey, as wells as a focus group session and four key informant interviews with informaticians. A total of 292 survey respondents

completed the "guideline developer" module of the survey. Non-response rates to these questions were low (typically 3%-7% or lower).

The section presents the findings from informaticians on their use of NGC data as an input for developing clinical decision support systems or for other Web-based systems. It also examines their use of other NGC tools intended for systems developers, and their interests in other tools not yet available on the NGC Web site.

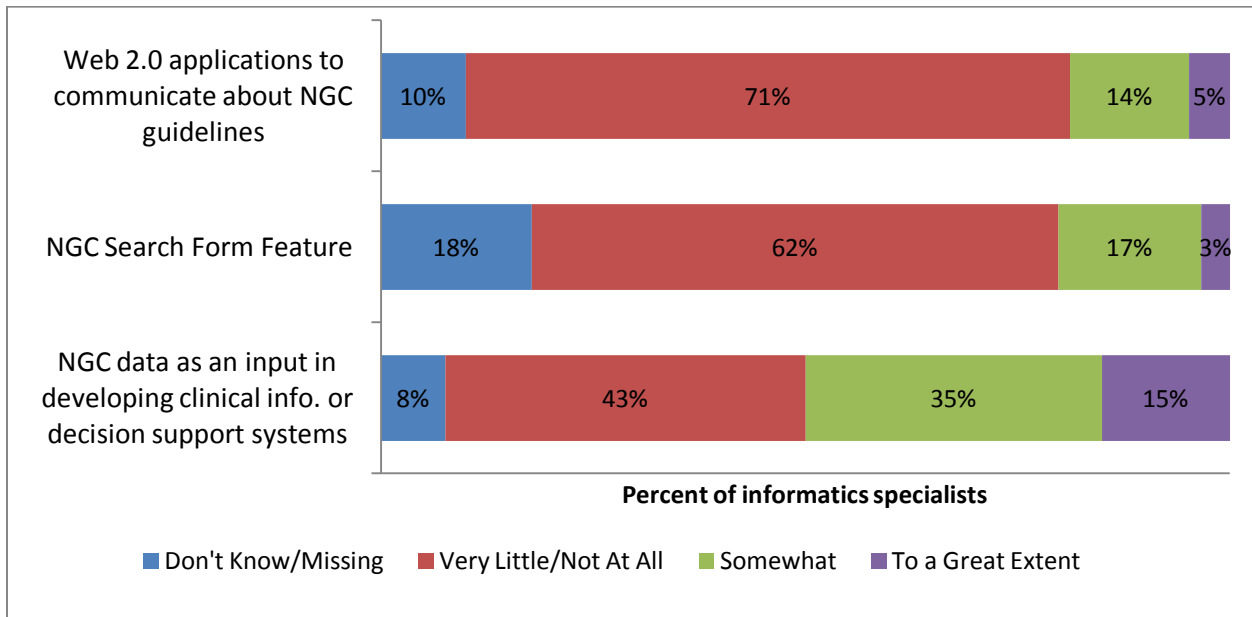## 1. Use of NGC   Informaticians

a) *Survey Findings*

Three of the questions included in the informatician module asked respondents about their use of NGC data and NGC tools. Specifically, they were:

- *Do you currently use or develop Web 2.0 applications (e.g., blogs, wikis, RSS) to communicate information about NGC guidelines?*

- *Do you utilize NGC data as an input in developing clinical information or decision support systems?*

- *Do you utilize the NGC search form feature, which allows developers to create search interfaces with NGC on external sites?*

This module also asked if respondents use NGC's RSS downloads (NGC content inventory and "What's New" file) and if having NGC output for individual guidelines in XML format according to the Guideline Elements Model (GEM) would be useful.
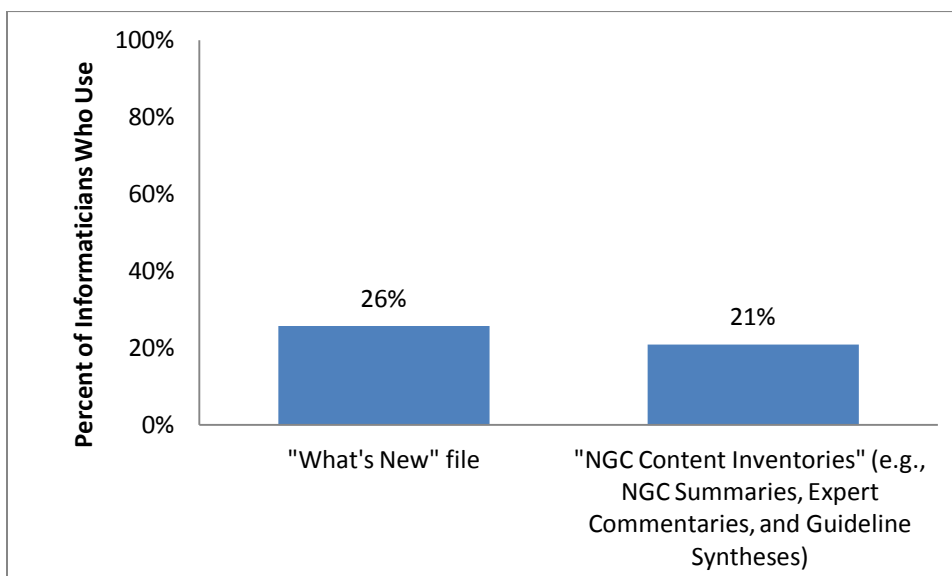
The response frequency distributions for these questions are presented in Figure 23, below. Informatics specialists queried in this survey do not generally use Web 2.0 applications or the NGC search form feature, with only 19% and 20% stating that they use the features "somewhat" or "to a great extent." On the other hand, 50% of informatics specialists said they use "NGC data" as input information in developing clinical information or decision support systems "somewhat" or "to a great extent."

Figure 23: Informaticians' Use of Web 2.0, NGC Data, and NGC Search Form Feature

Category	Don't Know/Missing	Very Little/Not At All	Somewhat	To a Great Extent
Web 2.0 applications to communicate about NGC guidelines	10%	71%	14%	5%
NGC Search Form Feature	18%	62%	17%	3%
NGC data as an input in developing clinical info. or decision support systems	8%	43%	35%	15%

Percent of informatics specialists

■ Don't Know/Missing ■ Very Little/Not At All ■ Somewhat ■ To a Great Extent

As shown in Figure 24, about 26% and 21% of informaticians who responded to this question (n=240, and 271, respectively) indicated that they used the NGC "What's New" file, and "NGC's Content Inventories," respectively.

Figure 24: Use of NGC's RSS Feeds

	Percent of Informaticians Who Use
"What's New" file	26%
"NGC Content Inventories" (e.g., NGC Summaries, Expert Commentaries, and Guideline Syntheses)	21%

b)   Qualitative Findings   Informaticians

Data from a focus group session and four key informant interviews with informaticians highlight some of the primary reasons this stakeholder group uses the NGC. Participants in the

informatician focus group described NGC as one of the primary resources that they use to find guidelines, and said that they use guidelines in their work to develop clinical decision support systems and tools. However, there was no clear indication of how the guidelines available in NGC support their work with things like developing clinical decision support tools, beyond serving as a resource to identify guidelines. There were also discussions about how guidelines are only one component used in developing decision support systems.

A few excerpts on how and why informaticians use guidelines, and NGC, are presented below.

- *"We use them in computer systems... [incorporating them] ...into logic."*

- *"Guidelines are used in all the clinical decision support, in the clinical applications. Guidelines.gov is an excellent source of knowledge for decision support, but it's one of many and it has certain limitations."*

- *"We're interested, in my group, in knowledge representation for clinical guidelines. Particularly, guidelines for chronic care, guidelines as it relates to complications for co-morbidity and patients who may be on ... a variety of guidelines for those interactions."*

- *[Guidelines used as] "a template where we can document on this particular patient that has a certain kind of condition, we may go to the guideline literature to look, to see if there are any references to pull to inform that build."*

- *[There are four layers to developing decision support:] "Layer 1 is the guideline. Layer 2 is a human-readable, you know, but still XML pseudocode, like a GEM document. Level 3 is something that is much more specified and encoded with controlled medical terminology and possibly GELO or other expressions where computations are called for, etc. And then Level 4 is an actual implemented CDS artifact, such as a Web service or other type of decision support that, you know, people can subscribe to and use. So, that's the full range. If you think about what a guideline has to do, from its creation and sitting on a shelf to its actual use in EMR, you know, as a rule, or an alert, or an order set, or a care pathway, what have you, there are just many, many, many, many steps. So, you know, to answer your question, I guess, the NGC is extremely helpful as a repository of guidelines that are tagged and searchable, and rated, to a degree, even as well. But even starting with all of that, there are many, many steps to get to decision support."*

Some comments from the informaticians about why they are not using NGC as much, or why they may use other resources more than NGC, are noted below.

- *"The main thing about NGC is there's not – at least as far as I know – but there's no way to say, OK, shift me into pediatric mode. Don't show me anything that's just adult only, because that's noise....We use Up to Date, the online textbook. We've got a license for that, and what's nice about that is right by the search field, there's a button that says "limit to pediatrics." So it's baked into the product. They know they have pediatric users, so there's not a lot of hassle about selecting that. So, I mean it's good to know there's an advanced search – that's really good."*

- *"We used to link from our reference – [Web site] – directly to NGC, and we've had to stop doing that, because so often, NGC pulls, you know, they pull one-fifth of the guidelines every year, and that's 300 guidelines that are cited each four or five times, so we're having to change 1,500 hyperlinks a year manually, and it just got to be too much."*

2. Desired Enhancements to NGC   Informaticians

a)   *Survey Findings*

Informaticians were specifically asked: "Would having an NGC output for individual guidelines available as an XML file according to the Guideline Elements Model (GEM) be useful to you in your work?" As shown in Figure 25, 50% of informatics specialists said that they would use individual guideline output according to GEM "to a great extent" or "somewhat." A large proportion, 31%, either said "don't know" or did not respond to the question.

Figure 25: The Extent to Which Informatics Specialists Would Use Individual Guideline Output According to GEM
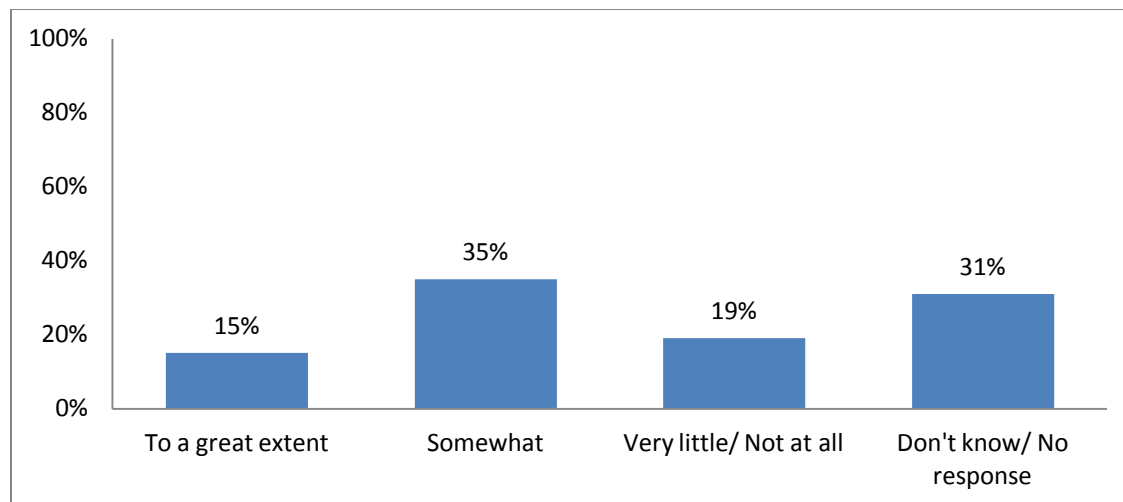
Informaticians were also asked "*What type of data and what type of Application Programming Interface (API) would you like NGC to provide?*" Forty-two individuals answered this question, and the primary response from respondents was "a structured interface for search query and XML output for search results."

b)   *Qualitative Findings*

Data from a focus group session and four key informant interviews with informaticians highlight some of the enhancements that were suggested for NGC by this stakeholder group. A number of informaticians discussed having some way to assess the executability or implementability of guidelines included in NGC.

A few excerpts of responses to the question about NGC enhancement are presented below.

- *"You know, this kind of stuff, where do you apply that kind of screen [of guideline executability]?*

Well, you'd want to apply it in a very neutral context. So a government-sponsored repository of guidelines might be exactly the sort of neutral context to apply that in. So it just seems like that would be a nice thing to think about for the future for NGC….., it would make the site more useful, but that's not the main reason why you want to do it. The main reason why you want to do it is to drive people to make the things executable from the get-go. Where they say, gee, I know, this is going to be looked at in a certain way. I'd better look at my logic. And make sure it makes sense before I publish it. So, it's about changing the guideline environment, I think."

- *"Well, you know, GEM as I understand it is a way of representing a guideline, in a highly formatted way that in some future state would be machine readable. And there's a tool for doing – that may be part of it, but I'm actually more interested in the human readable part. And that's more like GLIA, which is a tool for just evaluating the executability of a guideline. Just assessing it."*

- *"I think NGC is doing a lot of what it should do. What perhaps might be more in the way upstream part of this whole knowledge evolution, you know, I might suggest NGC could be more rigorous in identifying preferred guidelines, or even best guidelines. The problem is the average knowledge engineer, or the average clinician, doesn't know even where to start when there's 20 diabetes guidelines. Or do the first pass at the knowledge abstraction – that is, from the 20 guidelines, you know, across guidelines, identify those key concepts or highly resolved, that is, highly agreed upon, you know, fundamental core concept statements from across guidelines. But that's risky, because that gets into the actual knowledge engineering process, and there are liabilities associated with that."*

- *""What could NGC do by way of next steps? I think looking at the Compare Guidelines, for example, that could be made much more rich. And perhaps, just thinking along implementability issues, as we've been describing, or GLIA issues, take the Compare Guidelines function as it's currently implemented in the NGC browser, or the Web site, and maybe do a GLIA comparison of guidelines. You know, that's at least a step in the right direction. It's not enough detail to help the user identify an implementable guideline, per se, or it doesn't do all the knowledge engineering stuff, but it's a step in the right direction. Another thought would be, just to go out on a limb a little bit for the NGC and say, the preferred guideline idea – how do they, could it be the NGC, or a function of the AHRQ somewhere to say, you know, for meaningful use, these are the preferred guidelines to use."*

- *"…about next steps for NGC, if there were a guideline authoring tool, something like the Bridge-Wiz tool; if there were a standard guideline authoring tool, that would certainly help to standardize guidelines. That authoring tool could actually begin to use controlled medical terminology, and the building blocks, if you will, from clinical informatics to make guidelines much more implementable by creating them correctly in the first place."*

D.   Medical Librarians

A small subset of survey respondents identified themselves as "medical librarians" (n=204). In this section, we summarize the influence of NGC on medical librarians. In addition, key findings from a focus group session with medical librarians are also presented.

1. Use of NGC – Medical Librarians

Data from the focus group session with medical librarians highlight some of the primary reasons this stakeholder group uses NGC. Participants in the medical librarian focus group described NGC as one of the primary resources that they use to find guidelines and said that using guidelines was important for their work. Four respondents reported using guidelines as part of teaching at all levels, including undergraduate, graduate, medical students, and residents. These respondents also indicated they help to inform clinical faculty about guidelines at their respective institutions. The topics mentioned by the respondents were nursing, hospital practice, clinical practice, dentistry, pharmacy, and overall medical education. Five respondents use guidelines as part of research activities, including identifying information for systematic evidence review development (in the scope development process), and/or when developing or updating clinical practice guidelines or protocols.

A few excerpts on how and why medical librarians use NGC are presented below.

- *"Primarily just to find guidelines and to work with the people who are creating their new protocols and guidelines, either within the hospital or for a special education project or something along that line."*

- *"We use it very frequently in class preparation since we're instructing on it [NGC] all the time. We really teach it and give exposure to it in our sessions all the way from undergraduate and nursing school through our clinical faculty."*

- *"We work to support the development of systematic reviews and at the early stages of this, we do searches involving scoping; trying to decide whether topics are ripe for doing a systematic review. And, as part of this process, we of course want to see if there are published guidelines on those topics. It's under that heading, I guess, that we search for guidelines because, before we go forward with doing a systematic review, we would like to see what other systematic reviews and guidance are available."*

- *"I work with guidelines in my basic reference work finding guidelines. I'm also a liaison to the School of Nursing and teach the use of guidelines, work with undergraduate and master's students doing papers who need guidelines, and work with our practice center in the hospital who are doing protocols and guidelines."*

## 2. NGC's Influence and Impact – Medical Librarians

a) Survey Findings

The medical librarian module of the NGC survey included a question to assess NGC's influence on five guideline-related activities relevant to medical librarians. Specifically, NGC influence among medical librarians was assessed for:

- Data collection processes
- Approach to identifying guidelines

- Ability to meet clients' needs regarding evidence-based clinical practice guidelines
- Ability to identify "high quality" guidelines
- Ability to identify "current" guidelines

Medical librarians could respond based on a Likert scale for the degree of NGC's influence which ranged from "not at all" to "to a great extent." ("Don't know" was also an option.) As shown in Figure 26, below, a large portion of the medical librarians responded that NGC greatly influenced their work with clinical guidelines. More than 86% (86% - 88%) of medical librarians responded that NGC influenced "to a great extent" or "somewhat" their approach to identifying high and current guidelines, and their ability to meet their clients' needs with respect to guidelines. In contrast, 32% said that NGC influenced their data collection processes "very little" or "not at all."

Figure 26: NGC Influence on Medical Librarians' Guideline-Related Activities

Percent of medical librarians

- Don't Know/Missing
- Very Little/Not At All
- Somewhat
- To a Great Extent
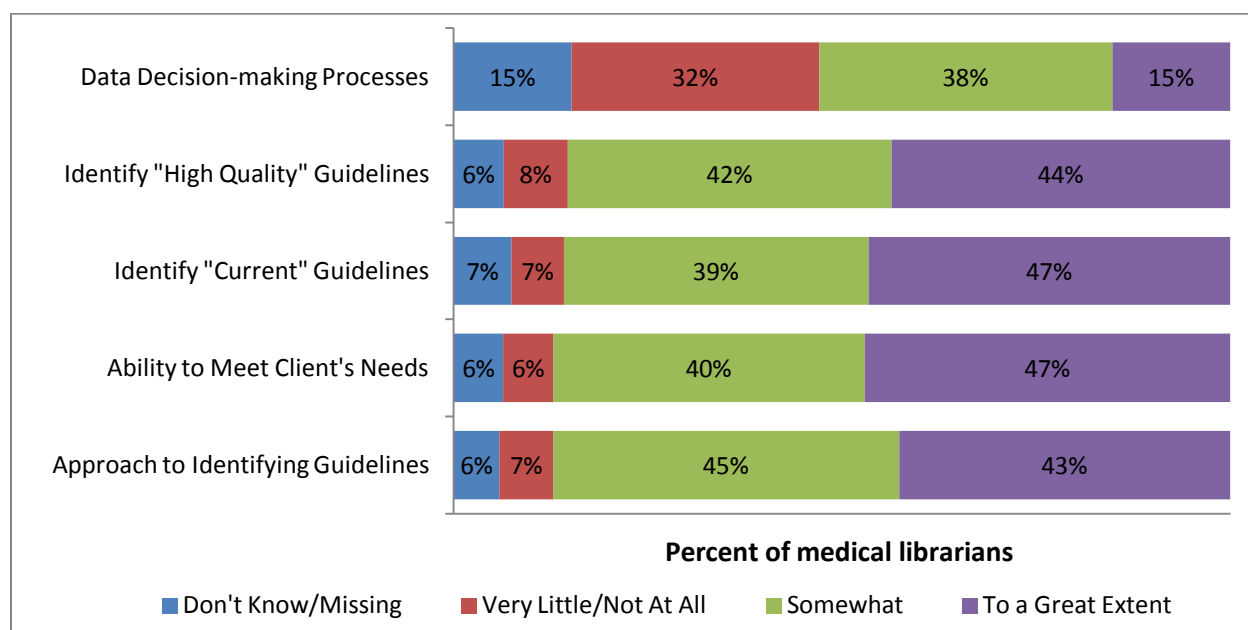
b) Qualitative Findings – Influence of NGC for Medical Librarians

The findings from the survey presented above are consistent with responses from participants of the medical librarian focus group session. Participants were asked:

How, if at all, has NGC influenced [their guideline-related] activities?

All of the focus group participants stated that NGC has influenced their approach and ability to find guidelines. The primary reason mentioned was that NGC consolidates guidelines into one location with rigorous standards and comparison features. These attributes reduce time spent searching for guidelines and therefore reduce decision-making time in a clinical setting or ease time spent gathering information in a research setting. For these reasons, the respondents

indicated that NGC has become an essential research tool. One respondent also mentioned that NGC improves awareness of and focus on guidelines in their institutions.

A few excerpts related to NGC's influence for medical librarians are presented below:

- *"I think it does help us find high quality guidelines, to identify them, and current guidelines."*

- *"It's really so valuable, the ability to say, 'I think these are the three best choices, but let me make sure this is right audience and that they're talking about the right clinical question that I'm looking at, to use that comparison utility, to look at the syntheses to see, 'Is my question really answered in these guidelines? Is that really what they're telling you to do? Is that really what my people are trying to treat?' That's really valuable   all of the extra stuff that is there. Like you say, it's not just locating the guidelines; it's all of the extra things that are there."*

- *"Because guidelines.gov exists in our sort of going down the list to see what other things exist on a topic, it means that we don't have to go to all of the various individual organizations that may be producing guidelines."*

3. Desired Enhancements to NGC – Medical Librarians

a)   Qualitative Findings

Data from a focus group session with medical librarians highlight some of enhancements that were suggested for NGC and/or changes to the controlled vocabularies used to index content that were suggested by this stakeholder group.

A few excerpts of responses to the question about additional NGC enhancements are presented below.

- *"I don't know if there necessarily needs to be more [controlled vocabularies]. I don't know if more is necessarily going to be better at this point. I think the ICD-9s are in there right now. ICD-10s, maybe. But, other than that, I don't think there needs to be anything else – if that would contribute positively to the functionality of the site."*

- *"I just had this idea because lots of times when I'm in PubMed, I start by searching MeSH then click the buttons and say 'Take these terms and search it in PubMed.' I wonder if there would be either at the level of integration of having when you're searching the MeSH Web page to allow it so say, 'Search in guidelines.gov' or have that be part of… Instead of just the way … now you can just sort of browse through the various different topics. If, much like PubMed, you could enter the MeSH controlled vocabulary and to build your search that way and to say now that I've selected the subject heading that I'm interested in, search the guidelines database."*

- *"I think the integration [with PubMed] would be really cool if it could be done …maybe going back and forth both ways."*

E.   Researchers

Data sources for this section come from the NGC evaluation survey, as well as key informant interviews with individuals who identified themselves are "researchers." A relatively large subset of survey respondents identified themselves as researchers (n=1,219).

The "researcher" module of the survey gathered information on 1) the influence of NGC on researchers' efforts and processes when trying to obtain guidelines, and 2) their use of other AHRQ products in their research efforts. Qualitative data from a single individual who was exclusively within the researcher stakeholder group was also conducted. The results from this single interview are not presented here.

1. NGC's Influence and Impact   Researchers

a)   *Survey Findings*

The "researcher" module of the NGC survey included a question to assess NGC's influence on four guideline-related activities relevant to researchers. Specifically, NGC influence among researchers was assessed for:

- Data collection processes
- Approach to identifying guidelines (in general)
- Ability to identify "high quality" guidelines
- Ability to identify "current" guidelines

Researchers could respond based on a Likert scale for the degree of NGC's influence which ranged from "not at all" to "to a great extent." ("Don't know" was also an option.) As shown in Figure 27, below, a large portion of researchers responded that NGC greatly influenced their work with clinical guidelines. More than 75% (ranging from 76% - 80%) of researchers responded that NGC influenced "to a great extent" or "somewhat" their approach to identifying guidelines, and their ability to identify high quality and current guidelines. In contrast, 30% said that NGC influenced their data collection processes "very little" or "not at all."

**Figure 27: NGC's Influence on Researchers**
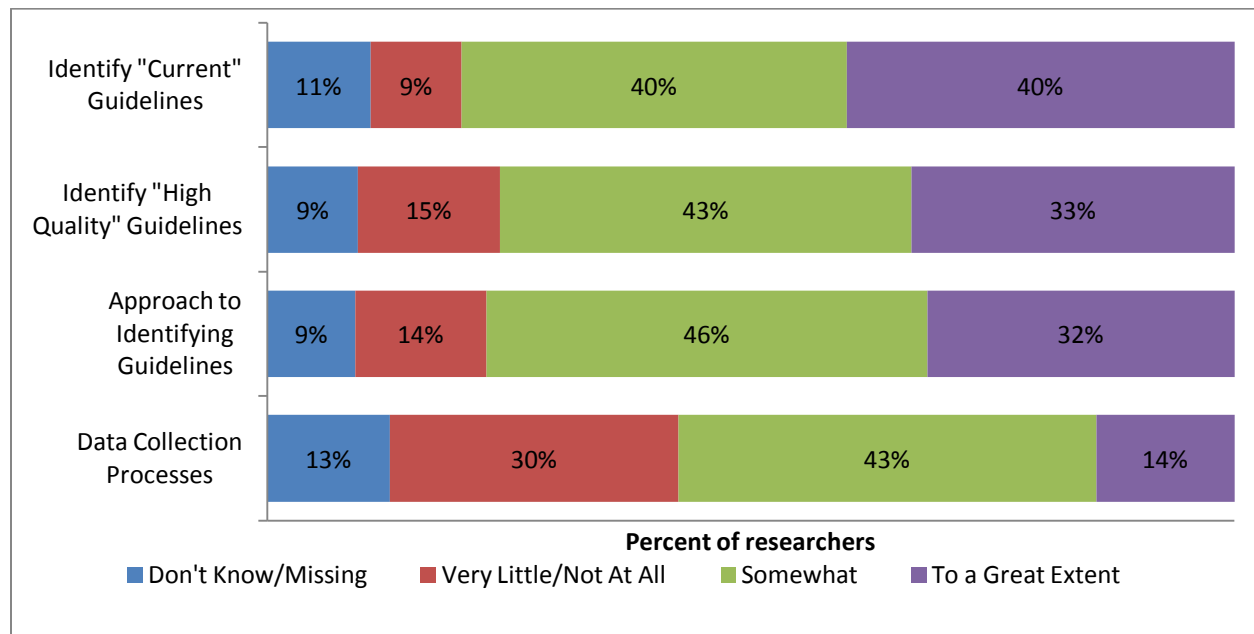
2. Use of other Research Tools – Researchers

a)   Survey Findings

AHRQ is also interested in whether or not NGC stakeholders use other AHRQ products. One question in this module asked researchers to identify all AHRQ-sponsored products that they use in their research efforts. As shown in Figure 28, the most commonly used products include: systematic evidence reviews (68%), comparative effectiveness reviews (52%), and other AHRQ products (44%). Those less commonly used include DEcIDE and CERT project reports (9%). This overall pattern was similar to the pattern of use reported by guideline developers; however, the percentage of researchers who used each product was slightly higher than it was for guideline developers.

Figure 28: Percentage of Researchers that Use AHRQ-sponsored Products for Research Efforts
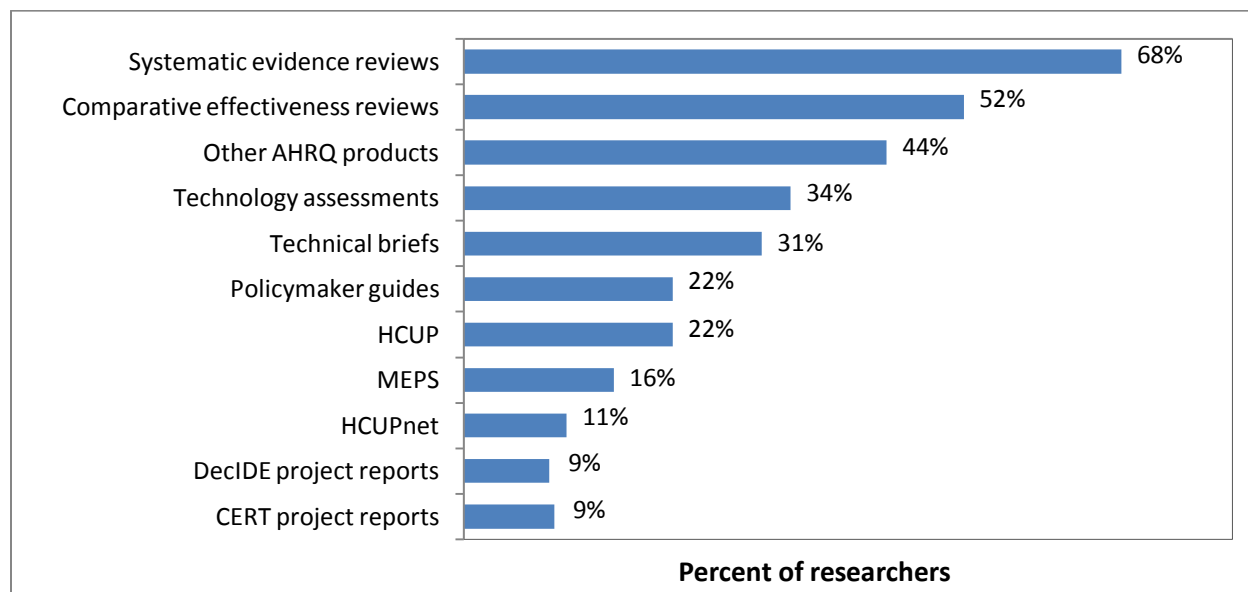
F.   Measure Developers

A small subset of survey respondents (6%) identified themselves as "measure developers" (n=351). In this section, we summarize survey responses from this stakeholder group. In addition, key findings from a small number (n=4) of key informant interviews with "measure developers" are also presented.

The measure developer survey module gathered information on: 1) the influence of the NGC on measure developers' development and implementation of quality measures; 2) their use of NGC as an input to measure development efforts; and 3) if they submitted measures to AHRQ's National Quality Measures Clearinghouse™ (NQMC).

1.   Use of Guidelines and NGC in Measure Development

a)   Survey Findings

One question of the NGC evaluation survey asked "measure developers" the degree to which they or their organizations use NGC as an input for their measure development activities. Respondents answered this question using a Likert scale with options ranging from "to a great extent" to "not at all." Sixty-two percent of the respondents said that they used NGC as an input for their measure development activities either to a "great extent" or "somewhat." This is shown in Figure 29, below.

Figure 29: Use of NGC as Input for Measure Development Activities

	To a great extent	Somewhat	Very little	Not at all	Don't know
■ Percent	14%	48%	17%	8%	9%
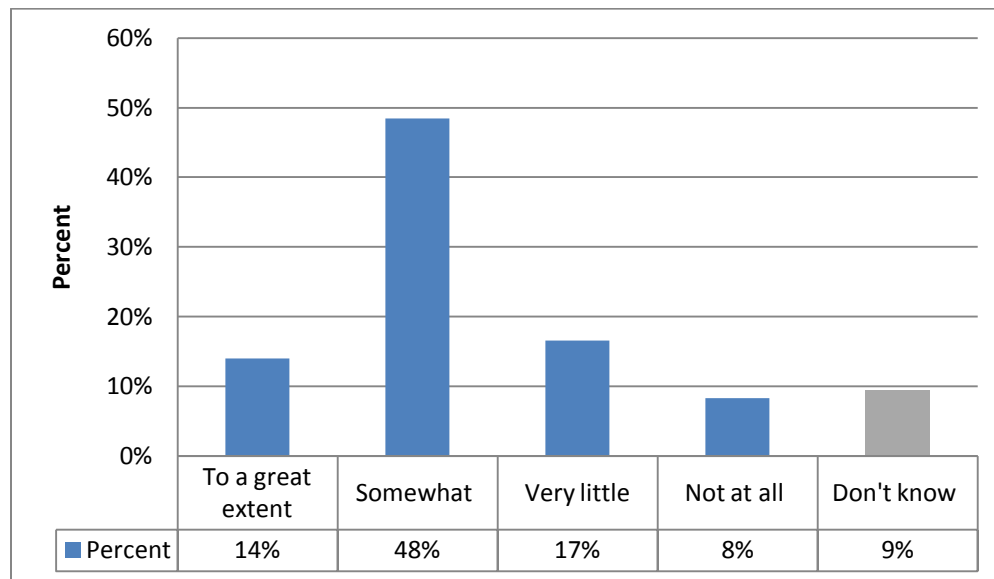
b)   Qualitative Findings – Use of Guidelines and NGC in Measure Development

The finding from the survey presented above is comparable to reports from a limited number of key informant interviews (n=4) with individuals who were identified as measure developers. Participants in this module were asked:

Does your organization use NGC as an input for its measure development activities?

In these reports, evidence-based guidelines, and those available through NGC in particular, were identified as a starting point or a key input in measure development activities. However, these individuals also noted that measure developers must evaluate a large range of evidence when developing measures, and guidelines are only one source of this evidence. Therefore, many of their comments indicate that they use guidelines in association with a myriad of other evidence sources.

A few excerpts from the respondents' discussions on how they use NGC in their measure development activities are presented below:

- *"..in the process of measure development, we always look for evidence-based measures that are reliant on randomized control trials, meta-analysis types of articles, and existing guidelines. So, as part of our evidence review and literature review process, we look to NGC, initially, actually, to display the existing guidelines on a particular topic. Once we have those guidelines, I then look at the references on which those guidelines were based, so that I can judge the level of evidence."*

- *"I work with a couple of organizations when they need to develop measures... When they have a call for measures in a given area, a group, an organization, may decide that they want to try to submit some measures into that project to see if they can get endorsed. So they'll contact me, and my colleague, to help them develop the measure to appropriate and up-to-date, evidence-based measure as possible. So in that regard, I actually do [use NGC], because I'm trying to collect the*

most up-to-date evidence, and the most widely accepted evidence, I do turn to guidelines very frequently, when developing measures. And, to answer your next question, the most common source that I use is the National Guidelines Clearinghouse. I do go to it quite often to see what's out there in a particular area, and then use that to help guide us in our decision-making."

- *"I used it [NGC] as a reference, just to, when we had a project and we had measures come in, I would go in and double check to see if the measures were consistent with the most up-to-date guidelines that were out there."*

- *"It's [NGC] definitely used in the development of quality measures. Yeah, just because it's a source people turn to, to make sure that they're up to date when they're developing the measures."*

2. NGC's Influence and Impact – Measure Developers

a) *Survey Findings*

A question in the "measure developer" module of the survey asked respondents about the influence of NGC on three activities relevant to measure developers:

- Development of quality measures
- Use of quality measures
- Approach to identifying guidelines

Measure developers could respond based on a Likert scale which ranged from "to a great extent" to "not at all." ("Don't know" was also an option.)

The large majority of measure developers responded that the NGC influences the three activities "to a great extent" or "somewhat." For instance, 87% of measure developers said that NGC has influenced their measure development activities "somewhat" or "to a great extent." Similarly, 78% of respondents said that NGC has influenced "somewhat" or "to a great extent," their approach to identifying guidelines. This is shown in Figure 30, below.

Figure 30: NGC Influence on Measure Developers' Guideline Activities
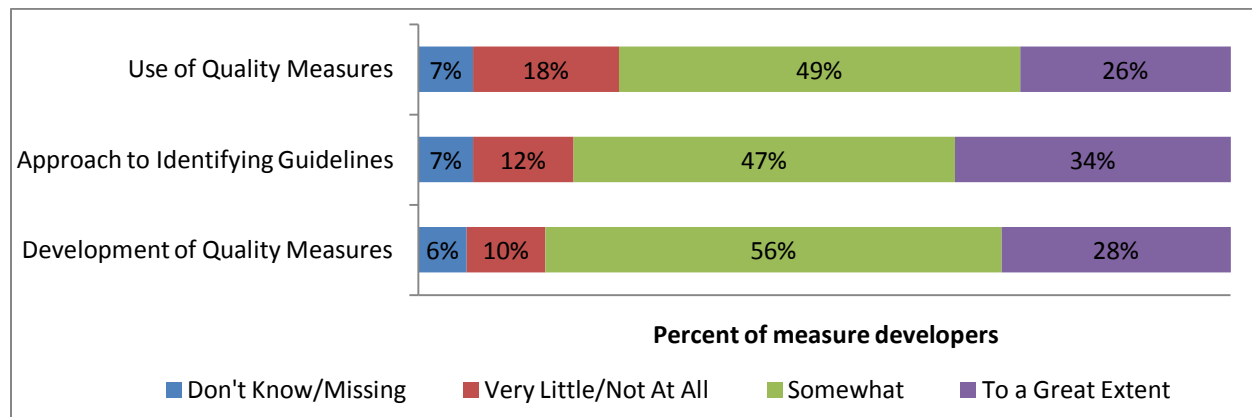
However, although measure developers who responded to the survey report using NGC, only 16% said that they (or their organization) submit their quality measures to AHRQ's National Quality Measures Clearinghouse™.

b)   Qualitative Findings – NGC Influence for Measure Developers

The findings from the survey presented above are consistent with a limited number of key informant interviews (n=4) with individuals who were identified as measure developers. Participants were asked:

How, if at all, has NGC influenced your development and/or use of quality measures?

In these reports, NGC has been a useful source of information when developing measures and serves as a convenient resource or accessing guidelines, which are often used to inform quality measure development. No other trends in NGC influences were noted.

A few excerpts from the respondents' discussions on how they use NGC in their measure development activities are presented below:

- *"..I would say it's [NGC] definitely used in the development of quality measures. Yeah, just because it's a source people turn to, to make sure that they're up to date when they're developing the measures."*

- *"I do go to it [NGC] quite often to see what's out there in a particular area, and then use that to help guide us in our decision-making."*

- *"I think in terms of influence, it's minimal, if any... It really is more just a tool for you when you're in need of guidelines."*

G.   Policymakers, Purchasers, Quality Improvement Specialists, Other

A relatively large subset of survey respondents identified themselves as "healthcare purchaser, policymaker, quality improvement specialist, other" (n=1,219). In this section we summarize for this stakeholder group, 1) the uses of NGC; 2) the influence of NGC; 3) the use of other AHRQ resources by this group; and 4) enhancements that would be of use to this stakeholder group. In addition, key findings from key informant interviews with individuals from this stakeholder group are presented.

1. Use of NGC – Policymakers/Purchasers, Other

Data from the key informant interviews with healthcare policymakers/purchasers highlight some of the primary reasons this stakeholder group uses the NGC. Participants in the key informant interviews described NGC as one of the primary resources that they use to find guidelines, particularly when they are developing policies or making coverage decisions. Information from guidelines is one of the pieces of information that is considered in their decision-making.

Some excerpts are presented below.

- *"Any time that we are revisiting policy or trying to establish new policy, or which, there's a report of an update. So it comes up not infrequently – probably several times, several times a quarter would not be unusual… NGC is in my view kind of a one-stop shopping. I'm hoping that every relevant guideline will probably be there on any given topic."*

- *"One reason is to use guidelines as part of a larger umbrella, which is evidence-based medicine; hopefully EBM guides policy. Guidelines are a part of EBM, so part of policy formulation is understanding if the evidence has been synthesized and been made specific, in the form of guidelines."*

- *"I use the National Guideline Clearinghouse a lot.…in my policy role at Medicaid, we are constantly approached about new therapies, diagnostics, other interventions, referrals that are being requested, and we…have worked up a process by which we do a checklist analysis of things. And one of the checks on the checklist, whenever we have a request, is to simply look at the guidelines that might govern something."*

- *"There's a section of the published decision memoranda for Medicare and national coverage determinations that includes the space for us to list evidence-based guidelines that may bear on the topic under review. So we literally, just either list them there with a brief summary of what the guideline says, or something along those lines… [NGC] is usually a convenient first place to look for guidelines that have at least had some level of vetting."*

2. NGC's Influence and Impact – Policymakers/Purchasers, Other
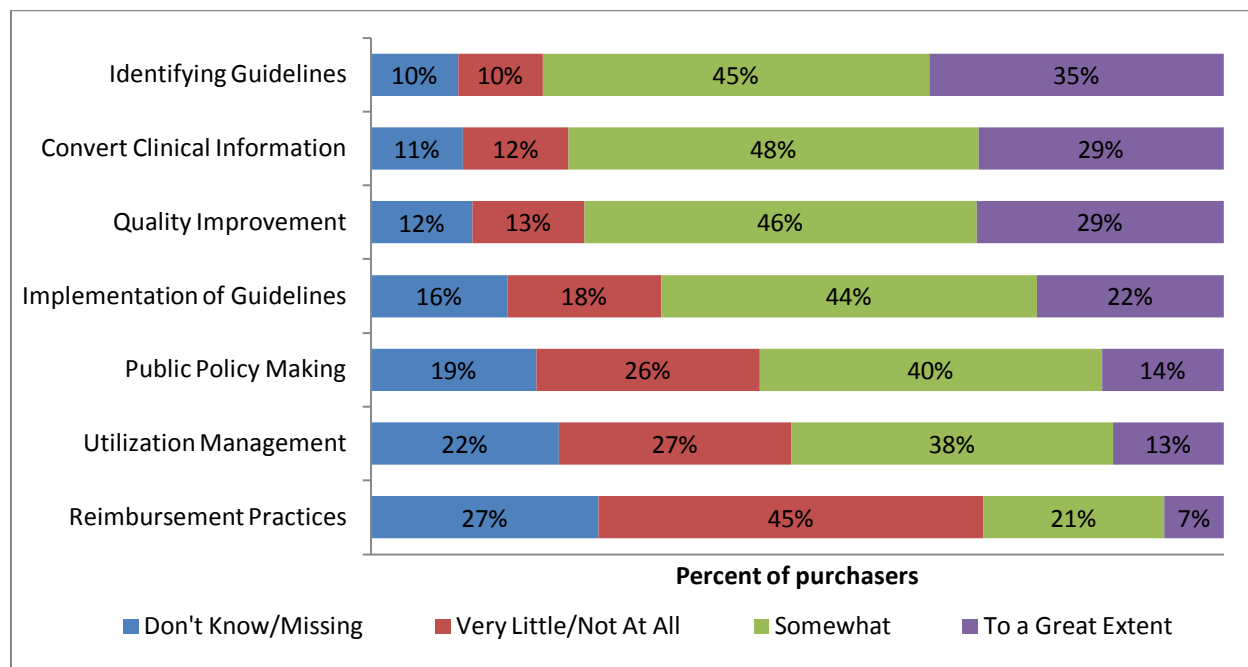
a) Survey Findings

The policymaker/purchaser module of the NGC survey included a series of questions to assess NGC's influence on eight guideline-related activities relevant to policymakers, purchasers, quality improvement specialists, and others. Specifically, NGC influence was assessed for their:

- Decision-making processes
- Organization's approach to public policymaking
- Efforts to convert clinical information to knowledge that can be acted on
- Utilization management
- Medical reimbursement practices
- Organization's implementation of clinical practice guidelines
- Quality improvement efforts
- Approach to identifying guidelines

Respondents could respond based on a Likert scale for the degree of NGC's influence, which ranged from "not at all" to "to a great extent." ("Don't know" was also an option.) As shown in Figure 31, below, a large portion of the policymakers, purchasers, and others completing this module responded that the NGC greatly influenced their work with clinical guidelines.

Approximately 80% responded that NGC influenced "to a great extent" or "somewhat" their approach to identifying guidelines. Nearly as many (75%-77%) also responded that NGC has influenced "somewhat" or "to a great extent," their ability to convert clinical information into action and their quality improvement activities. In contrast, 45% said that NGC influenced their reimbursement practices "very little" or "not at all."

Figure 31: NGC Influence on Policymakers/Purchasers' Guideline-Related Activities

b)   Qualitative Findings – NGC's Influence on Policymakers/Purchasers

The findings from the survey presented above are consistent with a limited number of key informant interviews (n=4) with individuals who were identified as measure developers. Participants were asked:

How, if at all, has NGC influenced the following activities?

In these reports, NGC has been a useful source of information for policymakers in identifying information on a topic of interest and assisting, in some instances, with coverage decision-making.

A few excerpts from the respondents' discussions on how they use NGC in their policymaking and other activities are presented below:

- *"I think it's been influential, but I think it's been most important as an intermediate step in the development of other published material that describes the guidelines."*

- *"It [NGC] has helped us make a decision on whether to cover or not to cover a certain service. We make those decisions for coverage in our Medicaid system. If we're asked to cover something*

that has very little evidence, or something that has one guideline, and the guideline is not all that helpful, we may choose to wait and see what happens on that. … There have been times that we've been asked to cover something for a population that was much larger than the population really described in the guideline. And so, that's enabled us to say, we're only going to cover it in this particular situation. A good example of that would be spinal cord stimulator devices, and people want to use them for a wide range of pain disorders. We actually were able to use guidelines, including those published on NGC, to sort of say, this is the place that there is data. We will cover it for failed back surgery syndrome, we will cover it for complex regional pain, but we're not covering it for these other conditions."

- *"If you use it [NGC], and you use it more often as you get familiar with it, then you are introducing a bit more of an evidence-based style of practice."*

- *"It [NGC] does play an important role in quality…. And anything that pulls together, helps people access the available information is important to be able to drive quality…by ensuring that we have the right denominator – I mean, we've looked at all the relevant guidelines on a particular topic – that it has improved quality, because we're able to compare and say this is what the current thinking is in the practice community, this is what the best understanding of the literature says should be done."*

3. Use of other Research Tools – Policymakers/Purchasers

a) *Survey Findings*

A question in this module asked policymakers, purchasers, and others to identify all AHRQ-sponsored products that they utilize to inform their policy decision-making. The most commonly used products include: systematic evidence reviews (42%), comparative effectiveness reviews (33%), and other technology assessments (25%). Those less commonly used include DEcIDE and CERT project reports (4 and 7%, respectively). This overall pattern was similar to the pattern of use reported by guideline developers and researchers. See Figure 32 below.

Figure 32: Percentage of Policymakers, Purchasers, and Others that Use AHRQ-sponsored Products for Research Efforts
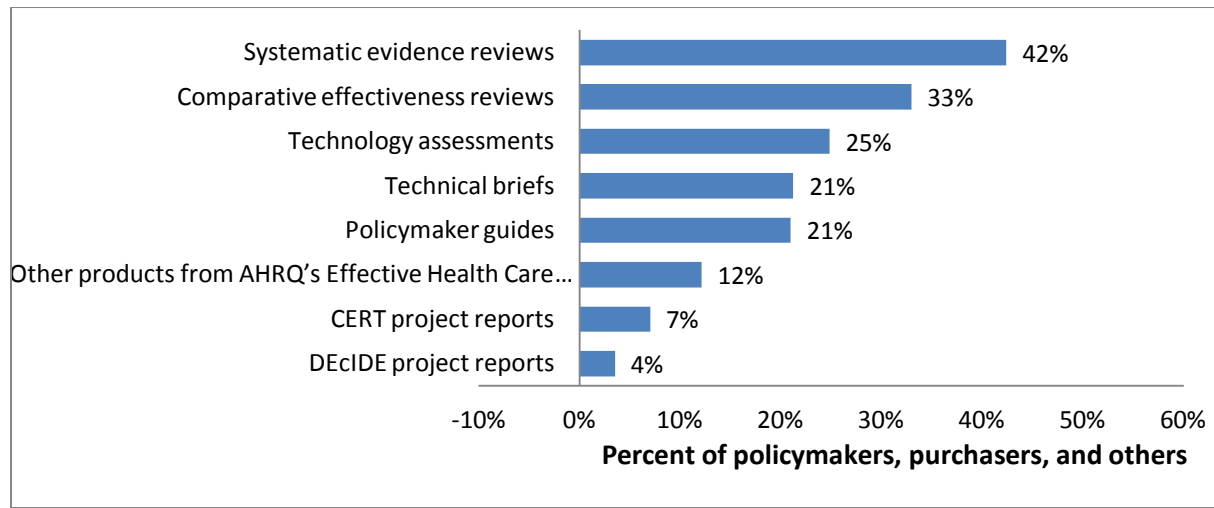
b)   Qualitative Findings – Use of AHRQ Products by Policymakers/Purchasers

The findings from the survey presented above are consistent with a limited number of key informant interviews (n=4) with individuals who were identified as policymakers. Key informants were each asked:

To the best of your knowledge, does your organization use other AHRQ-sponsored products to inform its policymaking activities?

Several of the respondents reported using other AHRQ products. Two excerpts from the respondents' discussions on whether or not they or their organizations use other AHRQ products are presented below:

- *"I like looking at the AHRQ Web site in general when I have a question and search through it, so, I've at some point used many of those [AHRQ products]… and the U.S. Preventive Services Task Force. But I like to look periodically on there… So the answer is yes, we try and use AHRQ in general, the Web site, and try and find, whether it's a clearinghouse or, as you say, evidence review, to help out."*
- *"We do [use other AHRQ products], but NGC was there long before these others really came to our attention."*

V.   Conclusions and Recommendations

The evaluation demonstrated that NGC is a well-known and trusted source for clinical guidelines among all stakeholder groups who participated (either through the electronic survey or through focus group sessions or key informant interviews.

Those that used NGC were more satisfied with NGC relative to other guideline sources, had used NGC for a long time, and were likely to recommend it to others. Key findings are summarized below.

Awareness and Use of NGC

Measures of NGC awareness were obtained using a Web-based survey fielded using e-mail subscription lists for AHRQ, AMA, and AHIP.

- **Most survey respondents were aware of NGC (n=7,223; 78%) and the large majority of those who were aware reported that they use NGC (n=5,828; 81%).**

- **A relatively large proportion of respondents who were not NGC users (75%) reported that they used clinical guidelines frequently or very frequently.**

Use of Other Guideline Sources

- **NGC use was complementary to the use of other guideline sources; survey respondents who used NGC tended to use more alternative sources than those who did not use NGC.**

Based on results from the survey, NGC users were more likely to use six or more sources in addition to NGC (30%) than those unaware of NGC (6%) and non-users who were aware of NGC (10%). Among stakeholder groups, librarians were more likely to use six or more guideline sources in addition to NGC when searching for guidelines (42%) compared to other stakeholder groups (range: 30% -33%). Of the 17 sources listed, the most popular alternative source used to locate clinical guidelines was PubMed/Medline (54%).

Data from the qualitative component of this evaluation were consistent with this finding. Most stakeholder groups who participated in focus group sessions or key informant interviews noted that NGC is one of the sources they use to find guidelines, but not the only source. However, many of these participants noted that NGC is often their "first go-to source" for guidelines.

Length and Frequency of NGC Use

- **NGC users tend to have used the site frequently over a long period of time.**

The largest proportion of survey respondents who report using NGC also reported they had been

using the site for between two and five years (37.7%). The second-most-frequent category was newer users of less than two years (32.7%), followed by experienced users of greater than five years (27.7%). Among stakeholder groups, librarians were the most likely to have used the NGC Web site for more than five years (42%) and were less likely to have used for less than two years (20%). Guideline developers followed librarians, at 34% and 26%, respectively.

Almost all NGC users used the site at least once in the past one year (97.1%). A majority accessed the NGC Web site between one and 10 times (65.1%), and a substantial number used the site more than 10 times within the last year (29.6%).

Qualitative data were consistent in many ways with this finding. Most stakeholder groups who participated in focus group sessions or key informant interviews noted that they have been using NGC "for a very long time." There was wide variability in terms of the frequency of their use ranging from weekly to once or twice a year. Their frequency of use was often related to their specific uses of the NGC Web site.

Satisfaction, Trustworthiness and Appropriateness of Inclusion Criteria

- **NGC users were equally satisfied or more satisfied with NGC compared to other guideline sources.**

Thirty-eight percent of survey respondents rated NGC as about equal to other sources, while a near majority (47%) of respondents were either slightly or much more satisfied with NGC. Few respondents reported being slightly less satisfied or much less satisfied with NGC (13%).

Among stakeholder groups, librarians and informatics specialists were the most likely to choose "more satisfied" with NGC than other guideline sources (60% and 58%, respectively). Guideline developers were the most likely to choose "less satisfied" with NGC than with other guideline sources (18%).

Qualitative data were consistent with this finding. There were very few reports from participants of NGC being less useful than other sources. Some notable features of NGC that were commonly cited by respondents as better through NGC relative to other sources were the diversity and comprehensiveness of the content available on the Web site, the guideline comparison tools (including both guideline syntheses and the dynamic guideline comparison tool), and the fact that it is publicly available. Some features or issues that were commonly cited as problems for NGC when compared to other guideline sources were the currency of the information available, the time that it takes for new content to be posted, and search result sets that contain a lot of irrelevant content. However, even among those participants identifying features of the Web site that they didn't like, most still highly valued the accessibility and comprehensiveness of the resource.

- **NGC was rated as good as or better than other guideline sources in meeting its users' needs.**

Survey respondents reported that NGC did well in fulfilling NGC users' needs across 11 potential uses of NGC. NGC fulfilled the needs of NGC users particularly well for the following activities: finding clinical guidelines, comparing clinical guidelines, developing clinical guidelines and quality measures, professional knowledge building, and supporting clinical decision-making. Therefore, NGC met its mission in providing a source for individuals interested in finding, comparing, and developing clinical guidelines.

- **The large majority of users found the guidelines on the NGC Web site trustworthy. However, based on qualitative data, some differences in the degree of trust exist among stakeholder groups.**

When NGC users were asked how they would rate the trustworthiness of the guidelines on the NGC, three-quarters of users rated the guidelines' trustworthiness as "very good" or "good," with only 1.25% rating it as "poor." Additionally, based on the survey responses, there were no perceived differences in the trustworthiness of guidelines found on NGC among the different stakeholder groups that were targeted in the survey

Qualitative data were somewhat inconsistent with the findings from the survey. Notably, a number of the participants from the guideline developer and the medical informatician stakeholder groups believed that some of the guidelines included in NGC were, in fact, not trustworthy. Participants from the other stakeholder groups (e.g., medical librarians, measure developers, policymakers) were generally trusting of the content included in NGC and cited that it was a trusted source because it is sponsored by AHRQ.

- **A majority of users believe the NGC inclusion criteria are appropriate. However, based on qualitative data, some differences among stakeholder groups appear to exist, with guideline developers and informaticians being more likely to believe the criteria are too loose.**

Over 60% of users responded that NGC's guideline inclusion criteria were "appropriate." Only 11.5% said they were either too stringent or too loose. Users who had been using NGC for five years or longer were more likely to say that the inclusion criteria were "loose" (7%) compared with those who had used the site for two to five years (4%) or less than two years (2%). Among stakeholder groups, guideline developers were the user group most likely to rate the NGC inclusion criteria as "too loose" (6.3%). While 6% is low, this might suggest that those who develop guidelines would like more clear standards for what is included in NGC.

Qualitative data were inconsistent with the findings from the survey. Notably, a number of the

participants from the guideline developer and the medical informatician stakeholder groups believed that NGC's inclusion criteria are too loose. Participants from the other stakeholder groups (e.g., medical librarians, measure developers, policymakers) were generally in agreement that the criteria were appropriate.

- **The five-year age criterion for guideline inclusion was seen as too long by a large proportion of users in both the quantitative and qualitative findings.**

Compared to responses regarding stringency, respondents were less satisfied with NGC's age criterion. Currently, to be posted on the NGC Web site, a guideline must have been developed, reviewed, or revised within the past five years. Guidelines that do not meet this requirement are either rejected for inclusion or are placed in the NGC Guideline Archive when they become more than five years old. Survey responses regarding the five-year age requirement were bimodal — 43% felt it is "appropriate" and nearly as many (39%) felt that five years is too long. Of those who felt it was too long, the most common recommendation was three years (54% of all responses).

Among stakeholder groups, librarians were the least likely to respond "too long" (37%) and purchasers were the most likely to respond "too long" (49%).

Qualitative data were consistent with the general findings from the survey, with numerous participants in focus group sessions and key informant interviews stating that five years was too long. However, numerous participants from the focus groups also qualified their statements about the age criterion by saying that the appropriate time frame or shelf-life of a guideline is often topic-dependent. Guideline developers also identified the challenges that they face, namely available resources, as the primary challenge they have in keeping their guidelines up to date.

Influence of NGC by Stakeholder Group

NGC has had a significant positive impact on guideline development, implementation, and use across all stakeholder groups. In particular, survey respondents indicated that NGC has to a great extent, or somewhat, influenced:

- **Guideline developers'** ability to identify guidelines and develop and use quality measures

- **Providers'** ongoing learning efforts, clinical decision-making processes, and identification of guidelines

- **Medical librarians'** ability to meet their client's needs

- **Medical librarians'** and **researchers'** ability to identify current and high quality guidelines

- **Measure developers'** development of quality measures
- **Policymakers' and purchasers'** ability to identify guidelines and convert clinical information

The above survey findings are generally supported by the comments of stakeholders in focus groups and key informant interviews. A common theme across all stakeholders in qualitative analyses is that NGC is a useful source for identifying evidence-based guidelines. Among guideline developers, NGC has been less influential in terms of advancing guideline development programs (e.g., guideline methodology and reporting). However, there is some support in both the quantitative (particularly for guideline developers who submit their guidelines to NGC) and qualitative data that NGC's five-year age criterion has had some influence on the frequency with which guideline developers update their guidelines.

Areas for Expanding NGC's Use and Impact

While the findings of this evaluation suggest that most users rate NGC highly, the findings also point to a number of opportunities for AHRQ to expand the use and impact of this public resource:

Potential for Building on NGC's User Base

- **Respondents not currently using NGC desire more information about it.** Among survey respondents who were unaware of NGC or aware of NGC but do not use NGC (n=3,301), approximately 75% report that they use guidelines occasionally, frequently, or very frequently. In addition, 84% (n=2,649) said they would be interested in learning more about NGC. In addition, although based on a very small sample size, awareness among survey respondents solicited through the AMA newsletters (which target healthcare providers) was lower than that observed in the AHRQ and AHIP sampling frames.

    AHRQ has an opportunity, through heightened marketing, to increase its reach to individuals interested in learning about and/or using the NGC Web site, particularly among healthcare providers.

Potential for Advancing Knowledge and Awareness about Good Quality and Executable Guidelines Among Organizations that Submit to NGC

- **Based on qualitative data from various NGC stakeholders, namely guideline developers and informaticians, users think that AHRQ can play more of a role in advancing good practices in developing guidelines.** Informaticians suggested that NGC should play more of a role in advancing efforts to improve the executability or

implementability of guidelines. Some suggest that NGC could do this by rating that attribute of guidelines. Guideline developers likewise reported that having some measure of a guideline's quality would help to distinguish rigorous guidelines from less rigorous guidelines. Guideline developers also expressed interest in guideline developer conferences and/or methodology workshops.

Potential for Enhancing Guideline Dissemination Activities

- **Thirty-five percent of guideline developers who submit their guidelines to NGC rated NGC's dissemination of their guidelines neutral or poor.** AHRQ may want to consider researching additional mechanisms that might be used to enhance the dissemination of evidence-based guidelines included in the clearinghouse.

Potential for Enhancing Healthcare Provider's Use of NGC

- **NGC can improve support for providers' use of clinical guidelines and their ability to practice medicine on a day-to-day basis.** Seventy-two percent (72%; n=2,342) of providers stated that having NGC content delivered to them at the point of care would be useful. Sixty-six percent (66%; n=2,270) said they would take advantage of continuing medical education.

Potential to Revisit NGC's Guideline Age Criterion

- **Based on both quantitative (39% of the survey respondents) and qualitative data collected in this evaluation, many NGC users find the five-year age requirement for guideline inclusion to be too long.** This may contribute to difficulties using NGC if a lot of material is outdated compared to available evidence, or if users feel that the content is not trustworthy because of its age.

Potential to Revisit Inclusion Criteria

- **In qualitative data, both guideline developers and informaticians were more likely to say that NGC's inclusion criteria are too loose. In addition, among survey respondents, guideline developers (in particular, those who submit their guidelines for inclusion in NGC) were the most likely to rate the NGC inclusion criteria as "too loose" (6.3%).** While 6% is low, this might suggest that those who develop guidelines would like clearer standards for what is included in NGC.

Potential to Add Significant Value-Add Enhancements to the NGC Web site

- **Potential enhancements to the NGC Web site resonated with a majority of users.** The survey inquired about the value of 12 potential enhancements to NGC. The most

popular potential enhancements were subject-specific e-mail alerts and ratings of guidelines' quality or methodological rigor. These were closely followed by offering the ability to search archived guidelines, the ability to limit searches of guidelines to information in specific fields, and the ability to access archived guidelines.

Appendix A: PET Roster

Names, Affiliation
Florence Chang National Library of Medicine
Belinda Ireland, The EvidenceDoc, LLC
Richard Shiffman Associate Director for Education Yale Center for Medical Informatics
Katrin Uhlig Tufts Medical Center Director, Guideline Development Tufts Center for Kidney Disease Guideline Development and Implementation
Cally Vinz Director of Evidence-Based Health Care Institute for Clinical Science Improvement (ICSI)

Appendix B: Evaluation Research Questions and Data Sources

Research Questions and Proposed Data Collection Methods

	Research Question	Outcome Measures	Data Does Not Exist to Address Question (Proposed Data Collection Methods)	Data Exists to Address Questions (Either Direct or Indirect)	Comparison Data Available
Questions Related to Process Measures					
1	How often is the NGC Web site accessed annually?	Number of visits per year	NONE	**Direct**: Annual reports, longitudinal analysis of NGC survey data	✓
2	What is the total number of NGC subscribers, on a year-by-year basis?	Number of subscribers	NONE	**Direct**: Annual reports, longitudinal analysis of NGC survey data	
3	Do developers submit guidelines to NGC? All of their guidelines? Why/why not?	Number of guidelines submitted to NGC; percent of developed guidelines that are submitted	1) Interviews with developers 2) Focus groups with developers	**Indirect**: Annual reports, longitudinal analysis of NGC survey data	
4	How many submitted guidelines are accepted to NGC annually?	Percent of guidelines submitted that are accepted by NGC	NONE	**Direct**: Annual reports, longitudinal analysis of NGC survey data	
5	How do developers rate components of the NGC process?	Level of satisfaction with multiple components of NGC (submission process, providing copyright, verification of content, etc.)	1) Focus group with developers 2) Interviews with developers 3) Survey of developers	NONE	
6	How many guidelines are published on NGC annually?	Number of guidelines published annually (new and updates)	NONE	**Direct**: Annual reports, longitudinal analysis of NGC survey data	✓
7	How many research requests does NGC receive annually? What types of requests do they receive?	Number of research requests; types of requests	NONE	**Direct**: 2008 annual report	
8	How long does it take to post a guideline?	Average time from guideline abstraction to verification	NONE	**Direct**: 2nd annual report; 8/08 – 7/09	
Questions Related to Intermediate Outcome Measures					
9	What percent of potential users are aware of NGC?	Percent aware of NGC	1) Interviews 2) Focus groups 3) Survey	NONE	
10	What percent of potential users use NGC?	Percent aware of NGC that use NGC	1) Interviews 2) Focus groups 3) Survey	NONE	
11	How often do users access	Frequency of NGC use in	1) Interviews	**Indirect**: Annual reports,	✓

	NGC? Does it vary by stakeholder group?	total and by stakeholder group	2) Focus groups 3) Survey	longitudinal comparison of NGC survey data	
12	How long, on average, have stakeholders used NGC?	Length of time of NGC use	1) Interviews 2) Focus groups 3) Survey	**Direct:** Annual reports, longitudinal comparison of NGC survey data	
13	Has NGC saved users time in the search for guideline information?	Percent of users who said NGC saved time	1) Interviews 2) Focus groups	NONE	
14	Is the information provided by NGC trusted by users?	Level of trust	1) Focus groups 2) Interviews 3) Survey	NONE	
15	Are users satisfied overall with NGC relative to other sources?	Overall satisfaction with NGC relative to other sources	1) Interviews 2) Focus groups 3) Survey	NONE NGC satisfaction (not relative to other sources) in annual reports, longitudinal comparisons	✓
16	How well do NGC and other guideline sources fulfill your needs in various tasks?	Satisfaction with specific uses of NGC	1) Interviews 2) Focus groups 3) Survey		
17	Does NGC influence guideline development program?	Scale of influence NGC has on various components of guideline development program	1) Interviews with guideline developers 2) Focus groups with guideline developers 3) Survey of guideline developers	NONE	
18	Does NGC influence quality measure development, use, and dissemination efforts?	Scale of influence NGC has on various components of quality measure development, use, and dissemination	1) Interviews with guideline and measure developers 2) Focus groups with guideline and measure developers 3) Survey of guideline and measure developers	NONE	
19	Does NGC influence various data collection, research efforts, and identification of guidelines?	Scale of influence NGC has on various components of research activities	1) Interviews with researchers and medical librarians 2) Focus groups with medical librarians 3) Survey of researchers and medical librarians	NONE	
20	Does NGC influence delivery of care and use of guidelines by clinicians?	Scale of influence NGC has on various components of clinical practice	1) Focus group with clinicians 2) Survey of clinicians	NONE	✓
21	Do informatics specialists currently use or develop Web 2.0 applications to communicate about NGC?	Scale of use and development of Web 2.0 about NGC	1) Interviews with informatics specialist 2) Focus group with informatics specialist 3) Survey of informatics specialist	NONE	✓
22	Do informatics specialists use NGC content as input in developing clinical	Scale of use of NGC content within decision support systems	1) Interviews with informatics specialist 2) Focus group with informatics specialist	NONE	

	information or decision support systems?		3) Survey of informatics specialist		
23	Does NGC influence various activities by provider organizations, health plans, policymakers, others? How?	Scale of influence NGC has on various components of organization's activities	1) Interviews with purchaser, policymaker, other 2) Survey of purchaser, policymaker, other	NONE	
Questions Related to Mediating factors/Intervening variables					
24	Do measure developers that use NGC to identify, evaluate, and/or compare guidelines also submit measures to NQMC?	Percent of quality organizations that submit measures to AHRQ's NQMC	1) Interviews with measure developer 2) Survey of measure developer	Indirect: Annual reports, longitudinal comparison of NGC survey data	
25	How do users rate the guideline inclusion criteria?	Scale of inclusion criteria	1) Interviews 2) Focus groups 3) Survey	NONE	
26	Why do stakeholders use NGC and other guideline sources?	Reasons for use	4) Interviews 5) Focus groups 6) Survey	Direct: Annual reports, longitudinal comparison of NGC survey data (for NGC but not other sources)	✓
27	Where else do stakeholders access guidelines? Why?	Other sites where guidelines accessed	1) Interviews 2) Focus groups 3) Surveys	NONE	
28	What potential enhancements to NGC would be useful/valuable?	Potential NGC enhancements that will be useful/valuable	Users only: 1) Interviews 2) Focus groups 3) Survey	NONE	
29	Do organizations use any other AHRQ-sponsored products to inform guideline development activities?	List of other AHRQ-sponsored products used to inform guideline development activities	1) Interviews 2) Focus groups 3) Survey	NONE	
30	Do respondents use guidelines in their work?	Percent who use guidelines in work	All users/non-users: 1) Survey	NONE	
Questions Related to Longer-term Outcome Measures					
31	Do stakeholders perceive NGC has an influence on the healthcare system, including quality, efficiency, and healthcare costs?	Percent of responses who perceive NGC has an influence on multiple components of the healthcare system	1) Interviews 2) Focus groups	NONE	

Appendix C: NGC Evaluation Questionnaire and Codebook

Agency for Healthcare Research and Quality

Evaluation of the National Guideline Clearinghouse™

Survey Questionnaire and Codebook

OMB No.: 0935-0174

Expiration Date: 29 February 2012

Schematic of the NGC Evaluation Survey Branch Pattern

```
                        ┌─────────────────┐
                        │    Section 1     │
                        │ Initiate Survey  │
                        │      NGC         │
                        │   AWARENESS      │
                        │    SCREENER      │
                        └─────────────────┘
                   ┌──Yes──────────No──┐
                   │                    │
        ┌─────────────────┐   ┌─────────────────┐
        │   Section 2A     │   │   Section 2B     │      ┌─────────────┐
        │  (NGC AWARE)     │   │ (NGC UNAWARE)    │─────▶│ END Survey  │
        │   NGC User       │   │  Respondent      │      └─────────────┘
        │   SCREENER       │   │ Characteristics, │
        └─────────────────┘   │  Guideline Use   │
           ┌─Yes──────No─┐    └─────────────────┘
           │              │
  ┌─────────────────┐  ┌─────────────────┐
  │    Section 3     │  │    Section 2B    │     ┌─────────────┐
  │  (NGC USER)      │  │ (NON NGC USER)   │────▶│ END Survey  │
  │  Respondent      │  │  Respondent      │     └─────────────┘
  │ Characteristics, │  │ Characteristics, │
  │ Guideline Use,   │  │  Guideline Use   │
  │   NGC use        │  └─────────────────┘
  └─────────────────┘
```

Section 4 **Guideline Developer**	Section 4 **Physician, Nurse, Other Healthcare Professional**	Section 4 **Medical Librarian**	Section 4 **Informatics Specialist**	Section 4 **Researcher**	Section 4 **Health Plan, Policymaker, Other**	Section 4 **Measure Developer**
END Survey	END Survey	END Survey	END Survey	END Survey	END Survey	END Survey

Section 1 – NGC Awareness Screening			
#	Question	Measurement Scale	Skip Pattern
1	Are you aware of the Agency for Healthcare Research and Quality (AHRQ) **National Guideline Clearinghouse**™ (NGC; www.guideline.gov), a Web-based clearinghouse for access to evidence-based clinical practice guidelines?	□ Yes □ No	If "YES", skip to Section 2A If "NO", skip to Section 2B

Section 2A – Use of NGC (AWARE OF NGC; "yes" to question 1)			
#	Question	Measurement Scale	Skip Pattern
2	Have you ever used the **National Guideline Clearinghouse**™ Web site?	□ Yes □ No	If "YES", move to Section 3 If "NO", move to section 2B

Section 2B – Respondent Characteristics and Use of Clinical Practice Guidelines (UNAWARE OF NGC; "NO" to question 1, section 1 OR AWARE OF NGC but have never used the NGC Web site; Answered "NO" to question 2, section 2B)			
#	Question	Measurement Scale	Skip Pattern
2	Where do you reside?	□ United States Northeast Region (Maine, New Hampshire, Vermont, Massachusetts, Rhode Island, Connecticut, New York, New Jersey, Pennsylvania) □ United States Midwest Region (Ohio, Indiana, Illinois, Michigan, Wisconsin, Minnesota, Iowa, Missouri, North Dakota, South Dakota, Nebraska, Kansas) □ United States South Region (Delaware, Maryland, District of Columbia, Virginia, West Virginia, North Carolina, South Carolina, Georgia, Florida, Kentucky, Tennessee, Alabama, Mississippi, Arkansas, Louisiana, Oklahoma, Texas) □ United States West Region (Montana, Idaho, Wyoming, Colorado, New Mexico, Arizona, Utah, Nevada, Washington, Oregon, California, Alaska, Hawaii) □ Canada □ Latin America □ Europe □ Africa □ Asia □ Australia/New Zealand □ Other	Go to question 3 (2B)

3	Which one of the following occupational categories best describes you?	□ Physician □ Physician Assistant □ Nurse/Nurse Practitioner □ Pharmacist □ Dentist □ Other Clinical Specialist □ Hospital/Health Plan Administrator □ Health Care Consultant □ Health Services/Clinical Researcher □ Epidemiologist/Biostatistician □ Guideline Developer □ Measure Developer □ Health Care Purchaser/Employer □ Health Care Provider □ Federal/State/Government Policymaker □ Legal Professional □ Informatician/Informatics Specialist □ Medical Librarian/Info Specialist □ Medical Writer/Editor □ Medical Student □ Nursing Student □ Pharmacy Student □ Other Student □ Patient/Consumer □ Quality Manager/Specialist □ Other [Please Specify]	Go to question 4 (2B)
4	Do you use clinical practice guidelines in your occupation?	□ Very Frequently □ Frequently □ Occasionally □ Rarely □ Very Rarely □ Never	If NEVER, go to question 6 (2B) If anything other than NEVER, go to question 5 (2B)

5	From which of the following sources have you obtained clinical practice guidelines in the past 12 months? (Check all that apply)	□ Pubmed/Medline □ From a search using a general purpose Web search engine (e.g., Google) □ Point-of-care Web-based resources (e.g., DynaMed, Essential Evidence Plus, EMedicine) □ Medscape □ U.S. Preventive Services Task Force □ UK Guideline Sources (e.g., NICE, SIGN) □ Guidelines Advisory Committee (Canada) □ Guidelines International Network (G-I-N) □ Institute for Clinical Systems Improvement (ICSI) □ Colorado Clinical Guidelines Collaborative (CCGC) □ Milliman Care Guidelines® □ Expert Consensus Guidelines® (EKS®) □ Medical Specialty Society guidelines (e.g., AACE, AAFP, AAN, AAO, AAOS, AAP, ACC, ACCP, ACEP, ACP, ACPM, ACR, AGA, ASCO, ASGE, IDSA, SAGES) □ Professional or Disease Specific Society guidelines (e.g., AASM, AARC, ACS, ADA, AHA, ASPEN, BTF, HFSA, NKF, SCCM) □ Government guidelines (e.g., CDC, NHLBI, SAMHSA, TFCPS, DoD/VHA) □Commercial products (e.g., UpToDate; ACP Pier) (please specify) □ Other government entities □ Other [Please Specify]	Go to question 6 (2B)
6	Would you be interested in learning more about the National Guideline Clearinghouse™ as a source for evidence based clinical practice guidelines?	□ Yes □ No	Complete survey and provide link to NGC for interested respondents
Section 3 – Respondent Characteristics, Use of Clinical Guidelines, and Use of NGC (AWARE OF NGC and have used the NGC Web site)			
# Question	Measurement Scale	Skip Pattern	

| 3 | Where do you reside? | □ United States Northeast Region (Maine, New Hampshire, Vermont, Massachusetts, Rhode Island, Connecticut, New York, New Jersey, Pennsylvania)
 □ United States Midwest Region (Ohio, Indiana, Illinois, Michigan, Wisconsin, Minnesota, Iowa, Missouri, North Dakota, South Dakota, Nebraska, Kansas)
 □ United States South Region (Delaware, Maryland, District of Columbia, Virginia, West Virginia, North Carolina, South Carolina, Georgia, Florida, Kentucky, Tennessee, Alabama, Mississippi, Arkansas, Louisiana, Oklahoma, Texas)
 □ United States West Region (Montana, Idaho, Wyoming, Colorado, New Mexico, Arizona, Utah, Nevada, Washington, Oregon, California, Alaska, Hawaii)
 □ Canada
 □ Latin America
 □ Europe
 □ Africa
 □ Asia
 □ Australia/New Zealand
 □ Other | Go to question 4 (3) |

4	Which one of the following occupational categories best describes you?	□ Physician □ Physician Assistant □ Nurse/Nurse Practitioner □ Pharmacist □ Dentist □ Other Clinical Specialist □ Hospital/Health Plan Administrator □ Health Care Consultant □ Health Services/Clinical Researcher □ Epidemiologist/Biostatistician □ Guideline Developer □ Measure Developer □ Health Care Purchaser/Employer □ Health Care Provider □ Federal/State/Government Policymaker □ Legal Professional □ Informatician/Informatics Specialist □ Medical Librarian/Info Specialist □ Medical Writer/Editor □ Medical Student □ Nursing Student □ Pharmacy Student □ Other Student □ Patient/Consumer □ Quality Manager/Specialist □ Other [Please Specify]	Go to question 5 (3)
5	How did you learn about the National Guideline Clearinghouse (NGC)?	□ General purpose Web search engine (e.g., Google, Yahoo, etc.) □ AHRQ Web site □ Link from another health-related Web site □ Print media □ Word of mouth, or from a colleague or friend □ Do not recall □ Other [Please Specify]	Go to question 6 (3)
6	How long have you been using the NGC Web site?	□ Less than 12 months □ 1 to 2 years □ >2 to 3 years □ >3 to 4 years □ >4 to 5 years □ More than 5 years	Go to question 7 (3)

7	How often have you visited the NGC Web site in the past 12 months?	□ 0 times □ 1-10 times □ 11-25 times □ 26-50 times □ 50+ times	If "0 times", go to question 7 (3) Otherwise, skip to question 8 (3).
8	If you have not visited the NGC in the past 12 months, why not?	□ No need to locate clinical guideline information □ Needed the information, but went without it □ Needed the information, but used other guideline source instead of NGC □ Other [Please Specify]	Go to question 8 (3)
9	From which other sources have you obtained clinical practice guidelines in the past 12 months? (Check all that apply)	□ Pubmed/Medline □ From a search using a general purpose Web search engine (e.g., Google) □ Point-of-care Web-based resources (e.g., DynaMed, Essential Evidence Plus, EMedicine) □ Medscape □ U.S. Preventive Services Task Force □ UK Guideline Sources (e.g., NICE, SIGN) □ Guidelines Advisory Committee (Canada) □ Guidelines International Network (G-I-N) □ Institute for Clinical Systems Improvement (ICSI) □ Colorado Clinical Guidelines Collaborative (CCGC) □ Milliman Care Guidelines® □ Expert Consensus Guidelines® (EKS®) □ Medical Specialty Society guidelines (e.g., AACE, AAFP, AAN, AAO, AAOS, AAP, ACC, ACCP, ACEP, ACP, ACPM, ACR, AGA, ASCO, ASGE, IDSA, SAGES) □ Professional or Disease Specific Society guidelines (e.g., AASM, AARC, ACS, ADA, AHA, ASPEN, BTF, HFSA, NKF, SCCM) □ Government guidelines (e.g., CDC, NHLBI, SAMHSA, TFCPS, DoD/VHA) □Commercial products (e.g., UpToDate; ACP Pier) (please specify) □ Other government entities □ Other [Please Specify]	Go to question 10 (3)

10	Please indicate the degree to which use of the NGC Web site fulfills your needs for each of the following tasks:		To a great extent	Somewhat	Very little	Not at all	Not a current need when using NGC	Go to question 11 (3)
		Finding clinical practice guidelines	□	□	□	□	□	
		Comparing guidelines	□	□	□	□	□	
		Development of a clinical practice guideline	□	□	□	□	□	
		Development of quality measures	□	□	□	□	□	
		Academic/medical research	□	□	□	□	□	
		Research or class assignment	□	□	□	□	□	
		Professional knowledge building	□	□	□	□	□	
		Supporting clinical decision-making	□	□	□	□	□	
		Reducing errors/malpractice (risk management)	□	□	□	□	□	
		Rationalizing and controlling healthcare expenditures	□	□	□	□	□	
		Determining coverage of services	□	□	□	□	□	
		Other task or reason for use o N C: (Please specify)	[Please Specify]					

11	Please indicate the degree to which use of OTHER GUIDELINE SOURCES (other than NGC) fulfill your needs for each of the following tasks:		To a great extent	Somewhat	Very little	Not at all	Not a current need when using OTHER SOURCE	Go to question 12 (3)
		Finding clinical practice guidelines	□	□	□	□	□	
		Comparing guidelines	□	□	□	□	□	
		Development of a clinical practice guideline	□	□	□	□	□	
		Development of quality measures						
		Academic/medical research	□	□	□	□	□	
		School assignment	□	□	□	□	□	
		Professional knowledge building	□	□	□	□	□	
		Supporting clinical decision making	□	□	□	□	□	
		Reducing errors/malpractice (risk management)	□	□	□	□	□	
		Rationalizing and controlling healthcare expenditures	□	□	□	□	□	
		Determining coverage of services	□	□	□	□	□	
		Other task or reason for use of OTHER SOURCE: (Please specify)	[Please Specify]					
12	Overall, how would you rate your satisfaction of the NGC compared to the other guideline source you frequent most often?	□ Much less satisfied with NGC □ Slightly less satisfied with NGC □ Satisfaction about equal □ Slightly more satisfied with NGC □ Much more satisfied with NGC						Go to question 13 (3)

13	How likely are you to continue using the NGC Web site?	□ Definitely □ Very likely □ Probably □ Possibly □ Probably not □ Definitely not □ Don't know	Go to question 14 (3)
14	How likely are you to recommend the NGC Web site to your colleagues?	□ Definitely □ Very likely □ Probably □ Possibly □ Probably not □ Definitely not □ Don't know	Go to question 15 (3)
15	How would you rate the trustworthiness of the guidelines included in NGC?	□ Very poor □ Poor □ Acceptable □ Good □ Very good □ Don't know	Go to question 16 (3)
16	How would you rate NGC's guideline inclusion criteria	□ Stringent □ Appropriate □ Loose □ Don't know	Go to question 17 (3)
17	NGC's current inclusion criteria require that guidelines included on the Web site have been reviewed, revised, or developed within the last five years. How would you rate this timeframe?	□ Too long (should be reduced to 4 years) □ Too long (should be reduced to 3 years) □ Too long (should be reduced to 2 years) □ Appropriate □ Too short (should be lengthened) □ Don't know	Go to question 18 (3)

18	How likely would you be to use any of the following enhancements to the NGC Web site		Definitely	Very likely	Probably	Possibly	Probably not	Definitely not	Don't know	Go to the introduction to Section 4 which allows users to select the most appropriate questions to answer
		Subject-specific e-mail alerts	□	□	□	□	□	□	□	
		Ratings of a guideline's quality and/or methodologic rigor (e.g., AGREE score)	□	□	□	□	□	□	□	
		NGC user forums (e.g., blogs, bulletin boards) that promote discussion, education, and collaboration on clinical guidelines	□	□	□	□	□	□	□	
		NGC summary content formatted for mobile device (e.g., cell phone, pocket PDAs)	□	□	□	□	□	□	□	
		Additional data exporting options	□	□	□	□	□	□	□	
		XML output for all guidelines included in NGC	□	□	□	□	□	□	□	
		The ability to download references into a citation manager utility (e.g., Endnote)	□	□	□	□	□	□	□	
		The ability to limit searches of NGC to data contained in specific fields in the NGC summary	□	□	□	□	□	□	□	
		The ability to export the entire NGC database	□	□	□	□	□	□	□	
		The ability to export targeted elements of the entire NGC database	□	□	□	□	□	□	□	
		The ability to search archived guideline	□	□	□	□	□	□	□	
		Access to archived guidelines	□	□	□	□	□	□	□	
		Other?	[Please Specify]							

SECTION 4: The last section of this survey provides more focused questions depending on your primary use of the site. Please select the topic area that best reflects your primary role when using NGC. If you would like to answer questions for more than one topic area, you will have an opportunity to do so after you complete the section.

Guideline Developer	Physician Nurse Other Healthcare Provider/Students	Medical Librarian	Informatics Specialist	Researcher	Healthcare Purchaser, Policymaker, Quality Improvement Specialist, Other	Measure Developer

Question	Measurement Scale	Skip Pattern

Section 4 Respondent-Specific [GUIDELINE DEVELOPER (GD)]

	Question	Measurement Scale							Skip Pattern
19	Do you (or your organization) submit guidelines for inclusion in the National Guideline Clearinghouse (NGC)?	□ Yes □ No □ Don't know							If NO or Don't Know, go to question 22 (GD) If YES, go to question 20 (GD)

20	If "Yes", in your experience, how would you rate each of the following components of the NGC process:		Don't know	Poor	Fair	Neutral	Good	Excellent	Go to question 21 (GD)
		Your experience with the submission process	□	□	□	□	□	□	
		Providing copyright	□	□	□	□	□	□	
		NGC's preparation of the NGC Summary and abstraction of your organization' guidelines	□	□	□	□	□	□	
		NGC's verification process (per each guideline summary and/or annually)	□	□	□	□	□	□	
		NGC's dissemination of your organization's guidelines	□	□	□	□	□	□	
		NGC's response to FDA warnings	□	□	□	□	□	□	

21	How do you or your organization use NGC's Annual Summary usage reports? (--Note: These are the reports which identify how many times your guidelines have been viewed on the NGC Web site--)	□ As an indirect measure of the dissemination of your organization's guidelines? □ Research/agenda priority setting? □ Budget justification □ Don't know □ This information is not used at all Other, PLEASE SPECIFY						Go to question 22 (GD)
22	Has NGC influenced any of the following components of your organization's guideline development program:		To a Great Extent	Some-what	Very Little	Not at all	Don't know	Go to question 23 (GD)
		Guideline topic selection?	□	□	□	□	□	
		Guideline development methodology?	□	□	□	□	□	
		How your organization documents or reports its guidelines?	□	□	□	□	□	
		How frequently your organization updates its guidelines?	□	□	□	□	□	
		Collaboration with other guideline developers?	□	□	□	□	□	
		Your approach to identifying guidelines?	□	□	□	□	□	
		Other?	[Please Specify]					
23	Does your organization create implementation tools that can be used to facilitate implementation of your organizations guidelines?	□ Always □ Occasionally □ Rarely □ Never □ Don't know						Go to question 24 (GD)
24	Does your organization create quality measures that can be used to assess the implementation of your organization's guidelines?	□ Always □ Occasionally □ Rarely □ Never □ Don't know						Go to question 25 (GD)
25	Does your organization develop guidelines in a format that can be integrated into electronic medical records or other clinical decision support tools?	□ Always □ Occasionally □ Rarely □ Never □ Don't know						Go to question 26 (GD)

26	If you answered always, occasionally, or rarely to any of the three preceding questions, has NGC had an influence on any of the following:		To a Great Extent	Some-what	Very Little	Not at all	Don't know	Go to question 27 (GD)
		Development of quality measures?	□	□	□	□	□	
		Use of quality measures?	□	□	□	□	□	
		Development of implementation tools?	□	□	□	□	□	
		Use of implementation tools?	□	□	□	□	□	
		Integration of your organization's guideline into electronic medical records?	□	□	□	□	□	
		Integration of your organization's guidelines into clinical decision support systems?	□	□	□	□	□	
		Other?	[Please Specify]					
27	Does your organization use any of the following AHRQ-sponsored products to inform its guideline development activities? Check all that apply	□ Systematic evidence reviews □ Technology assessments □ Comparative effectiveness reviews □ Technical briefs □ Policymaker guides □ DEcIDE project reports □ CERT project reports □ Other products from AHRQ's Effective Health Care Program □ Other [Please specify]						Provide links to other Section 4 survey options; If respondent chooses to end survey, go to last question before exiting.

Select ANOTHER topic area that reflects your role when using NGC OR End Survey:
Physician, Nurse, Other Healthcare Provider, Student
Medical Librarian
Informatics Specialist
Researcher
Healthcare Purchaser, Policymaker, Other
Measure Developer
COMPLETE Survey (Advance to last page of survey)

Section 4 Respondent-Specific [PHYSICIANS, NURSE, OTHER HEALTHCARE PROVIDER/STUDENT (PNOHP)]

#	Question	Measurement Scale	Skip Pattern

19	Has NGC influenced any of the following:		To a Great Extent	Some-what	Very Little	Not at all	Don't know	Go to question 20 (PNOHP)
		Your clinical decision-making processes?	□	□	□	□	□	
		Your ongoing learning efforts?	□	□	□	□	□	
		Your implementation of clinical practice guidelines?	□	□	□	□	□	
		Your organization's implementation of clinical practice guidelines?	□	□	□	□	□	
		Your approach to identifying guidelines?	□	□	□	□	□	
20	Do you or your organization utilize electronic medical records?	□ Yes □ No □ Don't know						Go to question 21 (PNOHP)
21	Do you or your organization utilize clinical decision support tools at the point of care?	□ To a Great Extent □ Somewhat □ Very Little □ Not at All □ Don't know						If YES, go to question 22 (PNOHP) If NO, go to question 23
22	Would having content from the NGC Web site delivered to you at the point of care be useful to you?	□ To a Great Extent □ Somewhat □ Very Little □ Not at All □ Don't know						Go to question 23
23	Is there a need to broaden the scope and type of guidelines (e.g., credentialing, privileging, ethical, procedural, training) included in NGC?	□ Strongly Agree □ Agree □ Undecided □ Disagree □ Strongly Disagree □ Don't know						Go to question 24 (PNOHP)

24	If continuing medical educations were available through NGC would you take advantage of it?:	□ Definitely □ Probably □ Possibly □ Probably Not □Definitely Not	Provide links to other Section 4 survey options; If respondent chooses to end survey, go to last question before exiting.

Select ANOTHER topic area that reflects your role when using NGC OR End Survey:
Guideline Developer
Medical Librarian
Informatics Specialist
Researcher
Healthcare Purchaser, Policymaker, Other
Measure Developer
Click here to Complete Survey (Advance to last page of survey)

Section 4 Respondent-Specific [MEDICAL LIBRARIAN (ML)]

#	Question	Measurement Scale						Skip Pattern
19	Has NGC influenced any of the following:		To a Great Extent	Some-what	Very Little	Not at all	Don't know	Go to question 20 (ML)
		Your data collection processes	□	□	□	□	□	
		Your approach to identifying guidelines	□	□	□	□	□	
		Your ability to meet your clients needs regarding evidence based clinical practice guidelines	□	□	□	□	□	
		Your ability to identify "high quality" gu delines	□	□	□	□	□	
		Your ability to identify "current" guidelines	□	□	□	□	□	
		Other?	[Please Specify]					

20	NGC currently uses the UMLS Metathesaurus to index the guideline summary content included on the site to support browsing and searching. Should NGC use other controlled medical vocabularies for this purpose?	□ Yes □ No □ Don't know □ If Yes, Please specify_____	Provide links to other Section 4 survey options; If respondent chooses to end survey, go to last question before exiting.

Select ANOTHER topic area that reflects your role when using NGC OR End Survey:
Guideline Developer
Physician, Nurse, Other Healthcare Provider, Student
Researcher
Informatics Specialist
Healthcare Purchaser, Policymaker, Other
Measure Developer
Click here to Complete Survey (Advance to last page of survey)

Section 4 Respondent-Specific [RESEARCHER (RS)]

#	Question	Measurement Scale							Skip Pattern
19	Has NGC influenced any of the following:			To a Great Extent	Somewhat	Very Little	Not at all	Don't know	Go to question 20 (RS)
		Data collection processes		□	□	□	□	□	
		Your approach to identifying guidelines		□	□	□	□	□	
		Your ability to identify "high quality" guidelines		□	□	□	□	□	
		Your ability to identify "current" guidelines		□	□	□	□	□	
		Other?			[Please Specify]				

20	Do you use any of the following AHRQ-sponsored products in your research efforts? Check all that apply	Products from AHRQ's Effective Health Care Program □ Systematic evidence reviews □ Technology assessments □ Comparative effectiveness reviews □ Technical briefs □ Policymaker guides □ DEcIDE project reports □ CERT project reports AHRQ Databases or Survey Data □ MEPS: Medical Expenditure Panel Survey □ HCUP: Healthcare Cost & Utilization Project □ HCUPnet: Interactive Tool for Hospital Statistics □ Other [Please specify]	Provide links to other Section 4 survey options; If respondent chooses to end survey, go to last question before exiting.

Select ANOTHER topic area that reflects your role when using NGC OR End Survey:
Guideline Developer
Physician, Nurse, Other Healthcare Provider, Student
Medical Librarian
Informatics Specialist
Healthcare Purchaser, Policymaker, Other
Measure Developer
Click here to Complete Survey (Advance to last page of survey)

Section 4 Respondent-Specific [INFORMATICS SPECIALIST (IS)]

#	Question	Measurement Scale	
19	Do you currently USE or DEVELOP Web 2.0 applications (e.g., blogs, wikis, RSS) to communicate about NGC guidelines?	□ To a Great Extent □ Somewhat □ Very Little □ Not at All □ Don't know	Go to question 20 (IS)
20	Do you utilize NGC data as an input in developing clinical information or decision support systems?	□ To a Great Extent □ Somewhat □ Very Little □ Not at All □ Don't know	Go to question 21 IRS)
21	If you utilize NGC data to develop clinical information or decision support system, what type of data and what type of Application Programming Interface (API) would you like NGC to provide? (For example, structured interface for search query and xml output for search results)	Free Text	Go to question 22 IRS)

#	Question	Measurement Scale				Skip Pattern
22	Do you utilize any of NGC's current RSS downloads?	NGC Content Inventory (e.g., NGC Summaries, Expert Commentaries, and Guideline Syntheses	Yes □	No □		Go to question 23 (IS)
		"What's New" File	Yes □	No □		
23	Do you utilize the NGC Search Form Feature which allows developers to create search interfaces with NGC on external sites?	□ To a Great Extent □ Somewhat □ Very Little □ Not at All □ Don't know				Go to question 24(IS)
24	Would having an NGC output for individual guidelines available as an XML file according to the Guideline Elements Model (GEM) be useful to you in your work?	□ To a Great Extent □ Somewhat □ Very Little □ Not at All				Provide links to other Section 4 survey options; If respondent chooses to end survey, go to last question before exiting.

Select ANOTHER topic area that reflects your role when using NGC OR End Survey:
Guideline Developer
Physician, Nurse, Other Healthcare Provider, Student
Medical Librarian
Researcher
Healthcare Purchaser, Policymaker, Other
Measure Developer
Click here to Complete Survey (Advance to last page of survey)

Section 4 Respondent-Specific [Healthcare Purchaser, Policymaker, Quality Improvement Specialist, Other (HPPO)]

#	Question	Measurement Scale	Skip Pattern

19	Has NGC influenced any of the following:		To a Great Extent	Some-what	Very Little	Not at all	Don't know		Go to question 20 (HPPO)
		Your clinical decision-making processes?	□	□	□	□	□		
		Your organization's approach to public policy making?	□	□	□	□	□		
		Your efforts to convert clinical information to knowledge that can be acted on?	□	□	□	□	□		
		Utilization management?	□	□	□	□	□		
		Medical reimbursement practices?	□	□	□	□	□		
		Your organization's implementation of clinical practice guidelines?	□	□	□	□	□		
		Your quality improvement efforts?	□	□	□	□	□		
		Your approach to identifying guidelines?	□	□	□	□	□		
20	Does your organization use any other of the following AHRQ-sponsored products to inform its policy decision making? Check all that apply	□ Systematic evidence reviews □ Technology assessments □ Comparative effectiveness reviews □ Technical briefs □ Policymaker guides □ DEcIDE project reports □ CERT project reports □ Other products from AHRQ's Effective Health Care Program □ Other [Please specify]							Provide links to other Section 4 survey options; If respondent chooses to end survey, go to last question before exiting.

Select ANOTHER topic area that reflects your role when using NGC OR End Survey:
Guideline Developer
Physician, Nurse, Other Healthcare Provider, Student
Medical Librarian
Researcher
Informatics Specialist
Measure Developer
Click here to Complete Survey (Advance to last page of survey)

Section 4 Respondent-Specific [Measure Developer (MD)]								
#	Question	Measurement Scale						Skip Pattern
19	Has NGC had an influence on any of the following:		To a Great Extent	Somewhat	Very Little	Not at all	Don't know	Go to question 20 (MD)
		Development of quality measures?	□	□	□	□	□	
		Use of quality measures?	□	□	□	□	□	
		Other?	[Please Specify]					
20	Does your organization use NGC as an input for its measure development activities?	□ To a Great Extent □ Somewhat □ Very Little □ Not at All						Go to question 21 (MD)

21	Does your organization submit its measures to AHRQ's National Quality Measures Clearinghouse™? (NQMC)	□Yes □ No □ Don't know	Provide links to other Section 4 survey options; If respondent chooses to end survey, go to last question before exiting.

Select ANOTHER topic area that reflects your role when using NGC OR End Survey:

Guideline Developer
Physician, Nurse, Other Healthcare Provider, Student
Medical Librarian
Researcher
Informatics Specialist
Healthcare Purchaser, Policymaker, Other
Click here to Complete Survey (Advance to last page of survey)

Last Page of Survey

# Question	Measurement Scale	Skip Pattern	
Please indicate which source referred you to this survey:	AHRQ E-mail AHIP E-mail AMA Wire AMA Morning Rounds Other [Please Specify]		Exit survey
Have you already taken this NGC Evaluation Survey? (Note: this survey is not the same as the Annual NGC Customer Satisfaction Survey)	□ Yes □ No □ Don't know		Exit survey

U.S. Department of **Health & Human Services**   Exit this survey

AHRQ *Agency for Healthcare Research and Quality*

National Guideline Clearinghouse™ Evaluation Survey (OMB Control Number: 0935-0174; Expires 2/29/12)

Thank you for taking time to share your thoughts about NGC.
To visit NGC, go to www.guideline.gov

Prev   Done

Agency for Healthcare Research and Quality

Evaluation of the National Guideline Clearinghouse™

*Focus Group
Discussion Guide*

OMB No.: 0935-0174
Expiration Date: 29 February 2012

Agency for Healthcare Research and Quality
National Guideline Clearinghouse (NGC) Evaluation

Focus Group Discussion Guide

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                    │   PRE-SCREEN    │
                    │  Guideline and  │
                    │    NGC Use      │
                    └────────┬────────┘
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                    ┌─────────────────┐
                    │   Background    │
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  Component 1       │  Use of NGC &   │
                    │ Other Guideline │
                    │    Sources      │
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                    │ Satisfaction of │
                    │  NGC and Other  │
                    │Guideline Sources│
                    └────────┬────────┘
  Component 2                │
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Guideline Developer (2 Focus Groups)	Medical Librarian (1 Focus Group)	Informatics Specialist (1 Focus Group)
END Focus Group	END Focus Group	END Focus Group

Screening questions would have already been asked of the participants. The moderator will have this information on the group before beginning the focus group.

Screener questions previously asked to focus group participants:

1) Do you use clinical guidelines in your work?
2) How many times per year, on average, do you use clinical guidelines in your work?
3) Are you aware of the National Guideline Clearinghouse?
4) Have you used the NGC to access information on clinical guidelines?

Participants:

Welcome/Background [5 Minutes]:

- Moderator introduction
- NGC overview
- Purpose of the evaluation
- Importance of their perspective/How it will be incorporated into the evaluation
- Focus group logistics
- Opportunity for questions
- Brief introductions of participants

Discussion Questions

Background
Question: Each of you uses clinical guidelines in your work. Can you briefly describe how and how often you use clinical guidelines in your work?

Probe: potential reasons they use clinical guidelines may include:
- *Finding clinical practice guidelines* - *School assignment*
- *Comparing guidelines* - *Professional knowledge building*
- *Development of a clinical practice guideline* - *Supporting clinical decision-making*
- *Development of quality measures* - *Reducing errors/malpractice (risk management)*
- *Academic/medical research* - *Determining coverage of services*
- *Rationalizing and controlling healthcare expenditures*

Question: Are you aware of the National Guideline Clearinghouse (NGC)?
a. How did you learn about NGC?
b. How long have you been aware of NGC?

Use of NGC & Other Guideline Sources
Question: Of the times you have needed to locate information on clinical guidelines, what percentage of the time do you use NGC for this information?
a. For those times when you do not use NGC for clinical guideline information, where do you access the information?

Probe: Potential other sources may include:
- *PubMed/Medline*
- *From a search using a general purpose Web search engine (e.g., Google)*
- *Point-of-care Web-based resources (e.g., DynaMed, Essential Evidence Plus, EMedicine)*
- *Medscape*
- *U.S. Preventive Services Task Force*
- *National Institute for Health and Clinical Excellence (NICE)*
- *Guidelines Advisory Committee (Canada)*
- *Guidelines International Network (G-I-N)*
- *Institute for Clinical Systems Improvement (ICSI)*
- *Colorado Clinical Guidelines Collaborative (CCGC)*
- *Milliman Care Guidelines®*
- *Expert Consensus Guidelines® (EKS®)*
- *Medical Specialty Society guidelines (e.g.,AACE, AAFP, AAN, AAO, AAOS, AAP, ACC, ACCP, ACEP, ACP, ACPM, ACR, AGA, ASCO, ASGE, IDSA, SAGES)*
- *Professional or Disease Specific Society guidelines (e.g., AASM, AARC, ACS, ADA, AHA, ASPEN, BTF, HFSA, NKF, SCCM)*
- *Government guidelines (e.g., CDC, NHLBI, SAMHSA, TFCPS, DoD/VHA)*
- *Commercial products (e.g., UpToDate; ACP Pier) (please specify)*
- *Other government entities*

Question: How long have you been using the NGC Web site? (NGC users only)

Question: How often would you say you have used the NGC Web site in the past 12 months? (NGC users only)
a. For those who have not visited NGC in the past 12 months, why not?

Probe: Potential reasons may include:
- No need to locate clinical guideline information

- Need the information, but go without it

- Need the information, but use other guideline source instead of NGC

Question: Thinking of the guideline source that you frequent most often other than NGC, how often have you used the source in the past 12 months?

Effectiveness and Influence of NGC and Other Guideline Sources
Question: We previously discussed how you use clinical guidelines. *Summarize how they use guidelines from Question 1.* Keeping these thoughts in mind, to what extent does the NGC site fulfill these needs? How? (NGC users only)

Probe: If there are ways in which the participants use clinical guidelines, but do not use NGC to assist in that activity, why not?

Question: When thinking of how you use clinical guidelines, to what extent does another guideline source besides NGC fulfill these needs? How?

Question: Overall, how would you rate your satisfaction with NGC compared to the other guideline source you frequent most often? (NGC users only)

Options to consider in your response may include: less satisfied with NGC, satisfaction about equal, more satisfied with NGC.

Probe: Why more/less satisfied with NGC?

Question: Do you find the NGC criteria for guideline inclusion appropriate?

Probe: Why/why not? Too stringent/loose?
The four criteria for NGC guideline inclusion are:

a. The guideline must contain systematically developed statements that include recommendations that assist in making decisions in specific circumstances.

b. Guideline must be produced, sponsored, or supported by an organization, association, society, or government agency. An individual without sponsorship cannot submit a guideline.

c. There must be documentation that verifies a literature search and a review of existing evidence were performed as part of developing the guideline.

d. Full text must be available in English.

Question: Do you feel that NGC saves you time regarding your work with clinical guidelines? (NGC users only)
a. If yes, how much?
b. How does it save you time?

Question: Do you trust the information provided by NGC (both NGC content and the guidelines included in NGC)? (NGC users only)

Probe: Why/why not?

STAKEHOLDER-SPECIFIC QUESTIONS AT THIS POINT IN THE DISCUSSION GUIDE.

Guideline developers

Question: Do you (or your organization) submit guidelines for inclusion in NGC?

Probe: Why/why not?

a. If yes, approximately what percentage of developed guidelines do you submit to NGC?

Question: For those of you that do submit your guidelines to NGC, how would you rate the following components of the NGC process? Options to consider in your response are don't know, poor, fair, neutral, good, excellent.

- Your experience with the submission process
- Providing copyright
- Preparation of the NGC summary and abstraction of your organization's guidelines
- Verification process (per each guideline summary and/or annually)
- Dissemination of your organization's guidelines
- Response to FDA warnings

Question: How, if at all, does NGC influence your organization's guideline development program?

Probe: guideline topic selection, guideline development methodology, documentation and reporting of guidelines, guideline update frequency, collaboration with other guideline developers

Question: For those of you whose organizations have created implementation tools that can be used to facilitate implementation of your organization's guidelines, how, if at all, has NGC influenced this activity?

Question: For those of you whose organizations have created quality measures that can be used to assess the implementation of guidelines, how, if at all, has NGC influenced this activity?

Question: For those of you whose organizations have developed guidelines in a format that can be integrated into electronic medical records or other decision clinical support tools, how, if at all, has NGC influenced this activity?

Question: To the best of your knowledge, does your organization use other AHRQ-sponsored products to inform its guideline development activities? Examples include:

- Systematic evidence reviews
- Technology assessments
- Comparative effectiveness reviews
- Technical briefs
- Policymaker guides
- DEcIDE project reports
- CERT project reports
- Other products from AHRQ's Effective Health Care Program

Probe: Why/why not? How?

Medical librarians

Question: How, if at all, has NGC influenced the following activities?

- Your data collection processes
- Your approach to identifying guidelines
- Your ability to meet your client needs regarding evidence-based clinical practice guidelines
- Your ability to identify "high quality" guidelines
- Your ability to identify "current" guidelines

Are there other activities that NGC has influenced? How?

Question: NGC currently uses the UMLS Metathesaurus to index the guideline summary content included on the site to support browsing and searching. Should NGC use other controlled medical vocabularies for this purpose?

Probe: Why/why not? Which ones?

Informatics specialists

Question: Do you currently USE or DEVELOP Web 2.0 applications (e.g., blogs, wikis, RSS,) to communicate about NGC guidelines?

Probe: Why/why not? How do you use these tools?

Question: Do you utilize NGC data as an input in developing clinical information or decision support systems?
a. If not, why not?
b. If yes, what type of data and what type of Application Programming Interface (API) would you like NGC to provide?

Probe: Why/why not? How? If not, can you think of some ways that NGC content might be used?

Question: Do you utilize any of NGC's RSS downloads?

Probe: Examples include: NGC content inventory (e.g., NGC summaries, expert commentaries and guideline syntheses or "What's New" file. Why/why not? How? Could other NGC RSS feeds be useful for informatics specialists?

Question: Do you utilize the NGC search form feature, which allows developers to create search interfaces with NGC on external sites?

Probe: Why/why not? How? If not aware of this feature (describe), now that you are, would you use it?

Question: Would having an NGC output for individual guidelines available as an XML file according to the Guideline Elements Model (GEM) be useful to you in your work?

Probe: Why/why not? How?

Additional Considerations [10 minutes]

Question: NGC is undergoing a redesign. We would like to discuss your thoughts and potential use of the following enhancements:

- Subject-specific e-mail alerts regarding new and updated guideline releases
- Ratings of a guideline's quality and/or methodological rigor (e.g., AGREE score)
- NGC user forums (e.g., blogs, bulletin boards) that promote discussion, education, and collaboration on clinical guidelines?
- NGC summary content formatted for mobile device (e.g., cell phone, pocket PDAs) viewing
- Additional data exporting options
- The ability to download references into a citation manager utility (e.g., Endnote)
- The ability to limit searches of NGC to data contained in specific fields in the NGC summary
- The ability to export the entire NGC database
- The ability to export targeted elements of the entire NGC database
- The ability to search archived guideline content
- Access to archived guidelines

Probe: Would you like to see any other additional functionality?

Question: Are there any specific changes that AHRQ could make to improve your

organization's experience with NGC?
Probe: What kinds of changes?

Question: Based on our discussion today, did you gather new knowledge of NGC?
a. What did you learn?
b. Does this new knowledge of the NGC increase your likelihood of using it in the future?

Question: Are there any final comments or questions?

This concludes our focus group. Thank you for your time and input. AHRQ greatly appreciates your participation.

Appendix E: Key Informant Interview Guide

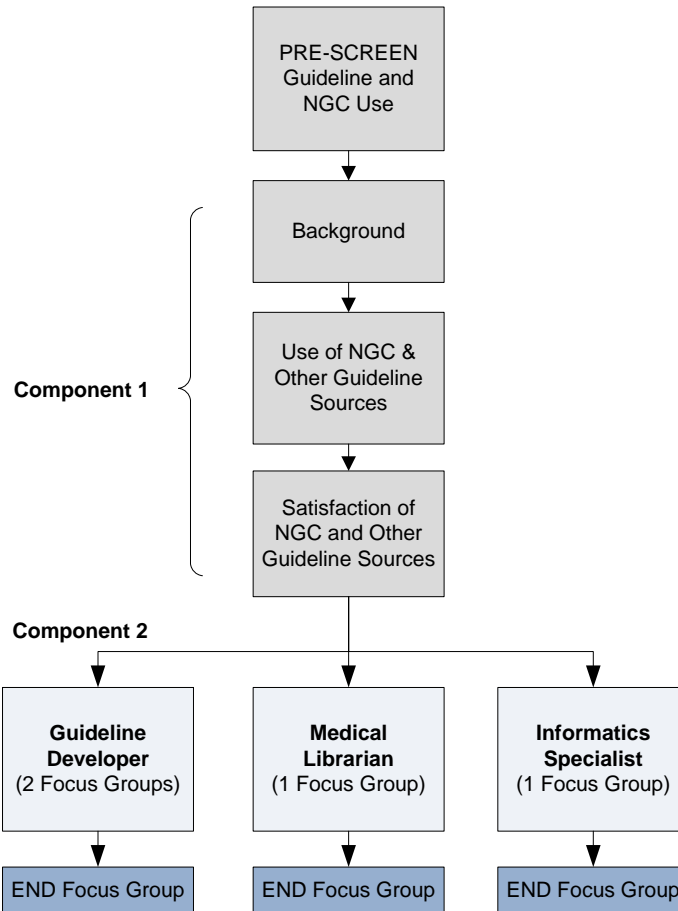*Agency for Healthcare Research and Quality*

Evaluation of the National Guideline Clearinghouse™

Key Informant Interview Discussion Guide

OMB No.: 0935-0174
Expiration Date: 29 February 2012

Agency for Healthcare Research and Quality
National Guideline Clearinghouse™ (NGC) Evaluation

Key Informant Interview Protocol

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                    │   PRE-SCREEN    │
                    │  Guideline and  │
                    │    NGC Use      │
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    Component 1     │  Use of NGC &   │
                    │ Other Guideline │
                    │    Sources      │
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                    │ Satisfaction of │
                    │  NGC and Other  │
                    │ Guideline Sources│
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Component 2

Guideline Developer (12 Interviews)	Informatics Specialist (5 Interviews)	Researcher (1 Interview)	Health Plan, Policymaker, Other (5 Interviews)	Measure Developer (4 Interviews)
END Interview	END Interview	END Interview	END Interview	END Interview

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Screening questions would have already been asked to key informants. The interviewer will have this information on the KI before beginning the interview.

Screener questions previously asked to KI:

1) Do you use clinical guidelines in your work?
2) How many times per year, on average, do you use clinical guidelines in your work?
3) Are you aware of the National Guideline Clearinghouse?
4) Have you used NGC to access information on clinical guidelines?

Welcome/Background:

- Interviewer introduction
- NGC overview
- Purpose of the evaluation
- Importance of their perspective/How it will be incorporated into the evaluation
- Interview logistics
- Opportunity for questions

Discussion Questions

Background/Screening

Question: I understand you use clinical guidelines in your work. Can you briefly describe how and how often you use clinical guidelines in your work?

Probe: potential reasons they use clinical guidelines may include:
- *Finding clinical practice guidelines*   *- School assignment*
- *Comparing guidelines*   *- Professional knowledge building*
- *Development of a clinical practice guideline* *- Supporting clinical decision-making*
- *Development of quality measures*   *- Reducing errors/malpractice (risk management)*
- *Academic/medical research*   *- Determining coverage of services*
- *Rationalizing and controlling healthcare expenditures*

Question: Are you aware of the National Guideline Clearinghouse (NGC)?
a. How did you learn about NGC?

b. How long have you been aware of NGC?

Use of NGC & Other Guideline Sources

Question: Of the times you have needed to locate information on clinical guidelines, what percentage of the time do you use NGC for this information?
a. For those times when you do not use NGC for clinical guideline information, where do you access the information?

Probe: Potential other sources may include:
- *PubMed/Medline*
- *From a search using a general purpose Web search engine (e.g., Google)*
- *Point-of-care Web-based resources (e.g., DynaMed, Essential Evidence Plus, EMedicine)*
- *Medscape*
- *U.S. Preventive Services Task Force*
- *National Institute for Health and Clinical Excellence (NICE)*
- *Guidelines Advisory Committee (Canada)*
- *Guidelines International Network (G-I-N)*
- *Institute for Clinical Systems Improvement (ICSI)*

- *Colorado Clinical Guidelines Collaborative (CCGC)*
- *Milliman Care Guidelines®*
- *Expert Consensus Guidelines® (EKS®)*
- *Medical Specialty Society guidelines (e.g.,AACE, AAFP, AAN, AAO, AAOS, AAP, ACC, ACCP, ACEP, ACP, ACPM, ACR, AGA, ASCO, ASGE, IDSA, SAGES)*
- *Professional or Disease Specific Society guidelines (e.g., AASM, AARC, ACS, ADA, AHA, ASPEN, BTF, HFSA, NKF, SCCM)*
- *Government guidelines (e.g., CDC, NHLBI, SAMHSA, TFCPS, DoD/VHA)*
- *Commercial products (e.g., UpToDate; ACP Pier) (please specify)*
- *Other government entities*

Question: How long have you been using the NGC Web site? (NGC users only)

Question: How often would you say you have used the NGC Web site in the past 12 months? (NGC users only)
a. For those who have not visited the NGC in the past 12 months, why not?

Probe: Potential reasons may include:
- No need to locate clinical guideline information

- Need the information, but go without it

- Need the information, but use other guideline source instead of NGC

Question: Thinking of the guideline source that you frequent most often other than NGC, how often have you used the source in the past 12 months?

Effectiveness and Influence of NGC and Other Guideline Sources
Question: We previously discussed how you use clinical guidelines. *Summarize how they use guidelines from Question 1.* Keeping these thoughts in mind, to what extent does the NGC site fulfill these needs? How? (NGC users only)

Probe: If there are ways in which the participants use clinical guidelines, but do not use NGC to assist in that activity, why not?

Question: When thinking of how you use clinical guidelines, to what extent does another guideline source besides NGC fulfill these needs? How?

Question: Overall, how would you rate your satisfaction with NGC compared to the other guideline source you frequent most often? (NGC users only)

Options to consider in your response may include: less satisfied with NGC, satisfaction about equal, more satisfied with NGC.

Probe: Why more/less satisfied with NGC?

Question: Do you find the NGC criteria for guideline inclusion appropriate?

Probe: Why/why not? Too stringent/loose?

The four criteria for NGC guideline inclusion are:

a. The guideline must contain systematically developed statements that include recommendations that assist in making decisions in specific circumstances.

b. Guideline must be produced, sponsored, or supported by an organization, association, society, or government agency. An individual without sponsorship cannot submit a guideline.

c. There must be documentation that verifies a literature search and a review of existing evidence were performed as part of developing the guideline.

d. Full text must be available in English.

Question: Do you feel that NGC saves you time regarding your work with clinical guidelines? (NGC users only)
b. If yes, how much?
c. How does it save you time?

Question: Do you trust the information provided by NGC (both NGC content and the guidelines included in NGC)? (NGC users only)

Probe: Why/why not?

Question: Thinking of the guideline source you most frequently use other than NGC, do you trust the information provided?

Probe: Why/why not?
Probe. More/less than information from NGC?

STAKEHOLDER-SPECIFIC QUESTIONS AT THIS POINT IN THE DISCUSSION GUIDE.

Guideline developers

Question: Do you (or your organization) submit guidelines for inclusion in the NGC?

Probe: Why/why not?

 a. If yes, approximately what percentage of developed guidelines do you submit to NGC?

Question: For those of you that do submit your guidelines to NGC, how would you rate the following components of the NGC process? Options to consider in your responses are don't know, poor, fair, neutral, good, excellent.

- Your experience with the submission process

- Providing copyright
- Preparation of the NGC summary and abstraction of your organization's guidelines
- Verification process (per each guideline summary and/or annually)
- Dissemination of your organization's guidelines
- Response to FDA warnings

Question: How, if at all, does NGC influence your organization's guideline development program?

Probe: guideline topic selection, guideline development methodology, documentation and reporting of guidelines, guideline update frequency, collaboration with other guideline developers

Question: For those of you whose organizations have created implementation tools that can be used to facilitate implementation of your organization's guidelines, how, if at all, has NGC influenced this activity?

Question: For those of you whose organizations have created quality measures that can be used to assess the implementation of guidelines, how, if at all, has NGC influenced this activity?

Question: For those of you whose organizations have developed guidelines in a format that can be integrated into electronic medical records or other decision clinical support tools, how, if at all, has NGC influenced this activity?

Question: To the best of your knowledge, does your organization use other AHRQ-sponsored products to inform its guideline development activities? Examples include:

- Systematic evidence reviews
- Technology assessments
- Comparative effectiveness reviews
- Technical briefs
- Policymaker guides
- DEcIDE project reports
- CERT project reports
- Other products from AHRQ's Effective Health Care Program

Probe: Why/why not? How?

Informatics specialists

Question: Do you currently USE or DEVELOP Web 2.0 applications (e.g., blogs, wikis, RSS,) to communicate about NGC guidelines?

Probe: Why/why not? How do you use these tools?

Question: Do you utilize NGC data as an input in developing clinical information or decision support systems?
a. If not, why not?
b. If yes, what type of data and type of Application Programming Interface (API) would you like NGC to provide?"

Probe: Why/why not? How? If not, can you think of some ways that NGC content might be used?

Question: Do you utilize any of NGC's RSS downloads?

Probe: Examples include: NGC content inventory (e.g., NGC summaries, expert commentaries, and guideline syntheses or "What's New" file. Why/why not? How? Could other NGC RSS feeds be useful for informatics specialists?

Question: Do you utilize the NGC search form feature, which allows developers to create search interfaces with NGC on external sites?

Probe: Why/why not? How? If not aware of this feature (describe), now that you are, would you use it?

Question: Would having an NGC output for individual guidelines available as an XML file according to the Guideline Elements Model (GEM) be useful to you in your work?

Probe: Why/why not? How?

Researchers

Question: How, if at all, has NGC influenced the following activities?

- Your data collection processes
- Your approach to identifying guidelines
- Your ability to identify "high quality" guidelines
- Your ability to identify "current" guidelines

Are there other activities that NGC has influenced? How?

Question: In your research, do you use other AHRQ-sponsored products? Examples include:

- Systematic evidence reviews
- Technology assessments
- Comparative effectiveness reviews
- Technical briefs
- Policymaker guides
- DEcIDE project reports
- CERT project reports
- MEPS: Medical Expenditure Panel Survey

- HCUP: Healthcare Cost & Utilization Project
- HCUPnet: interactive tool for hospital statistics

Probe: Any others? Why/why not? How?

Healthcare Purchasers, Policymakers, Other

Question: How, if at all, has NGC influenced the following activities?

- Your clinical decision-making processes
- Your organization's approach to public policymaking
- Your efforts to convert clinical information to knowledge that can be acted on
- Utilization management
- Medical reimbursement practices
- Your organization's implementation of clinical practice guidelines

Question: To the best of your knowledge, does your organization use other AHRQ-sponsored products to inform its guideline development activities? Examples include:

- Systematic evidence reviews
- Technology assessments
- Comparative effectiveness reviews
- Technical briefs
- Policymaker guides
- DEcIDE project reports
- CERT project reports
- Other products from AHRQ's Effective Health Care Program

Probe: Why/why not? How?

Measure developers

Question: How, if at all, has NGC influenced your development and/or use of quality measures?

Probe: Any other areas where NGC has had influence?

Question: Does your organization use NGC as an input for its measure development activities?

Probe: Why/why not? How?

Question: Does your organization submit its measures to AHRQ's National Quality Measures Clearinghouse?

Probe: Why/why not?

Additional Considerations

Question: The NGC is undergoing a redesign. We would like to discuss your thoughts and potential use of the following enhancements:

- Subject-specific e-mail alerts regarding new and updated guideline releases
- Ratings of a guideline's quality and/or methodological rigor (e.g., AGREE score)
- NGC user forums (e.g., blogs, bulletin boards) that promote discussion, education, and collaboration on clinical guidelines?
- NGC summary content formatted for mobile device (e.g., cell phone, pocket PDAs) viewing
- Additional data exporting options
- The ability to download references into a citation manager utility (e.g., Endnote)
- The ability to limit searches of NGC to data contained in specific fields in the NGC summary
- The ability to export the entire NGC database
- The ability to export targeted elements of the entire NGC database
- The ability to search archived guideline content
- Access to archived guidelines

Probe: Would you like to see any other additional functionality?

Question: Are there any specific changes that AHRQ could make to improve your organization's experience with NGC?
Probe: What kinds of changes?

Question: Based on our discussion today, did you gather new knowledge of NGC?
a. What did you learn?
b. Does this new knowledge of NGC increase your likelihood of using it in the future?

Question: Are there any final comments or questions?

This concludes our interview. Thank you for your time and input. AHRQ greatly appreciates your participation.

Appendix F: Guideline Developer Qualitative Summary

As a part of a larger evaluation of how the National Guideline Clearinghouse (NGC) is used, user perceptions of NGC, and suggested enhancements to NGC, two focus groups of five and eight participants whose expertise was in guideline development were conducted. The first was held on August 27, 2010 at the Guideline International Network (GIN) Conference in Chicago, IL. The participants were from five different institutions. The second focus group was held on June 20, 2011 through a conference call/Webinar session. The institutions represented in these focus groups were:

- American Academy of Neurology (AAN)
- American Academy of Otolaryngology (AAO)
- American College of Chest Physicians (ACCP)
- American College of Physicians
- American College of Radiology (ACR)
- American Society of Clinical Oncology (ASCO) (two individuals)
- Cancer Care Ontario, Program in Evidence-based Care
- Cincinnati Children's Hospital Medical Center
- Infectious Diseases Society of America (IDSA)
- Kaiser Permanente Southern California
- Scottish Intercollegiate Guidelines Network (SIGN)
- UMHS

The focus groups sessions took one and a half hours to complete.

In addition, one-on-one telephone interviews were conducted with 12individuals specializing in guideline development (hereafter referred to as interviewees). These individuals represented the following institutions:

- Endocrine Society
- Institute for Clinical Systems Improvement (ICSI)
- John Hartford Foundation (three individuals)
- Michigan Quality Improvement Consortium (MQIC)
- Milliman Care Guidelines
- Renal Physicians Association (RPA) (two individuals)
- Veterans Health Administration (VHA)
- Washington State Labor and Industries, Worker's Compensation

Each interview lasted from 30 minutes to one hour and followed approximately the same format as the focus group. Below is a summary of the highlights of comments from both focus group

participants and individual interviewees.

Preface

As part of the initial introductions, the moderator asked the participants if they had completed the Web-based evaluation survey, part of an earlier stage of this evaluation. One of the 12 individual interviewees had; none of the participants of the first focus group conducted at GIN had taken the survey because the survey had not yet been fielded at that time. All of the participants of the second, phone-based focus group had taken the NGC evaluation survey.

Question: How do you use guidelines in your work?

The first question concerned how each respondent either used guidelines in their work or their role in their organization's guideline development activity. Most of the institutions represented reported that guidelines are developed through a committee process. Therefore, the participants were not guideline writers per se, but managed or oversaw the guideline development process at their respective institutions.

Excerpts from the participants on use of guidelines are listed below.

- *"I am a clinical systems improvement facilitator. We facilitate the process for guidelines that we develop. We have established work groups that are content experts that we facilitate through our revision process of our multiple scientific documents that we develop, both guidelines and order sets. I am their scientific document team lead. We define processes for creating and revising our guidelines."*

- *"I am the director of evidence-based practice for the VHA. We're responsible for creating evidence-based guidelines to be used in the VHA. We also do this work with the DoD, so there is a liaison between us and the DoD. We're group-sanctioned by the Health Executive Committee of both senior VA and DoD leaders."*

- *"Milliman Care Guidelines produces guidelines across the continuum of care for use by clients across the spectrum of health care, from hospitals, we have approximately 1,000 hospital clients, various government sources   we are an approved vendor of CMS and insurance companies. The guidelines span the continuum of care. We will produce a guideline for a disease and the inpatient version of that will be structured along the clinical progression of care, so we'll have indications for admission to the hospital, alternatives to admission, then an abbreviated clinical pathway that shows the highlights of the care on a day-by-day basis, and what we call a GOAL   length of stay, which is the optimal length of stay in the patient who has optimal recovers. For those patients who do have complications, we have extended stay. And then discharge information. We'll have it for acute care, sub-acute care, skilled nursing care, and home care."*

- *"I'm the manager of the guideline development process, which basically means that I coordinate the administrative side, as well as the fulfillment and the marketing and advertising side of the guidelines."*

- *"Executive director, so, my role in guideline development is basically overseeing the staff who support the working groups that are made up of volunteers who develop the guidelines."*

- *"Staff support for these committees and work groups that are developing guidelines."*

- *"I am the manager of the group that develops our guidelines, and we work with physicians as content experts, and we have a variety of ways of producing the guidelines. Our job is to develop the guidelines and get them published and get them out, and updated when they need to be updated, to get them completed in a timely manner."*

- *"I'm in charge of the larger committee and subcommittee, in terms of organizing it, preparing for it, making sure our documents are disseminated properly. I'm an occupational nurse consultant."*

- *"I support the whole process for the Michigan Quality Improvement Consortium. It's a consortium of 13 health plans along with six or seven professional organizations. Somebody has to keep track of the committees, the Web site, and I do all of that."*

- *"Guidelines are my work. Being a user of guidelines, <u>I oversee all the guideline development panels in the organization</u>. We also look to the NGC to see what's available before we take on a topic or as we're evaluating a potential topic."*

- *"My research has included implementation of clinical policies. When I was a resident and an attending I had a consensus project with the emergency medicine informatics service looking at the implementability of past policies into electronic decisions support. My own little niche is in the electronic realm. Emergency physicians use the American College of Emergency Physicians clinical policies quite a bit. The amount that is actually being used at the point of care and that's influencing practice on a day-to-day basis."*
- *"…my role has been primarily in developing the guidelines, and then in deciding that we wanted to post the guidelines on the AHRQ Web site, and guiding that process."*

- *"Probably most otolaryngologists in general don't care too much about guidelines. They*

don't use them much, but we're trying to change that. As far as at the organizational level, we've combined research and quality into one business unit within the organization so the person who oversees research is also involved with guideline development. Anytime we undertake a project, we always scope out what guidelines are available through our Guideline Development Task Force. I also edit our journal, so I'll look at guidelines from time to time. For that, we're always going to check for guidelines as sort of a best source of evidence to get good advice before we do anything clinically."

- *"[My role is] to get the guidelines developed ... as a coordinator. I also worked with the authors on the evidence-based process."*

- *"We have a process we go through to decide whether to take a guideline on or not, and one of things we do is to see what existing guidelines are out there and in what particular context. We research other people's guidelines [on NGC] to make ours most accurate."*

- *"Guidelines is my work. My research is not around the development of guidelines but more about advancing different components and the evaluation of guidelines, but we do some implementation projects. The use of guidelines in the prevention realm is tied into our overall cancer organization. The guidelines are the quality standards."*

Question: Do you use NGC and how do you use it?

All but one participant noted that they used NGC in their work. Most of the participants used it when their group was developing a new guideline; they would reference the NGC database to determine what other guidelines on the specific topic were already out there. Many organizations used NGC as a dissemination tool for guidelines they developed.

Excerpts from the participants are listed below.

- *"Referencing the NGC for documents that we're working on. We'd reference NGC to be cognizant of what other guidelines exist. Sometimes we make that information available to our work group members. How we use the content varies on the particular topic."*

- *"When we're in the development of guidelines, we may use NGC for looking for seed guidelines for organizations who've already collected or done evidence synthesis on the same subject."*

- *"There is a section of NGC called Guideline Syntheses, which does a very thoughtful*

comparison of various guidelines on the same topic. That is extremely helpful, and we would like to see much more of that. We use those. There are often conflicting guidelines, or it's just good to have a thoughtful perspective on various issues where the evidence is either conflicting or there are gaps in the evidence. It's a helpful resource to think through some of the issues that we and everyone's dealing with. For example, screening mammography in women ages 40 to 49. That's an extremely hot topic, and so it's nice to have a thoughtful perspective on various recommendations there. I'd love to see it for other controversial things like low-back surgery and other surgical procedures, chiropractic   a whole host of things that are controversial and where there are very strong industry advocates for those particular modalities   who make everyone's life miserable."

- *"I mainly use the guidelines to show faculty and practitioners that they exist, what is available on the site, how to access our guidelines. So, I use them because when I present at meetings nationally and talk about the protocols, I say that they are listed on the Web site, and then I describe what the Web site is and how they can access primarily our guidelines."*

- *"As far as a tool to see what other guidelines are in the industry, in the area, yes. And to disseminate our guidelines."*

- *"…to see what's new, and to see if there's anything among our group that would be useful for anyone in our group."*

- *"We use NGC as a kind of a   I don't want to say benchmark or a goal   we look to NGC to be setting standards of what these documents   quality of documents, what kind of documents they will accept. Another key thing is when should documents be updated, so that drives our update process, looking to see what NGC says about how often they need to be updated, at least at a minimum. We're really looking to them to be a standards type on guidelines. I search maybe if we start a new project, just to see what's out there of a comparable nature. We want to make sure our guidelines are on there so other people can find them and that they're accepted, so that, a validation that they meet a standard, the national standard. Producing three or four guidelines per year is our goal. NGC is useful for our organization and we would not want to see it go away."*

- *"I look to see whether guidelines are up there. When we're looking at ours, we want to see what others are out there, whether they're written by associations, government entities, other payers, just evaluating what's available and how current they are, and compare them to ours."*

- *"When we're updating our guidelines we pull off the ICSI guidelines on NGC, or I might refer to their [ICSI] Web site and pull off the most recent information. Or we might research other guidelines on NGC as we are updating our guidelines to see what recommendations have changed with, say, the American Diabetes Association or something like that. We reach out and ask experts in the field in Michigan for feedback. But we also refer to our reference-based documents and pull everything we can together to have the most current recommendations out there."*

- *"It's a dissemination tool for us. I think it really has a wide reach and allows us the opportunity to get our guidelines out there."*

- *"We meet three times a year and our resident representative actually goes through the new guidelines that have come out [in NGC] since the last meeting and reviews any that are pertinent to emergency medicine and presents a summary to the group. In theory, that summary goes into our national newsletter and is disseminated to all membership."*

- *"Whenever we take on a task or we're thinking about a topic, we're going to go to the NGC to see what's there, if it's current, if it's relevant, if there is anything that we need to add upon, if it's efficient. In the context of research and policy development, we'll check NGC. More recently I became aware of the commentaries and the guideline syntheses."*

- *"When we're going to take on a new topic, we'll search for existing guidelines to primarily build the evidence base. NGC is pretty complete through that source. We also submit our guidelines to NGC, so it's another dissemination tactic for us, which is extremely useful. NGC has been helpful in terms of search projects with us and helping us develop samples of guideline developers and recruitment. In the early days when there were no other players out there, it was quite prestigious."*

Question: How frequently do you use NGC and have you used it in the past year?

Responses ranged from frequently, to once or twice a month, to once or twice a year. Many respondents have used NGC within the past year.

Question: What other sources do you use for guidelines? How do they compare to NGC?

The following table presents some of the other resources identified by the respondents.

Resource

PubMed
U.S. Preventive Services Task Force
Medical societies and professional societies—going directly to the source
International databases (e.g., NICE, New Zealand group, Australian group, Scottish group)
Cochrane Review
Word of mouth
Federal and State Web sites
GIN library

Many interviewees stated that even though they use other sources, they usually go to NGC first. They were pleased with the breadth and comprehensiveness of the information in the NGC database.

Excerpts from participants are listed below.

- *"NGC is a first go-to source, but it's only one of many sources that we go to. We have good confidence and want to always use NGC. But we want to be comprehensive, so sometimes we need to expand that into other ways to make sure that we're trying to cover everything we can."*
- *"NGC has a larger [selection]. When I go to SIGN it's just looking at SIGN, so if I want more of a variety, I'll go to NGC."*
- *"NGC is very comprehensive, user-friendly. It compares well, probably a little bit better than PubMed, because PubMed's more focusing on the citations, whereas NGC, you can locate the guideline by issue, by association, by author."*

- *"I usually start with NGC. But if I know – a lot of times I'll go to the site if I know a particular person has a certain type of guideline I'm looking for, like University of Iowa, or AMDA, or AGS, if they're geriatric-related, as well."*

- *"It's certainly easy to use as a jumping-off point of seeing maybe who else might have additional resources."*

- *"The NCG is just listing the abstracts or you have a lot of criteria. You're [NGC] not the end source of these guidelines. You're a resource that can guide me to whether I want to look further at the sources — whoever's produced the guidelines — and I think it's important for me and others I work with to remember that. So we have to go to the association or society or whatever organization it was that actually produced them if we want to cite it or if we want to use it or converse with the authors or whatever. If I go straight to another company or organization, I just get their guidelines straight from them, the full thing. But you [NGC] have a more representative — a broader array of topics than I'm often going to find with some of the other companies."*

- *"It depends. It's hard when you're actually going to, for example, the American Diabetes Association, their paper might be 2- or 300 pages long, trying to pull out the information that we're really looking for, you may have to really dig. Whereas using the NGC template, they probably have those things listed right there. They're the important things in their template. The NGC saves us time as long as it's been updated on their Web site."*

Question: How would you rate the appropriateness of the NGC inclusion criteria? Do you think the five-year time limit is appropriate?

There were mixed perceptions about the appropriateness of the inclusion criteria. Some believed that they are satisfactory. One respondent felt that if the criteria were more stringent, some guidelines would not be able to meet those criteria and therefore would not appear in the database. Others felt that the bar could be raised. A few thought that the five-year limit was too long; they suggested reviewing guidelines on a yearly, or at minimum, a three-year basis.

Excerpts from the participants for changing inclusion criteria are listed below.

- *"I don't think they're too stringent, and I would like to see the opportunity for this to be in sync with the IOM standards."*

- *"Sometimes they may be a little too loose, because of the conflicts of interest and NGC relies on people verbally disclosing. And then you go on to Google and you find that they're really linked to some drug company. Sometimes when I look at this recommendation I almost feel like I read the same article and I didn't make the same conclusion."*

- *"I can't comment on the inclusion criteria – what we see is all useful to us, and so we'd like to see more of that. The more controversial, the better. What I'm talking about is the guideline synthesis section, which does a comparative analysis of guidelines for the same condition. We don't submit our guidelines to NCG because they are proprietary."*

- *"No, I don't find it too stringent. I find it just right. It's the perfect type of criteria, and that's why we utilize it."*

- *"I can't really answer that because I don't have a good sense of the rigor of other guidelines that might not be as rigorous. To me it seems acceptable, and I think ours are rigorous, and ours get accepted. I don't know if there's some low fruit just barely making it somehow or what it is that they're deficient in."*

- *"I certainly support the need for them to be clinically oriented and peer-reviewed. Otherwise, it wouldn't really be of much value to anybody looking on the site. So there has to be some quality control like that."*

- *"I wasn't aware what the inclusion criteria were. Some of the criteria you listed are great. That's what we want."*

- *"I'm not sure the government guidelines would actually make it into NGC if they raised the bar that much."*

- *"If you raise the bar, some large number of specialty societies might actually write a recommendation that you find is poorly written or not at a high level in terms of the evidence. And what happens when you actually give feedback to a large medical society that this is not going to end up going onto the NGC site? That would be an interesting political situation."*

- *"If the goal is to be all inclusive, then the criteria are fine. If they keep those criteria, there needs to be some other ways to separate the wheat from the chaff and include some quality assessments, even a basic level, which could allow you to distinguish types of guidelines. I think the bar could be upped. Specifically, on a need to have completely distinct systems for great evidence versus making recommendations. You need a distinct method for making recommendations – you know grading and assessing the aggregate evidence. From a public relations standpoint, I don't think a government-run site should want to be exclusive. You need to be inclusive, but there has to be this second sort of tier to separate this big mass on few basic quality parameters or that would allow you from a methodological standpoint to determine what you are interested in and what doesn't pass muster for you."*

- *"I think the quality of the criteria was good when NGC started out but it has gotten more complicated."*

- *"They could raise the bar."*

Excerpts from the participants regarding the five-year limit are listed below.

- *"Adequate, because sometimes the evidence doesn't change significantly. And five years is about right. We're struggling at making five years. But I do take a look at it to make sure it's still current in my annual summary for the NGC."*

- *"I guess I would say they are subject to being out of date with a five-year window. We update all of our guidelines every year. And we're getting a lot of client feedback that they want some of them updated more frequently. And these are particularly in new technologies, new medications, things like that. We will be going to at least a twice-yearly, and perhaps four-times-a-year update in those particular areas. Now other areas probably don't change as frequently, but I think five years is really quite a long time."*

- *"The Endocrine Society revisits all of their guidelines every three years. That has proven to be beneficial, because that's just the right amount of time to capture any new data but allow the original publication of the guideline to be vetted in all the appropriate places. But then once that circulation has probably waned, then we come out with a new guideline. And you know, of course, the amount of time that it takes for clinical trials to go through and things like that. I believe three years has proven to be an appropriate length of time. Within five years, new information definitely would have been published."*

- *"The area we bump up against most often is the five-year longevity deadline, revising, because we're not unlike a lot of other companies. We have very limited staff; we're a public agency on top of that, so we can't just hire more resources to keep these updated. And if you're really going to do something evidence-based, I don't think anyone except those who are involved with it, really understand how lengthy that process is. The process to figure out what the evidence is and what it says and whether it's valid and useful is a very difficult, lengthy process. We're lucky if we can do two guidelines a year. And because topics are always coming up, and you want to build a library of them yourself, we could spend all our time doing nothing but revising guidelines. And never doing any new ones. And we can't keep them on the guideline clearinghouse, because we exceed the five years. And it's a challenge."*

- *"It is maybe a long period of time. We are required to update our guidelines at a minimum every two years. Although sometimes five years is probably reasonable. There's probably not too much more evidence-based recommendations that are coming*

*out [for certain things like hypertension]. And there's the annual report where you have
to confirm that yes, they have been looked at in the past five years."*

**Question: Clinical guidelines are generally expected to contribute to improvements in
quality of healthcare, efficiencies, reduce healthcare costs, and also improve clinical
decision-making. We wanted to know what your thoughts were on NGC's impact on each
of these.**

Excerpts from the participants are listed below.

- *"As a clinician, I think it could be a valuable tool, but all of us are saying we only use it
  a few times a year. I think the data would be very useful to you. I have, as an attending,
  shown it to some residents in the past and it has been something that they've been excited
  to see. I would think if you target physicians in training that they might go on and take it
  into practice."*

- *"It improves access to guidelines, but beyond that I think we'd all be in very grave
  waters to attempt to extrapolate that."*

- *"I would think that for some of these things it would help but you can't put that much
  weight on the guidelines."*

- *"NGC can help with some of the efficiencies. It saves us time in accessing the guidelines,
  but again you have people that haven't submitted, so you still have to poke around. I've
  never really considered the NGC as a tool for the clinical community. I've viewed it much
  more for quality improvement people and guideline development people rather than
  clinicians. I think it is more of a tool for folks who use guidelines and then go to the
  clinical community to leverage change and implement and all that sort of stuff."*

Question: Do you trust the information provided by NGC? Why/why not?

There was a general consensus among participants that they did trust the information on NGC.
They all trusted that after their organization had submitted a guideline the NGC did accurately
represent what was in the original guideline.

Excerpts from the participants are listed below.

- *"Yes, I would and so would my organization. That doesn't mean we always agree with*

the content, but we trust NGC. If there's some transparency, at least, you know. Given the criteria, you have a sense of them adhering to at least a framework."

- *"My concern sometimes is the conflicts of interest of the guideline developers that aren't clearly identified. Some guideline developers don't clearly state their conflicts of interest, especially from some professional societies."*

- *"The guideline synthesis, yes. The other material, the other guidelines, it really depends on the source. If it's from the American College of Cardiology, yeah, we have a high degree of confidence in them. If it's from a state of [a smaller, less-well known organization] that we don't know anything about and it hasn't been published in a peer-reviewed journal, then we tend to avoid those kinds of guidelines. But if it's part of a thoughtful analysis for all the guidelines for a particular topic, then we would want to see that. I'm just not sure of the value of guidelines that are produced by organizations that don't have any measure of credibility. If the guideline is produced by a sort of unknown organization and they haven't published things, I'm really not sure of the value of that."*

- *"Yes, because the organizations that have submitted guidelines seem to be reputable. Whenever I submit a guideline, I always receive a very comprehensive summary of the guideline. So I'm assuming that there's someone of the other end thoroughly reviewing the guideline. The reviewers have asked me questions about the reviews, the systematic reviews that we cite. So I'm assuming that someone on the other end is looking at the guideline, and therefore, it will make it a little bit more credible."*

- *"It's only going to be as trustworthy as the source. It makes a difference to me whether the entity submitting the guideline is a for-profit entity, is it a public interest group, if it's a pharmaceutical company. Because sometimes I'll see one that looks good, it's got a lot of comprehensive information, but I'm also looking, going, I'm not sure how much we can rely on this, when it's hard to see how much bias there is in a guideline. But I know what your [NGC] standards are, so from that standpoint, yes, I can trust that it's going to be something of interest. It's not going to be something that's a waste of my time. It may or may not meet my needs or be what I want, but I don't feel like I'm looking at tabloid guidelines."*

- *"Yes, no doubt. Whether or not the information would actually be added to our guidelines, I don't know, the doctors make all decisions on our guidelines."*

- *"I've worked directly with NGC on ensuring the accuracy of the summary. But you can't really know for sure about the content or if the guideline is good. I think with evidence or*

anything, you have to judge it for yourself."

- *"I believe they extracted correctly, but as far as quality I'm not sure. Even basic things, when I go to NGC, I'd like to be able to tell immediately was this guideline multidisciplinary, what was the mix of people who contributed to it. I can't get that off of the site right away. You really have to dig deep. I'd like to be able to see way up front the conflicts of interest and not have to pry down deep to figure out if this was a panel where everybody was conflicted. I know that appears on the site. And the other thing is that a lot of things I find on there are not even guidelines. It'll clearly say in the title of the comment that this is a practice parameter, or this is an evidence-based review, or an evidence-based summary. Those are not guidelines. That's a distraction. It is background noise and it gives an air of importance to documents that aren't that important. It deceives you."*

- *"I trust that what's there is what was in the guideline. Whether I trust the recommendations – that would go beyond what the NGC provides in terms of information. It's probably accurate but our group has to do stuff with what we find from the NGC to then start making decision with whether we will use what we have found or not."*

Question: Are you involved with measurement development?

This question was asked only of individual interviewees. While none were personally involved, some of the organizations were beginning to become active in developing measures. These measures will be hand in hand with guideline development. One interviewee stated that their organization actually uses non-HEDIS measures that line up with their guidelines.

Question: Has NGC influenced your organization's guideline development?

Overall, the answer to this question was no, NGC has not had any influence. The only influence from NGC was perhaps putting pressure on organizations to keep their information current on the NGC site.

Excerpts from individual interviews are listed below.

- *"I think that the AHRQ guidelines on performance guidelines – on practice guideline development – have influenced our process. We actually developed a position paper on processes for practice guidelines on performance measure development to outline what we think as an organization are criteria that should be followed. And we largely used criteria that were set by the Institute of Medicine and by AHRQ. But the NGC itself did*

not influence that…. We were already following that process before the NGC."

- *"Hard to say. A hallmark of ICSI, our organization, is guideline development. It's foundational to our work. We have a tremendous number of influencers on that as foundational work. I couldn't point to a particular example of something that has been cause-effect."*

- *"No. We take our evidence reporting from the USPSTF. And now we're moving to the GRADE system for recommendations. Ours have always had algorithms, which a lot of the ones on NGC do not."*

- *"No, not really. The program was started as a member-driven program; therefore, we really take what our members say to further develop how our guidelines are formatted and structure, and the methodology behind them. We really don't look at outside sources. We're trying to make sure that we focus internally first. We often ask other associations to co-sponsor guidelines. So we collaborate on them and see what works for them and we share our ideas with them. And we use the GRADE system; we contract with the Mayo Clinic to use our GRADE system for a methodology for our guidelines. That does have an influence on how our guidelines are structured."*

- *"As a benchmark for how frequently our organization's guidelines should be updated. NGC has also influenced at least the minimum requirements, which we do anyway, but just that it's a specific process, it's documented. But I think we also look to other groups as well, like IOM and some other published statements. We look at a range of people's recommendation on what – the method that should be used and the methods of reporting. But definitely, we want to make sure we meet whatever NGC says so that ours get on the NGC. We may look at the [NGC] summary to make sure the information is there. It does flag a few things, so it has some influence; maybe we're not as clear about how we actually came up with the recommendation. So it highlights things we could do better."*

- *"Not particularly. I wouldn't say that I am doing business differently because of NGC. I try to make sure that in writing a guideline I'm addressing the criteria I know I'm going to have to submit to you. But even that is not that difficult. I would only say it's influenced us from the standpoint of the resource information it provides. So when we're going to do the next guideline, it influences us in terms of often being able to get a better basis of knowledge to start with. We know what's out there, how many others have guidelines in this area, whether our plan for ours is going to be similar or different. It gives us a snapshot of what's in the landscape."*

- *"I am not aware of any influence. We do collaborate with other Michigan physicians and*

other groups. One update was developed and then we asked for more feedback, and then the doctors would discuss all the feedback and how to put it in there or if to put it in there. At some point the provider task force in the state signed off and felt that we've accomplished all that we'll accomplish in the guideline."

- *"The five-year thing is sort of pressure. Whether or not it affects the quality of our guidelines, I'd probably say that it doesn't have that much impact. We're always trying to improve our quality, but we are typically looking at other guidelines in the community. We more or less would get that from a specific guideline developer that's doing things in a really great way and we would try to model things after them and not necessarily NGC."*

- *"I'd agree, the update pressure is there, but, as far as anything else, no. I think we all agree that the threshold for NGC is pretty minimal and suspect that all of the people at this table exceed substantially the basic entry requirements for NGC."*

- *"The frequency has put a little pressure on our group. Guidelines sometimes have taken quite a bit longer and they are aware of that additional pressure to try to get it out faster, it is a little extra catalyst for them. The culture of putting a guideline into a more executive, bulleted summary has been a slow, cultural change within the group. It's been one of the many things that have raised awareness as far as where guidelines are potentially going in the future."*

- *"Early on, it might have been a first level to start. But for our organization, no."*

Question: Has your approach to facilitating the implementation of your organization's guidelines changed over the years?

A few of the interviewees responded to this question. They said that their organization has been developing guidelines for many years, and that their approach is constantly changing.

Excerpts from individual interviews are listed below.

- *"Certainly, we've been doing them for 15-plus years. We tried to respond to evolving kind of science, be it translation or whatever. The influence of technology and electronic health records, we are trying to respond in a way that allows our guideline to be something that is more implementable. It is insufficient to just have the documents produced and available. That's the whole implementation piece that really gets the documents and the science and the evidence to the point of care delivery."*

- *"It's constantly changing. It's interesting because a lot of the problem that we've run into – guidelines and the reviews, sort of intermixed, but we're constantly looking at ways to improve the process, ways to make it faster and more efficient. The models seem to be evolving because the physicians in the past had more time to do this and now they just don't. Yet we need to capture their expertise. So the process keeps evolving and then also the methodology process keeps evolving with GRADE and then how do you implement GRADE. And it just seems like we're kind of on the cutting edge as far as problems that we're encountering, it seems like when I read what's being published, other people are addressing these things concurrently."*

Question: Does NGC serve as an input in your organization's guideline development?

This question was asked only of individual interviewees. One respondent said yes, NGC does have an influence. However, many others stated that other resources have a greater influence on guideline development.

Excerpts from individual interviews are listed below.

- *"Possibly, we go to NGC to look up other organizations' guidelines."*

- *"The Cochrane Collaboration produces high-quality, systematic reviews on a number of topics. That, we find extremely useful. And we'd love to see that focus in the U.S., that the government would sponsor activities like that. This is similar to the evidence-based center program at AHRQ, which does something similar. We'd like to see more careful analyses of the medical literature. We'd love to have input in helping select topics."*

- *"No, besides just us perusing the Web site to see if there are any current guidelines on that topic. It's the second step. We identify the topic and then we research other areas. Or other resources in that topic to see what guidelines are currently available."*

Question: How would you rate the submission, verification, copyright, and other processes of NGC?

One of the individual interviewees had problems with the submission process; the rest rated the process as excellent. The problem with the process was that the participant felt the same information was being asked for multiple times. Also, the length of time from submission to actually going live on the NGC site was seen as another problem.

Excerpts from individual interviews are listed below.

- *"Very good. I let them know that we have a new guideline and then they do the summary."*

- *"Really simple and easy. Not anything would really improve the process."*

- *"It's been great. Vivian sends me the e-mail and says we need this and this from you. And it's very clear what she needs."*

- *"Difficult. The process is very tedious and very lengthy. It took months and months to get something published. I'd send them the guideline and they'd say OK, and I'd have to wait a month or something for them to come back and say now complete our form with how it meets this criteria. I already knew what criteria it needed to meet, so why don't I just send you that from the beginning and we're not waiting two months for you to turn it around. Some of the criteria I find a little confusing I'm not sure what the difference is between one or the other. And it seems to be very nuanced. In that way, I find it tedious. It's very laborious   60 different criteria or something that I have to answer. It's complicated to take what's already been a lot of work on the guideline and then distill it into answering each of your questions. What disturbs me is once I've sent everything, I'm waiting six months to a year for something to show up. And by that time, we've lost a year of the age process."*

- *"I haven't had any issues with NGC. Our guidelines are not copyright, so we don't have that issue. I guess the length of time with the NGC process is a little bothersome. When it seems to take several months before something I sent them actually was done and final and put on the Web site. People can go to our Web site and find the guideline pretty much right away after it was approved."*

- *"Someone else on my team is responsible for submitting. I always found it very easy to submit. I also like the fact that if we've published a guideline and haven't submitted it to NGC, they sort of find it on their own and they contact me and ask to put in on NGC."*

- *"I have worked with them directly, it has been fairly easy and I can't say I've had any significant corrections on things that were sent back."*

- *"I think the process is good."*

Question: Do you ever look at the summary or abstract that's prepared and do you think that NGC accurately reflects the content of your guideline?

Participants reported that they do review their guidelines after submission to the NGC, and no problems have been encountered.

Excerpts of individual interviews are listed below.

- *"That's been fine. I look through it and usually I have to do just minor changes if anything."*

- *"Hardly ever have I had to really change any of the content, or it may be that I felt like something was maybe a little bit more important, that I wanted to make sure to put it in a certain area on their template. They seem to do a great job."*

Question: Do you see the annual verification report and the summary usage reports and find it useful?

Many respondents responded positively to this also. They used the number of page views of their guidelines as a measure of their dissemination efforts.

Excerpts of individual interviews are listed below.

- *"Yes. We use that information with our work groups, especially when revising documents. It gives us a sense of how often these things are being accessed."*

- *"Yes. We also collect hits from our Web site, too. This information is a reporting criteria to higher headquarters. It's used for awareness leadership. It doesn't help me get any more money. Nor does it help us prioritize guidelines we're going to work on. Congress and providers provide this kind of input."*

- *"I just remembered that that was offered, because it's only provided annually. So maybe, I'm not sure. It's an annual report and I often forget that I even have it. We utilize other resources to track our Web hits, to check our sales."*

- *"I love the annual verification report. It highlights if we just didn't know, just a reminder, these [guidelines] are the ones that need updating. And the other big thing they send us is the number of hits. And I've used that many times as a tool to try to capture which ones are the most important ones, which ones have the most impact. If we have to prioritize, which ones really need to be worked on because people are really paying attention and reading them. When we have to make decisions about where the resources need to go, and to prioritize if we have to make a choice, you know these ones*

[with the biggest number of hits] we definitely have to update these, and the other ones maybe can wait a year. I'm also adding the charts over time, so I can see year to year what's changing, and that maybe gets at dissemination. Are certain topics, why aren't they being used? Are they not interested in that or maybe they don't know about it? Or is it just sort of a niche area that not too many people in general work in or something like that."

- *"We really appreciate the monthly counts of page views. Because it's very hard for us to evaluate the impact of a guideline. Has it changed practice, are we getting diagnoses made earlier and more accurately, is treatment happening more quickly, we don't always know. So, in the absence of more meaningful quality measures, it is helpful to us to see how often others are at least looking at them. And we have received correspondence directly from people who say, I saw your guidelines on NGC and I have a few questions. So it has been a good vehicle for receiving communication from other people. Our advisory group is very interested in how the guidelines are being used. And I give them a report of how many page views there have been. We don't use it for topic or priority setting or budget justification because it is a retrospective piece of data."*

- *"It's outstanding. We were so excited last year. I couldn't believe the increase in looking at our guidelines from the previous year. We don't use the usage figures in any other way, other than just more of a nice to know. We do compare from one year to the next because there was just such an increase in hits and stuff. So it's exciting for us."*

Question: Are you familiar with the NGC response to FDA warnings? Do you use that information in your organization?

Respondents were familiar with this process. They felt it was a very beneficial service that NGC provided.

Excerpts from individual interviews are listed below.

- *"We have a process that we follow. We get direct FDA alerts ourselves. And we do a comprehensive perusal of our own documents. It's important for us to get that information."*
- *"We've encountered it a few times, and I find it very helpful just to see a brief summary of what's happening. We track FDA and other drug announcements. But it [NGC] is very helpful. Because sometimes you just know that something has happened to that particular drug, but then we can't really relate it to a guideline. So it is very useful to see that this specific guideline has been affected and this is what's happening … It depends on the*

type of impact, the timeliness of the notice. Sometimes we might have a little more insight, and therefore we've already informed our members of how it will impact them. We revisit the guideline every three years, so we wouldn't republish the guideline just because of an update on a drug. However, we would contact the work group and let them know that this has happened, and just FYI for when we actually update the guideline; we should include this or revisit this update."

- *"Yes. I just got one. I think it is useful to know what's happening, because I'm not on FDA all the time, it just depends on my project, so it's good to see [e.g.] on this paper that was done a little while ago, something has changed, and we may need to relook at something. So I could see that as possibly being very helpful if the drug happens to be something that was mentioned in one of the papers."*

- *"There are other people I work with who have other subscriptions or communications systems, so I wouldn't say I wouldn't have picked up on it. I actually got other messages about it through other sources and other colleagues. But I'm satisfied with receiving the information from NGC."*

- *"Yes, it has been useful. The physicians and myself were signed up to get alerts from various places. But NGC is always right there, sending us something and to let us know we found something on your guideline that refers to that drug, or whatever it was. And also the fact that they put something on the actual guideline, even though it's not a guideline that we've just recently updated, whatever is helpful to make sure the physicians out there treating patients have the most current information, that's great."*

Question: Should NGC rate the quality of the guidelines?

Respondents were in agreement that this is something NGC should consider doing.

Excerpts from the individual interviews are listed below.

- *"I think under the auspice of transparency, the degree to which that can be done is good. It's helpful for users of the content to have a sense of what the robustness is, or whether it relates to COI or the grading methodology that might be used in the document. The more that there is something that can be easily identifiable by the users, that's helpful."*

- *"That would be fine. We're using tools similar [AGREE, GLIA] to that."*

- *"There needs to be some other ways to separate the wheat from the chaff and include some quality assessments, even a basic level, which could allow you to distinguish types*

of guidelines.”

- *“That would be a really good idea because it would be nice to see how other associations or other users are viewing our guidelines. And especially if they don't have a vested stake in the review. If the request for a review was very random, and assigned, then that reviewer wouldn't have an invested stake so they would be unbiased, I guess. That would be great, for us to see how an unbiased reviewer would rate our guidelines.”*

- *“I'm not in a position to say they [the organization] would support it, but I would from a personal point of view. I would support it just being in this department, and to try to explain it to the higher-level people, and I think it would be a great tool because, you would finally get sort of a benchmark   well, how good are we doing? We think we're following these things. And maybe if an outside source said well, yeah, but in this area or that area, you know that would have a huge impact, I think on this is where we need to pay attention, and we've got to push, and everyone would then be persuaded to implement things, whereas they might not be if they're not sure. You know, this would be sort of an outside way of saying, well, yes it does need to be that way.”*

- *“I think that's probably a good idea. I would not only like to see something that helps establish sort of the quality of the guidelines that are on there, but I'd love to see some training on really developing quality guidelines, whether it's a Webinar tutorial or a conference. Maybe NGC could put something on like a conference that trains us how to improve guidelines. And that way you'd get some uniformity, exchange of information and cross-training. Especially if you're going to blend both public and private together, it could really make an important mark in the field of guideline development.”*

- *“I can't really answer that for the consortium. But for myself, as far as quality and implementability, that would be an awesome thing also. We [the consortium] want to make our guidelines the best we can.”*

Question: Does your organization use any other AHRQ products?

Excerpts from individual interviews are listed below.

- *“We're in the process of implementing GRADE. We are modifying the way in which we approach the review of literature in our work. We are moving towards a greater emphasis on systematic reviews than we have had in the past. It isn't like we're not aware of them and haven't used them in the past. As we expand some of our work, we may have greater reliance on that.”*

- *"It depends on what the topic is. There have been times that we've looked at those [comparative effectiveness, evidence-based practice centers, systematic evidence reviews]."*
- *"Yes, we use the systematic evidence review and other technologies and find them extremely valuable. We'd like to see a lot more of that."*
- *"Yes, we always look to AHRQ. I love all the methods guides. [Re: systematic evidence reviews]: "I don't think the topics that they have done have branched over into our area yet. We're in sleep medicine, it doesn't seem to reach sometimes the national agenda as far as getting some of that work done. But their methodology-related documents have been influential."*
- *"Possibly. It depends on what the topic is. There have been times that we've looked at those….[But] We haven't, at this point, submitted any [requests for specific topics]."*
- *"Not that I'm aware of."*
- *"We would use them if they had anything in any of the topic areas that we address, but to date that hasn't been the case."*

Question: Any comments on the new NGC design?

Respondents were happy with the new design of NGC. They felt it was easy to navigate and find the information they needed quickly. One respondent commented that they appreciated the weekly e-mails that get sent out with updates about the site. One person did comment about the annotated bibliography and said it wasn't what they thought it should be. Perhaps the naming of this function was not appropriate.

Question: Is NGC an important dissemination mechanism for your organization? If NGC weren't around, what would be your primary mechanism for disseminating your guidelines?

Respondents felt that NGC was a valuable tool for dissemination of guidelines. One respondent saw NGC as a reliable, credible source, and said that as such, people accessed guidelines through that vehicle. For one organization [a hospital-based guideline developer], NGC was described as the primary mechanism for disseminating their guidelines. For another organization [a health plan], dissemination through NGC was listed as their way of meeting the IOM's criteria for publicly disseminating their guidelines. Most organizations, however, had their own Web site where they also posted their guidelines.

In one of the focus groups there was a discussion around whether or not NGC should rate or assess the quality of the guidelines included on the site. Most welcomed some form of assessment and noted that this would not impact whether they submit, or likely, the way they do things. One participant wanted to make sure that whatever system might be implemented, that it

was implemented by skilled individuals and underwent some sort of reliability and validity testing. But all agreed that something should be done to provide an assessment of the quality of the variable guidelines currently included in NGC.

Question: What enhancements would you like to see to the NGC site?

Excerpts from participants are listed below.

- *"Downloading options."*

- *"Right now, all is see in the e-mail is just a list of links directing me to the updates. If it's not pertinent to me, then I'm not really going to pay attention. So if there was any way that I can tailor it to my needs, obviously that would be more useful. [subject specific e-mails]"*

- *"The idea of grading the guidelines. I look to NGC of being the standard, setting the standards, and the methods, this is an acceptable method and this is not an acceptable method. So then you drive to keep improving so that you can make sure that you keep being on the NGC. If the NGC could be the place you go to get the latest methods and thinking on how these things should be done and the standards   pulling all that information into NGC, that would be helpful."*

- *"Some kind of commentary or feedback mechanism so that I can see how the public is responding to the guidelines. Things they like or dislike or additional information. It would be good to have more feedback, because right now the only thing I know of is page views, which is only one little data point. Qualitative information like how are users using the guideline."*

- *"Have information about guidelines that are in progress, new topics that an organization is working on."*

- *"To make all of this data more useful to the clinician, be able to put in a pica formatted questions and then get feedback specifically to recommendations. Have a field like patient intervention, and then have specific recommendations from different groups come back to me at point of care. Use more implementable language."*

- *"If you were able to, when you pull up a guideline there was a field that said does this organization have a formally published methodology manual and, if so, provide a link to it."*

- *"It may be useful to have at least links to the guideline manual. For SIGN and NICE, they provide links to the actual guideline manual so you can see the methodology they used, which gives some context."*

- *"If they have the resources to provide maybe more information around quality so we can start identifying thresholds that align with the types of thresholds that you're seeking. Allow users to know what's in progress from other organizations."*

Question: Does your organization develop implementation tools to support their guidelines? Has NGC been involved with that?

Some organizations do develop other implementation tools such as pocket cards to support their guidelines. However, NGC has not been involved in any of these development activities.

Excerpts from participants are listed below.

- *"Yes, education tools for patients and providers."*

- *"We have pocket cards and CME. We have systematic review papers, so those papers are also published outside of our primary journal."*

- *"We're just getting into that. We brought the topic up and had some discussions but we haven't yet really had anything. We're talking about should we have pocket cards, or how should we let people know."*

- *"Not really. Mainly, we like to use something that's tried and true versus coming up with a new wheel. Most of the tools we have are things that are out there like a BMI calculator, substance abuse screening tools."*

Question: Other comments:

Excerpts from participants are listed below.

- *"It's a valued resource for us. We get so focused internally sometimes that we don't perhaps take advantage enough or even contribute to it. There's probably ways in which we don't maximize things."*

- *"I'm glad they're there. They're a great resource that we use. They've disseminated our guidelines, which has been helpful, and I get letters from internationally as well as different academic universities who use our guidelines. And they found out about our*

guidelines through NGC."

- *"I get the e-mail from AHRQ, and one thing I like to look at is the expert commentaries. Some of them have been very valuable. Other ones, not so much. But I specifically remember one that influenced me a great deal, and that was their commentary on use of active language. Our organization was using evidence statements as the recommendation and it was just highlighted   no, that's not how you're supposed to say it. You're supposed to say…   And actually I've been actively this whole year and they finally agreed to it. I'd be 'Look, this is what they say. Believe me, we should change this,' you know, and that was a big change."*

- *"I appreciate NGC being out there and doing what they're doing and obviously their role on a larger basis. We want to have these evidence-based guidelines there for people to use, and to help increase, help outcomes for people."*

Appendix G: Informatician Qualitative Summary

As a part of a larger evaluation of how the National Guideline Clearinghouse (NGC) is used, user perceptions of the NGC, and suggested enhancements to the NGC, a focus group of 10 participants whose expertise was in medical informatics was conducted on November 15, 2010 at the American Medical Informatics Annual Symposium in Washington, D.C. The participants were from 10 different institutions. These institutions were:

- University of Alabama at Birmingham
- Duke University
- National Institutes of Health (NIH), National Heart, Lung, and Blood Institute (NHLBI)
- Office of the National Coordinator for Health IT (ONC)
- NIH National Library of Medicine (NLM)
- Partners Healthcare System
- Veterans Health Administration (VHA)
- Stanford University
- Department of Health and Human Services (HHS) – Office of the Assistant Secretary for Planning and Evaluation

The focus group took one hour and a half to complete.

In addition, one-on-one telephone interviews were conducted with five individuals specializing in informatics (hereafter referred to as key informants). The participants were from 10 different institutions. These institutions were:

- Cincinnati Children's Hospital Medical Center (CCHMC)
- NLM
- Partners HealthCare
- University of Georgia, Department of Epidemiology and Biostatistics
- Vanderbilt University, Department of Biomedical Informatics

Each interview lasted from 30 minutes to one hour and followed approximately the same format as the focus group.

Below is a summary of the highlights of comments from both focus group participants and individual key informants from the informatics stakeholder group.

Preface

As part of the initial introductions for the key informant interview, the moderator asked the participants if they had completed the Web-based evaluation survey, which was part of an earlier stage of this evaluation. None of the respondents noted having taken the NGC evaluation survey. This was not asked of focus group participants because the focus group was hosted prior to the

survey deployment.

Based on prescreening questions, all focus group participants and key informants noted that they were aware of NGC. Most participants noted that they have been using NGC since its early days on the internet.

Question: How do you use guidelines in your work?

The first question concerned how each respondent uses guidelines in their work. All focus group participants except one said that they did use clinical guidelines. The individual who did not use guidelines worked in the Veterans Affairs Office of Health Information, where they do not use guidelines per se, but instead use performance measures based on guidelines.

All but one of the key informants also used clinical guidelines.

Among this stakeholder group (informaticians), individual's use of guidelines varied. For those participants who were practicing physicians, their use of clinical guidelines was in clinical decision support and clinical applications, including integrating guidelines into the electronic health record. Some physicians were also teachers/instructors, who reported using guidelines as an aid in didactic teaching methods. One interviewee, in addition to being an informatics specialist and Web developer, also noted being a journal editor, and reported using guidelines to assist authors in writing journal articles. Others used guidelines in their research, to help frame research questions.

A common role of most of the focus group participants and key informants involved conducting research on the process of taking clinical guidelines and figuring out how to represent those guidelines in clinical decision support systems. That is, how to parse apart guidelines so that they can be implemented into electronic decision systems to support clinical staff, i.e., other physicians, in their daily activities and patient care. One focus group participant from the Office of the Secretary of the HHS noted that the office is working on consumer-oriented tools for fostering the application of clinical guidelines and dissemination of information to consumers. Finally, one participant in the focus group was also a guideline developer.

Excerpts from the individual interviews on uses of guidelines are listed below.

- *"I practice part-time. My main job is as chief medical info officer, so I deal with how to design the electronic medical record to meet the needs of care providers. If we need a template where we can document on this particular condition or disease, we may go to the guideline literature to look to see if there are any references to pull to build on that information. I don't use guidelines that frequently. In the clinical environment I work in, we've got numerous order sets and documentation artifacts already built that reflect various sources of best practice, including guidelines."*

- *"As medical educator   outright didactic teaching and incorporating guideline knowledge within our ambulatory electronic health record. At NLM, formalisms for representation of guidelines within clinical decision support systems. I use NGC to find guidelines in order to examine their structure to ensure it can be faithfully represented in whatever health IT standard I'm working on. NGC may come in use as a tool not so much for the specific knowledge but for the way that knowledge is represented, what kinds of variables appear in the knowledge, how references are structured."*

Excerpts from the focus group are listed below.

- *"We use clinical guidelines operationally for randomized clinical trials. Also, we have a standard set for working on clinical decision support standards. There are thoughts of what do you actually standardize from representing this knowledge in a machine-executable format and how do you standardize accessing that kind of content."*

- *"We use them in computer systems, for decades. More recently, in a project we're working on called The Personal Health Record. We incorporate those into logic."*

- *"Guidelines are used in all the clinical decision support, in the clinical applications."*

- *"I'm coming from the realm of Federal programs and we use them for decision support. Also working on consumer-oriented tools for fostering the applications of guidelines and non-traditional ways in terms of disseminating info in guidelines."*

- *"My role is as a guideline developer."*

- *"In some research on developing clinical decision support systems."*

- *"Trying to figure out how to take clinical decision support to a national scale. We are increasingly contemplating how to build on top of meaningful use and interoperability, a rapid learning health system in the nation. Guidelines represent the learning that the health system generates. As the system studies itself through aggregation of data in a private and secure way, the results of various analyses will be insights into better ways of doing things."*

- *"In research centered around doing systematic evidence reviews and meta-analyses including, through the Cochrane Collaboration, various interventions. The guidelines are typically included in the background context of framing the questions."*

- *"Knowledge representation for clinical guidelines."*

- *"I'm a clinician attached to our informatics headquarters. We have no mandated electronic clinical logic; we have performance measures based on guidelines. There has never been an explicit statement that we will have our systems be electronically smart. We've found through lessons and experiences that every network in the VA has had to adopt things like clinical reminders and vet guideline knowledge as a way to meet performance requirements because there was really no achievable way to do that otherwise. We do not have internal consensus on collecting, curating, clinical knowledge and where the logic should be imbedded. One of the Secretary's transformational initiatives will drive this in a much stronger fashion because it will provide the 'umph' to make progress. We are aware of multiple sources of clinical guidelines and how professional specialty groups tend to use them and cite them. We are kind of expected to produce results and behavior that is consistent with them, but we have a ways to go."*

Question: How/why do you use NGC?

- *"In the context of my work as the developer and editor of something called Essential Evidence … as deputy editor for the journal called American Family Physician, and I also edit a medical school textbook , so when I'm doing that editorial work, sometimes I will search – NGC is one of the places I will search – when I'm trying to help an author. We identify any evidence-based guidelines that we think they [authors] ought to be aware of before they start writing a review article for us. And the same thing for any new chapters or new topics; and actually for Essential Evidence, every quarter – or actually every four months – we look at each topic, we do a search of NGC for each topic to identify any new or updated guidelines, and then we share those with the relevant editor or author. We're basically using it [NGC] as a repository for figuring out what the new guidelines are.*
- *"When trying to find a guideline, probably, I would say I almost always look there first.… 100% of the time I go to guidelines.gov first and look there. … Every two weeks we run an automated program that searches NGC and returns any new or updated guidelines on a topic, so really it's almost daily or several times a week.*

Question: What percentage of the time do you use NGC when you have a need for clinical guidelines?

One interviewee stated that he used NGC 95% to 98% of the time. Another interviewee stated that he used it a couple of times a year. Two of the key informants specifically stated that they had used the NGC site within the past year. Prior usage information was not collected in the focus group.

Question: What other sources do you use for guidelines? How do they compare to NGC?

The following table presents the other resources used by the respondents and the number of times each resource was mentioned.

Resource	N
Local source (e.g. Cincinnati Children's Hospital Medical Center, Mass General)	1
Cochrane Reviews	2
U.S. Preventive Services Task Force	3
CDC	1
Medical societies (going directly to the source guidelines)	4
Drug vendor sites	1
International guideline developer Web sites and databases (e.g., NICE, New Zealand group, Australian group, Scottish group)	2
DARE (database of abstracts and review effectiveness)	1
AHRQ's EPC site	1
Google	1

When asked how these other mentioned sites compared to NGC, two key informants stated that other sources for guidelines might not always be evidence-based (a requirement for inclusion on the NGC site), especially on various society pages. One interviewee liked the feature of his internal site (CCHMC), which allowed him to easily search for guidelines specifically related to pediatric topics. Although the NGC site does allow for this through the advanced search, he felt that it wasn't easily accessible up front and took three [mouse] clicks instead of one. The interviewee who used the USPSTF site said it compared about the same to NGC.

Another interviewee noted that they prefer NGC because they have been able to set up automated searches of content on NGC, and that this type of process is not as easy to do with medical and professional society Web sites. However, he also noted some problems that he has encountered with NGC that have impacted his ability to use NGC efficiently.

- *"…the society Web sites – they tend to change their Web site structure every six months or so it seems like – so again, when we have 800 topics and we want to kind of automate it or create a program that will search for us, rather than have to do it manually, topic by topic; if they're always changing their Web site, it screws us up. We look at NGC first, and then we click through to the society Web site if we need to. …But we've actually had*

to just go through a process. We used to link from our reference – essentialevidence.com – directly to NGC, and we've had to stop doing that, because so often, NGC pulls one-fifth of the guidelines every year … They kill a fifth of our links every year and all they do is put it in an archive and say 'Go to archive page.' Well, that doesn't do anybody any good; you can't find it then… So we're having to change 1,500 hyperlinks a year manually, and it just got to be too much, so now we're moving to just citing the journal reference for a guideline instead of NGC."

When asked why they use sites other than NGC, the interviewee who used the USPSTF site said that he liked it because it had a built-in process for analyzing the evidence and synthesizing it, and coming up with a single, unified recommendation. Another comment about the USPSTF recommendations is that they tend to be actionable. Another interviewee liked his own internal organization's Web site because it easily allowed him to shift into pediatrics mode.

A few of the focus group participants commented that the use of guideline sources may differ between clinicians and informaticians.

Excerpts from the focus group are listed below.

- *"I think the usage is a little bit different for informaticians versus clinicians. For clinicians, there's this disease I'm not used to, relatively uncommon and you want to look up a guideline. For informaticians, what you're really trying to do generally is implement what everyone agrees to, and you start with the lowest-hanging fruit because you start with a fairly low base unless you're some extraordinary institution."*

- *"I would underscore the thought that there's a clinician's view of guidelines which is going to be different than the 'informaticians' views, where they must be much more curated or even tagged and indexed in ways that they aren't currently for it to be accessible and useful."*

Question: To what extent does the NGC site fulfill your needs?

Many of the key informants held the NGC site in high regard. It is a good repository of guidelines that are tagged and searchable. Key informants also like the guideline syntheses and being able to compare multiple guidelines against each other.

Excerpts from the individual interviews are listed below.

- *"It answers the question 'is there a guideline' very efficiently. It's the best source to go to."*

- *"The advanced search is a little better than the old, but it is still a long list of items to scroll through. I think their summaries are helpful…. there are many times a very good*

summary of the key points of the article, and they bring all of them together in one place. The guideline syntheses are useful.”

- *“I find the syntheses more useful than the comparison part, also like the citation of the original guidelines. **One of the added values that the NGC provides is that it puts all of the guidelines into the same frame. From a knowledge management perspective that's very important**.”*

- *“Guidelines.gov is an excellent source of knowledge for decision support, but it's one of many and it has certain limitations.”*

Question: What do you dislike about NGC?

As far as dislikes go, one interviewee stated that he did not like the fact that guidelines are taken down after five years. In his job, he maintains a separate Web site that links directly to the NGC and searches for guidelines automatically every two weeks. However, for those guidelines that are out of date, the hyperlinks to out-of-date guidelines need to be changed manually, which total about 1,500 annually, which is a cumbersome task.

Excerpts from the individual interviews are listed below.

- *“There is no way to shift into pediatric mode, can do it in advanced search but I have to make three 'clicks.' How do you assure that your search finds the pediatric-relevant material, and then doesn't find the irrelevant material? And I'm left wondering how do I know if there are other guidelines out there? The advanced search helps with that, but I'm still left wondering.”*

- *“We've had to stop linking directly to NGC because so often NGC pulls one-fifth of the guidelines every year and you're having to change 1,500 hyperlinks manually. We've tried to work with them about this but they've been unresponsive. Now we have to curate that list ourselves, so every few months we go the NGC site, remove the old guidelines, add the new ones. But that creates all these broken hyperlinks. We want to integrate NGC search results into our results for a seamless way for the end user.”*

- *“The indexing by categories I don't find very useful. I don't find the comparison of guidelines all that useful.”*

Question: Do you trust the information provided by NGC? Why/why not?

In general, participants did maintain a certain level of trust in the information provided on NGC. One interviewee said that because this is an independent organization that is not trying to promote any specific product or viewpoint, he felt the information was truly unbiased. However, some expressed concern about the quality of the inclusion criteria, which may in an indirect way influence the trustworthiness of content NGC provides. These inclusion criteria concerns are discussed in a later question.

Excerpts from focus group participants and interviews are listed below.

- *"This is not an organization trying to sell anything, where they would be flogging their own guidelines. It removes that thought that it's biased. But it's not like all these guidelines have been vetted for executability and consistency. They're just the best we have. In most of these searches you are willing to take a broad range of things, to consider anything. And the fact there's been at least one pass through the material...is a big time saver."*

- *"I see NGC as being a place where you can find all of them [guidelines]. I don't think they set out to say this is the pristine, very best. But you can find them all in one place."*

- *"Almost anything you want to get in, you can get in. ...It's a clearinghouse. I think you have to separate the two missions to some degree. You could be a clearinghouse and not be a trusted source, or you could be a trusted source and not be a clearinghouse. To do both is hard."*

- *"I don't think we should say they're not trustworthy and they're bad. The mission was never to do some of the things we want. Do they at least have everything that anyone would think is useful?"*

Question: Has NGC influenced your approach or ability to identify current/high quality guidelines?

Key informants were asked if NGC has influenced their approach or ability to identify current, high quality guidelines, and if NGC has influenced the quality of guidelines in general. Most of the key informants felt that it did not. Even though societies may be moving toward evidence-based guidelines, in general, key informants did not think that NGC had any influence over that. One interviewee said that NGC had the potential to influence guidelines. If they placed more structure on the guidelines from the "get-go," this would result in less ambiguity that clinicians would have to deal with.

Excerpts from participants are listed below.

- *"Probably not. Most of these organizations have publication engines that they're targeting these things at. So, the fact that they're compiled in a guideline clearinghouse I'm guessing is probably not salient enough."*

- *"I don't think it's NGC who have forced them [societies] to move towards evidence-based guidelines, because they have not been in any way enforcing that. It's a political issue; they [NGC] don't want to make people mad. So they have not at all been leading the way in terms of improving the quality of guidelines."*

- *"NGC has not played a part in influencing the way guidelines evolved. It's had the impact of making better guidelines, but not those that are implementable and executable."*

- *"No. There's been a lot of work in the guideline movement which has made them more structured and less ambiguous, and more understandable and more usable, and I see that reflected in the evolution of the NGC. But I don't know to what extent the NGC's existence actually stimulated that. NGC could influence the structure of guidelines. Placing structure on a guideline from the get-go actually results in a better guideline because it reduces the ambiguity that clinicians otherwise would have to deal with. Don't know to what extent NGC has actually already stimulated in lessening the ambiguity of guidelines. I think it was the increasing use of electronic health records that did that."*

Question: Should NGC change its inclusion criteria?

All participants who responded to this question felt that the inclusion criteria were too loose. Many felt that NGC set the bar too low for inclusion in the database. One participant said *"As long as we call ourselves an organization and fill out the right forms, we can be a guideline on the NGC … It doesn't have to be any sort of evidence-based methodology. I think the NGC basically takes all comers and doesn't really pay attention to quality."* Another participant said that in general, *"U.S. guidelines reflect too much self-interest of the originator of the guideline,"* and the NGC *"sets the bar too low"* for allowing guidelines on the NGC site. Regarding the criterion of being up to date within the past five years, one participant stated *"With the half life of one element of biomedical information being frequently cited as seven years, a guideline that can be as much as five years old does not lend a lot of face validity. I think that's [five years] a very weak inclusion criterion."* One interviewee suggested that NGC could be more proactive, and identify preferred guidelines, or even best guidelines. NGC could identify key concepts or highly agreed-upon core fundamental concept statements from across guidelines in an abstract

format.

Excerpts from individual interviews are listed below.

- *"Too loose. As long as we call ourselves an organization and fill out the right forms, we can be a guideline on NGC. It could be just a bunch of people sitting at a table deciding what they always do, it doesn't have to use any sort of evidence-based methodology. I think NGC still basically takes all comers and doesn't really pay attention to the quality. There is still a belief that NGC creates these guidelines and has a very rigorous process for letting guidelines in or that it endorses these guidelines. Which it doesn't."*

- *"NGC could be more rigorous in identifying preferred guidelines, or even best identify those key concepts or high agreed-upon fundamental core concept statements from across guidelines."*

- *"In most of these searches you are willing to take a broad range of things. You're usually in a state where you want some help, and you're just willing to consider really anything. And the fact that there's been at least one pass through the material to say, yeah, this counts in some way. That's a big time saver. It would be of mild interest perhaps for the mid-range to distant future, to apply some methods to this corpus and say, OK, for these topic areas we've applied these techniques, and we can rate these by executability."*

Excerpts from the focus group are listed below.

- *"A whole bunch of stuff that's in decision support has nothing to do with guidelines. It's procedural, local policy, even local expert opinion which never came anywhere near a guideline. I don't know if our goal is really to think about the NGC for NGC's sake, or trying to think about what' improving and transforming healthcare."*

- *"People who know about guidelines and know about an evidence-based approach to guidelines recognize that AHRQ is not necessarily a trusted source. It [NGC] is like a clearinghouse, and the bar for getting things into the clearinghouse is pretty low. But it's a good source because you can find any guideline that's new or been updated within five years. We actually recommend three years, but AHRQ says five because I guess they didn't want to be too stringent. One of the concerns is that people who aren't that savvy about guidelines probably do view it as a trusted source and that's probably the majority of clinical people out there who don't live in this world. They just look to guidelines to provide guidance and they go to NGC and they say, 'Oh, it's on NGC. This is probably good or a decent guideline.' So I think that's one of the issues we're going to get to is*

that at some point, should NGC set a higher bar and become a place that is really a trusted source and that in order to get your guidelines onto NGC, you have to meet certain criteria. You know, not overly restrictive, but at a certain level where you know that it's at least this good. Right now it's pretty easy to get into NGC. And the five-year thing, it's a pretty low bar."

- *"With the half-life of one element of biomedical information being frequently cited as seven years, a guideline that can be as much as five years old does not lend a lot of face validity. I think that's a very, very weak inclusion criterion."*

Question: Are there any future enhancements to the NGC Web site you would like to see?

Many participants and key informants stated that they would like the guidelines to be executable (also referred to as implementable). More specifically, they favor a way to parse the information in a guideline so that it can be acted upon and implemented in clinical decision support. This would probably come in the form of XML language that would be fully human readable.

One interviewee referred to PubMed and their Entrez utilities, which send back information in XML format that can then be manipulated by the end user [Web developer] to suit their needs. When the user wants to download the information into a local system, only minor tweaks would be necessary to make guidelines compatible with local standards.

If making guidelines executable was outside the scope of NGC, one interviewee felt that NGC could in that case at least rate the executability of the guidelines. That would be something that the societies are not currently doing, and it should be done in a neutral context such as the NGC, the interviewee said. Or the NGC might define the variables or terminology that is used in the guidelines to make them more structured and easier to implement.

Participants also talked about the development of quality criteria to rate the guidelines, and including more evidence-based guidelines. Both of these ideas would raise the standards of guidelines, as well as help them to become more "actionable" and executable. Another suggestion was to have on the home page of the NCG site a check box where the user can limit the search to evidence-based guidelines only. And finally, users wanted to be able to access archived guidelines in a quick, easy-to-use way.

Excerpts of the individual interviews are listed below.

- *the ability to actually put them into practice, a way of parsing the content that's in NGC with some sort of assessment of how executable it is, even their quality or level of how evidence-based they are. That would offer something that the professional societies really aren't doing. Screening for executability*

should be done in a neutral context, and NGC may be the place to do it. E-mail alerts, rating the quality, i.e., executability, content formatted for mobile devices, downloading abilities, ability to search archived guidelines would all be useful."

- *"Do what PubMed does with their Entrez utilities, which sends back XML and I can do with those what I want. It's easier for the end user if everything is in one site. Being able to access archived guidelines would be helpful. Sometimes a guideline gets updated and assigned a new tracking number. If they used the same number, that would be helpful. When you update a guideline, use the same hyperlink. Also, have on the home page a check box that would say 'Limit to evidence-based guidelines.'"*

- *'Include the algorithms and figures in the summaries if it doesn't violate copyright."*

- *"The implementability of the guidelines. There is a large void, or a chasm, between a guideline and implemented clinical decision support. And guidelines don't represent knowledge in an implementable format. Tools like GEM help parse guidelines into an XML-parsed representation that's fully human readable, but that's not fully implementable either. Breaking down guideline information and making it useful, but I don't think the NGC can do it. That's the right kind of target for a knowledge engineer to work for. The Compare Guidelines could be made much more rich, maybe do a GLIA comparison of guidelines. An authoring tool to use controlled medical terminology and the building block would be useful. If you standardize the guideline up front, it will help to standardize the guideline itself."*

- *"Ideally you might have a Web service that we could throw a UMLS concept   CUI against, and back comes some sort of representation of what pages that we might be interested in. Or if there was a cataloguing of the pages by type. I would want to create the dynamic links to that space."*

- *"Knowledge as it's published by a guideline writing organization in its narrative format would also be published in at least a structured, if not fully computable, format with the idea that importation, except for some tweaks that would be needed to localize a guideline for certain local things. The NGC would have another attribute that would say 'computable knowledge module.' Executable. The whole recommendation string wouldn't necessarily be computable, but what you could do is define the variables or terminology that's used in the guidelines so that it's more structured and easier to implement. One way the NGC can go is like similar activities taking place around quality indicators. There was a push in the last year or so by the NQF to create a standard knowledge representation formalism to represent quality indicators, because lots of organizations are being made through promise of financial reward or through outright regulatory*

requirement to implement and report quality indicators for the organization. A similar problem occurs because quality indicators are published in narrative format with varying degrees of specificity about the definition of the denominator and numerator populations for calculating the measure. Then they have to be translated into something that will actually run on the database that the organization maintains that contains patient data. The whole recommendation string wouldn't necessarily be computable, but what you could do is define the variables or the terminology that's used in the guidelines so that it's more structured and that it makes it easier for an implementer to implement a guideline."

Excerpts from the focus group are listed below.

- *"Would be interested if content were available in a downloadable way. We are working on a project where we are taking knowledge and trying to translate into a more accessible set of artifacts for humans to read, very distilled, simple statements of logic and then progressively more implementable in a computer system for decision support. One vision of NGC 2.0 is additional tagging and refraction of knowledge into various levels of artifacts or abstraction so that it is more usable. Much of it that is in there is not implementable in the first place, and not even well written."*

- *"I think AHRQ has done a nice job with their clearinghouse based on what it was intended to do originally. It is a clearinghouse and a repository of all of these different guidelines, and I've seen them really improve and listen to feedback and change as they've gone forward. I think the functionality is very good based on what it was intended to do. The question then is as we want to move forward and try and develop better guidelines that are not only more executable and implementable, but also more evidence-because you want them to be valid and trusted and let people know that this is what they should be doing   that's a key piece of it   and even when you do that , though, you actually have to write them in a way that they're implementable and they can be executed. I think at some point, NGC's role is to make the guidelines better, more evidence-based, more implementable, and you can't get into the NGC unless you meet certain criteria. Then you still have to take that and other people have to turn it into code and computer language, and I don't think that's AHRQ's role."*

- *"Get the guidelines developed in a form that allows them to be executable. And if we look to the future, that's going to be the only way that guidelines are probably going to be delivered. ... Maybe I'll back off a little bit from the executable form as much as being able to be put into that form. And that will be a natural filtering that will go on as that becomes the only form to us then. So if it's consider this and consider that, then you can't do anything with it. Those kinds of guidelines will probably have to fall by the wayside into something that is a little bit more actionable. And that's where the future will be. So*

the clearinghouse will have them all, but the ones that become the most useful are the ones that can be built into decision support more readily."

- *"Most of the stuff in there is on the level of don't mix stripes and plaids; it doesn't tell you how to get dressed. What you need is at least to categorize the guidelines on the basis of how specific they are, which is not AHRQ's problem, it's really the author's.   But there's no mandate for the guidelines to be more specific. ...*

- *"[To the question] Do we need a guideline clearing house? One of the things we haven't addressed is for whom? What is the need for programmatic access to such a clearinghouse, as such a resource? I think many of us would like the ability to be able to have information technology at least assess what guidelines are available, know on the basis of some categorization, which guidelines might be actionable, and even assist local implementers in accessing content that might be valuable. And that's something that's never been on the AHRQ radar screen."*

- *"Should there even be a clearinghouse? I think for a clinician, it's always good to have a source where you can find this kind of information. For an informatician, where, it's not like you're just going to do a search and you need to find it in five minutes. If you're going to actually use it, you're going to be spending hours, days, figuring out what you're going to do and which you aren't going to use and which one you should use. For that purpose, having a more convenient search function is not necessarily that much more helpful than just doing a Google search or talking to your colleagues and asking what are the guidelines they consider to be trustworthy. Just because you've found a guideline, that doesn't mean that any of the relevant specialists are going to use it."*

- *"Should there be a guidelines clearinghouse? Is the concept of a clearinghouse that is accessible in the way NGC is consistent with the nature and quality of what is in it? I don't know what the answer to that question is. I'm interested in what other people think."*

Question: Do you build or use Web 2.0 technologies, and do you use NGC for these activities? Are there other NGC tools that are useful or would be useful?

Participants reported using current Web 2.0 technologies such as the RSS feeds (e.g., syndication tool for sharing Web site content), XML content, and e-mail alerts. All participants would like to see the addition of other Web 2.0 technologies that are being considered by AHRQ, such as subject-specific e-mail alerts, formatting of information for mobile devices, and the ability to

export content. Limiting searches of NGC to specific fields within the guideline summary would be welcome, especially when formatting content for mobile devices.

One focus group participant cautioned about the use of XML content and said "XML format is useful for people who want to present to users text. But if you want to have something that the computer can actually take advantage of, that would mean categorizing guidelines into their various structures, guidelines that fit into various action rules, guidelines that fit into chronic care plans. No one has actually come up with this classification and enumerated the forms."

Excerpts from the individual interviews regarding NGC tools are listed below.

- *NGC Search Form: "We've been using it in a back-office kind of way, but not in a front-office – not in an end user kind of way…. as far as I can tell, it doesn't allow you to do, for example – like PubMed – I can do my own query of PubMed, and then it'll send me back some XML that includes the references I'm interested in that match my query. And then, I can do what I want with those – I can list those on our Web site, provide our own hyperlinks formatted the way we want to do it, integrated with our own search results – that kind of thing…. so what would be much more useful [from NGC] would be a way to do what PubMed does, with their Entrez utilities, which is that I would send NGC a query – I'm interested in acute bronchitis as the key disease term – and I want to limit it to ratings scheme, and I want to limit it to the last five years, or three years or two years or whatever. And then it'll return an XML document that lists the guidelines and their hyperlinks and how to link to them. Instead of forcing me to open up another browser window – the user then leaves our site – and then they maybe don't come back."*

- *"Yes. One of the big requirements to meet is coding to support billing. What we want to do is provide a system that supports a number of best practices, either ones that are identified in a guideline, or things that are just best practices. We build order sets, documentation templates, alerts, ways to take data in the system and compute a decision-making aid. What folks who think about informatics and guidelines always think about is: Well, here's this guideline, what computery things would you want to put in your EMR. In a perfect world, you would want a little appendix on each one, i.e., order set, risk computation, alerts (and criteria on which they should fire), documentation template that contains elements to support your decisions."*

- *"I use the RSS feeds. I find that very helpful. Subject specific e-mail alerts would be great. Rating of guidelines would be great. Formatting for mobile devices would be very useful. Limiting searches of NGC content to specific fields within the NGC summary would be absolutely great, especially if you want to display it on a mobile device. The ability to export content would be great, XML would be the most useful."*

- *"XML content does help to access, peruse, review, and even use the knowledge in the various guidelines as they're tagged and coded in the NGC. But it's miles away from this implementable concept I'm trying to describe."*

- *"XML content, e-mail alerts, RSS feeds all used. Interested in subject-specific e-mails. Formatting for mobile devices would be good. The extent that you can provide a filtered view that is just the recommendation of interest is good, would be useful."*

Excerpts from the focus group are listed below.

- *"XML format is useful for people who want to present to users text. But if you want to have something that the computer can actually take advantage of ... that would mean categorizing guidelines into their various structures, guidelines that fit into various action rules, guidelines that fit into chronic care plans. No one has actually come up with this classification and enumerated the forms. No one has actually talked about what the underlying structures are that would allow you to have not an XML that just gives you the very broad recommendations, but actually a machine-understandable output that a system could then suck in and do something with. Someone is going to have to fund a lot of very exploratory work to come up with those categorizations, to come up with punitive structures and to think about how we can think about guidelines in a way which will allow them to be translated to actual form a lot more readily than the current systems allow."*

Question: Does NGC provide you with information that is useful to you as an informatician? Would you be interested in using the content if it were available in a certain way?

This question of the focus group participants started an interesting dialogue about the value of a clearinghouse of clinical practice guidelines. The common theme emerging from this dialogue pertained to the executability of guidelines.

- "Most of the stuff in there [NGC] is on the level of don't mix stripes and plaids; it doesn't tell you how to get dressed. And, what you need is at least to categorize the guidelines on the basis of how specific they are, which is not AHRQ's problem, it's really the author's. But, there is no mandate for the guidelines to be more specific.

Question: Miscellaneous comments

Some interviews were positive about the NCG, but wished it could do more. For example, one interviewee wished that guidelines were more standardized, and felt that the NGC could play more of a role in that process. Another suggested that the NGC act more like the U.S. Preventive

Services Task Force, saying more controversial things and being more definitive in their recommendations. Another suggestion was that NGC serve in a consensus building role, giving more structure to guideline development. **One interviewee realized that activities from guideline development to implemented decision support are really a function of a "knowledge engineer" and probably outside the purview of the NGC.**

Excerpts from the individual interviews are listed below.

- *"Guidelines.gov is an excellent source of knowledge for decision support, but it's one of many and it has certain limitations."*

- *"We feel like there are some things that are better off standardized. And being clear about what part needs to be standardized and giving people the tools to do that, NGC could play a role in that."*

- *"The NGC is an important resource, but the fact that it's a clearinghouse, the name says it all. I wish AHRQ could do more. The U.S. Preventive Services Task Force is one example within AHRQ, they've managed to remain independent and managed to stay controversial, and say unpopular things that were true. I wish the guidelines clearinghouse looked more and behaved more like the USPS. I always keep in mind who our end users are and that they're really busy. They have one to two minutes to answer a question. So you have to have one place they can search."*

- *"The activities from guideline to implemented decision support is 'knowledge management' or 'knowledge engineering.' It's probably not in the purview of the NGC to take on those responsibilities. What would be nice is to have an entity that takes knowledge from the evidence base and delivers a set of implementable content in the EMR. There has to be a federal entity which assumes this knowledge engineering or management responsibility. It takes guideline content, working with investigators ... which takes knowledge from the evidence base and says, based upon national policy and clinical objectives, national priority partnerships and all the rest, it says here's a set of implementable content. It's implementable in EMR. NGC is a start; it's sort of the library."*

- *"NGC could serve as a consensus building role about how you might provide a greater structure for guideline development. Rating guideline quality of methodological rigor of guidelines by NGC would be less useful. Physicians tend to trust guidelines more if they are from an organization either they respect or are members of, as well as they tend to focus more on guidelines within their own specialties. So it would be a bit of a challenge for NGC to do that, a political challenge."*

- *Request: "…when you [NGC] update a guideline that you use the same hyperlink – the same ID number and the same hyperlink – so an updated guideline – when a guideline is updated, it doesn't break the link. And when a guideline is withdrawn, that it still remain findable – easily findable. Because right now, all it does is send you to this big archive … and then you have to scroll through this huge list and, you know, I give up most of the time. I can't find them. Instead, there should be a direct hyperlink – if you're going to remove it, just put up a warning and tell us it's five years old, or send it to the archive but have a direct hyperlink to that guideline in the archive so I can find it."*

In discussing the usefulness of NGC and the guidelines it includes, a participant asked the following question that led to a series of responses:

"Should there be a guidelines clearinghouse? Is the concept of a clearinghouse that is accessible in the way the NGC is consistent with the nature and quality of what is in it?"

Excerpts from participant responses to this question:

- *"I think for a clinician, it's always good to have a source where you can find this kind of information. I think the question is for an informatician, where, it's not like you're just going to do a search and you need to find it in five minutes. If you're going to actually use it, you're going to be spending hours, days, figuring out what you're going to do and what you aren't going to use and which one you should use. For that purpose, having a more convenient search function is not necessarily that much more helpful than just doing a Google search or talking to your colleagues and asking what are the guidelines they consider to be trustworthy. See, just because you've found a guideline, that doesn't mean that any of the relevant specialists are going to use it."*

- *"When you asked the question, 'Do we need a guideline clearinghouse,' one of the things we haven't addressed is for whom? We're sitting around this table talking about do informaticians need a guideline clearinghouse and think the resounding answer is probably not. Do clinicians? We're not the right people to ask, specifically. But, clearly, one of the things that has not been on the table is, what is the need for programmatic access to such a clearinghouse, as such a resource? And, I think many of us, including myself, would like the ability to be able to have information technology at least assess what guidelines are available, and know, on the basis of some categorization, which guidelines might be actionable, and even assist local implementers in accessing content that might be valuable. And, that's something that's never been on the AHRQ radar screen as far as I know."*

Appendix H: Medical Librarian Qualitative Summary

On July 21, 2011, AFYA convened a focus group consisting of medical librarians in order to evaluate their perception of the Agency for Healthcare Research and Quality's (AHRQ) National Guidelines Clearinghouse (NGC). This focus group was conducted with seven medical librarians. The participants were from five different institutions. These institutions were:

- Medical Library, Children's National Medical Center, Washington, D.C.
- The Oregon Evidence Based Practice Center, Oregon Health and Science University
- Health Sciences Library, University of North Carolina at Chapel Hill
- A. Alfred Taubman Health Sciences Library, University of Michigan
- Health Sciences Library, University of Colorado Denver

The focus group took one hour and a half to complete.

Preface

As part of the initial introductions, the moderator asked the participants if they had completed the Web-based evaluation survey as part of an earlier stage of this evaluation. None of the respondents had taken the NGC evaluation survey. One respondent remembers the survey but did not complete it.

Question: How do you use guidelines in your work?

The first question concerned how each respondent used clinical practice guidelines in their work. All respondents indicated that searching for and using guidelines were important activities for their work. Four respondents use guidelines as part of teaching at all levels, including undergraduate, graduate, medical students, and residents. These respondents also indicated they help inform clinical faculty about guidelines at their respective institutions. The topics mentioned by the respondents were nursing, hospital practice, clinical practice, dentistry, pharmacy, and overall medical education. Five respondents use guidelines as part of research activities, including identifying information for systematic evidence review development (in the scope development process), and/or when developing or updating clinical practice guidelines or protocols.

Excerpts from the respondents' statements are below:

- *"We use it within our medical education. So, M-1 though M-4 years. We also use if for guideline searching for faculty members."*

- *"…we instruct extensively on the use of practice guidelines in our undergraduate medical education. We also instruct on the use of practice guidelines in our graduate*

medical education and our clinical faculty. We are also involved in the process of creating clinical practice guidelines... We do all of the literature searching for them, for their guideline.""

- *"I work with guidelines in my basis reference work – finding guidelines. I'm also a liaison to the School of Nursing and teach the use of guidelines, work with undergraduate and master's students doing papers who need guidelines, and work with our practice center in the hospital who are doing protocols and guidelines."*

- *"We work to support the development of systematic reviews, and at the early stages of this, we do searches involving scoping; trying to decide whether topics are ripe for doing a systematic review. And, as part of this process, we of course want to see if there are published guidelines on those topics. It's under that heading, I guess, that we search for guidelines because, before we go forward with doing a systematic review, we would like to see what other systematic reviews and guidance are available."*

- *"I teach people how to use the guidelines in all phases of their educations and we have all of the health sciences programs – nursing, medicine, PT, dentistry, everything. Most of the teaching I do is in the drug information course in the second year of the School of Pharmacy where they are doing lots of searching on a variety of topics and a lot of time looking at clinical practice guidelines. And then we also use it when we're working with our clinical faculty at all levels... I help them find the latest guidelines."*

Question: How and when do you use NGC, and how frequently do you visit the Web site?

All respondents use NGC with varying frequency. Most frequent use is every day; the least frequent use is a couple dozen times a year. Variation in frequency of use was in part related to the purpose of the use.

Two respondents use guidelines a few times a month in accordance with systematic evidence review work. One respondent uses NGC with similar frequency as part of guideline research and creation, but not as frequently as other resources because of the lack of pediatric information that this respondent could find in NGC for pediatric populations. Two other respondents use guidelines more frequently in accordance with teaching schedules, with higher use occurring when student papers are due or when students conduct research activities. The final two respondents report daily use of NGC as part of clinical application and teaching activities. Excerpts from the respondents' statements are below:

- *"We mention it and go over it with the [students]. So, during orientation sessions. And, what do we use it for? Also, guideline searching in terms of building the guideline itself."*

- *"We use it very frequently in class preparation since we're instructing on it [NGC] all*

the time. We really teach it and give exposure to it in our sessions – all the way from undergraduate and nursing school through our clinical faculty."

- *"So we focus on going to NGC for topics that are not covered under [our hospital specific]-created guidelines. We also direct users to NGC as a way of easily accessing [our hospital specific] guidelines [which are included in NGC]. So, we do promote NGC as a very quick and easy way to get access to [our hospital specific] guidelines and of course all of the other guidelines out there. Specifically, we promote the guidelines syntheses [which often include the hospital's guidelines]."*

- *"I don't use them all that often because this [Children's National Medical Center] is a pediatric hospital and there are not a lot of pediatric guidelines there."* When NGC is used, it is used *"to identify and see if there is one there about the specific topic."*

- *"We use it more when the protocols are being rewritten, when students are working on their papers, those types of things."*

- *"Primarily just to find guidelines and to work with the people who are creating their new protocols and guidelines, either within the hospital or for a special education project or something along that line."*

- Our use is related to *"the workflow of scoping the systematic reviews."* … *"We're sort of trying to identify if guidelines exist or don't exist for a particular topic. And, as the librarians, we sort of just hand off the guidelines to other people who might be investigating whether or not those guidelines are evidence-based, to see if a systematic review might be warranted."*

- *"What I use it for is mainly for teaching and, within the library, we use if for answering questions, helping to locate clinical guidelines. When? It varies, depending on when the questions come in. Although, I use it much more frequently during the course of our drug information course for our P2 students and that is during the spring semesters… And then I also teach within the PA curriculum on evidence-based practice. So, I use it there as well and I use the comparison table tool which is really nice."* [The dynamic comparison tool] *"…where you select from the guidelines that show up and you compare to make sure you identified the ones that are more evidence-based."*

Question: What percentage of the time do you use NGC when you need to find clinical practice guidelines?

This question was meant to get at the percentage of time that stakeholders use NGC when they are trying to find guidelines. All respondents use NGC more than 50% of the time when trying to find clinical practice guidelines. One respondent reports using NGC 90% of the time, and

another respondent reports using NGC 50% of the time (since it isn't always useful in finding guidelines, she sometimes forgets that it is available). Five respondents report using NGC "100% of the time," "always," or "all the time." Additionally, three of the respondents report using NGC as part of a suite of guideline resources at their institutions or as one of several guideline resources they use when completing their work.

- *"I would say all the time. So, I go to a couple of different places and I would say I definitely always check there [NGC] to see what is in there."*

- *"Umm, maybe at least 50% of the time. I might not find it there, so sometimes I forget that it's there because it isn't always that helpful."*

Question 4: What other sources do you use for guidelines? How do they compare to NGC?

The following table presents the other resources used by the respondents and the number of times each resource was mentioned.

Resource	N
ACP PIER	4
CDC community guide	2
DyneMed	3
MD Consult	1
NICE guidelines	2
NIH consensus statements	2
PubMed	3
Publication Limit	1
Guideline developer Web sites directly	4
Publishing organizations	1

The focus group mentioned several features that were good about NGC. Several respondents found the NGC interface easy to use. NGC offers an effective aggregation tool for finding guidelines with a guideline grouping system. It also has an effective comparison tool. Three respondents also highlighted the fact that NGC is a free resource. This enables many different audiences to access the guidelines and tools without subscriptions. The respondents indicated

this was important for teaching, as students and faculty can always access NGC. Excerpts from the respondents' statements relating to the positive aspects of NGC are below:

- *"Well, in my opinion, it's a nice comprehensive resource. There are a few good features that we tend to highlight to people, in terms of browsing the guideline syntheses, the ability to browse by an organization, in terms of accessing our guidelines quickly and easily. And, honestly, the bottom line, from an educational standpoint, particularly with our undergrads, our meta and undergrads and our residents and fellows, is the fact that it's free."*

- *"I like that NGC sort of aggregates all of these [guidelines] and the new change in the interface has made it so much easier for me to use and for the people I work with to use. I too… like the comparison feature because that saves me a lot of time."*

- *"I'll have to say too that one of the reasons we use it with our students and house staff and nurses is because it's free and they don't have to have any kind of access, they can get to it anytime, anywhere, and I find that really important. And I find it is the first place that I go to because for me it is the most convenient place."*

- *"I find that, especially the new interface for the NGC is much easier to use in my experience than the NICE guideline site, where I just feel like I'm going down one gopher hole after another and I'm not entirely sure that I've gotten everything that I need to… I like the guideline comparison feature, personally, because of the structured abstracts. It's a lot easier to see and compare across multiple guidelines on one screen."*

- *"Compared to a lot of the other sources we're looking at are sort of like, say the Web site of an organization that produces systematic reviews or technology assessment reports and they're sort of limited and it might be harder to search and it's more browsing than searching and it's only content from one provider. So, compared to those things, having a guideline clearinghouse and interface, you know, I think it's one of the better ones and easier ones to search compared to some of these other things."*

The medical librarian focus group also discussed features of other resources and sources of guidelines that made them more appealing. Other resources have more current or recently published guidelines. This was especially true of PubMed and medical society Web sites, which respondents report have the most current information about clinical practice guidelines. Respondents also indicated that other resources are easier to use in terms of browsing by topic or specifying search terms. It was noted that some other sources of guidelines have a better organization or that it is easier to examine the evidence ratings than NGC. Excerpts from the respondents' statements relating to appealing aspects of other resources are below:

- *"ACP PIER and DyneMed… have things like the evidence rating system and they then*

list the guidelines that they've discussed."

- *"I will say that many of these resources are much more user-friendly. You know, the evidence ratings or grading is consistent across resources, whereas it may not be, depending on the guidelines that you are looking at, in NGC."*

- *"So many of our clinicians tend to like some of these other resources. They are a bit easier to use on a hand-held, which is, I think, for guideline-type use, that's really important – to have access."*

- *"It's easier for me to find something that is more current by going to PubMed because I can tell it the date that I'm interested in and I'm just more familiar with the interface of PubMed."*

- *"The decision factor for me on whether I'm going to search for guidelines in NGC is how current I'm being told the guideline is. If I'm told that it has come out in the last three to five months, I tend not to go to guidelines.gov first because my experience is there's a lag time before those new guidelines show up in NGC. And, I've never been sure why… I suspect it's because of the kind of review and editorial process that goes on, which is very valuable, but I wish that were faster."*

Question: How would you rate your satisfaction with NGC compared to other guideline sources?

All but one was satisfied with NGC. The other respondent was satisfied with NGC, but less satisfied when compared to her experiences with other resources. The reasons respondents indicated for their high satisfaction were NGC's good bibliographies and credible and detailed expert commentaries about the guidelines. The reasons respondents indicated for their lower satisfaction with NGC compared to other resources were that NGC does not necessarily include the most current information, pediatric content is difficult to find, there is no update notification system in NGC, it is difficult integrate or download guideline information to bibliographic management software, NGC does not have as effective a mobile interface as some other guideline resources (which is important for their clients), there is difficult subject browsing or searching by subject, it is difficult to limit search results to manageable listings, and it is difficult searching for specific guidelines if the user knows what specific guideline he/she is looking for. Excerpts from the respondents' statements are below:

- *"…allowing more specific subject searching. So, the current method that we have when we go in and search for a particular topic like chronic kidney disease or congestive heart failure, in our results set, we're pulling things that don't have anything to do with those topics. So, maybe improve that somehow. The second item that she mentioned was to let users pick and choose what they want to see and add a check box for each item they want*

to retrieve. And then, offer a way to deliver and save search results."

- *"I think one of the things that really bumps the use of this up, because I think it is a really good resource, is a more attractive or more enhanced mobile interface, which would involve, I think, some additional standardization of the entries to make it more clinically useful."*

- *"Some of the searches that seem quite basic that they've put together, and should be decent searches, will sometimes miss guidelines and things like that that could be relevant. So, I think enhanced search capability and search browsing would be great."*

- *""There are not a lot of pediatric guidelines there and that's what we look for and, if there is pediatric content, it's hard to find... It would be nice to have guidelines with a scheduled update process so we would know when it was going to be updated again, if that's possible."*

- *""...have some sort of download feature into the bibliographic management software ... so that people who want to cite them can cite them without having to copy and paste. What they're doing is going back to the original guideline to download that from PubMed and it's not always there, it gets messy. And that would save our folks a lot of time and make it much more convenient."*

- *"I'm usually doing pretty simple searches on broad topics but, the results I get, it's hard to distinguish between whether it's a guideline about that topic or if it's a guideline about another topic that mentions that in passing somewhere down the way. It would be nice to do like a title search to only search within the title of the guideline... If you're doing a sort of narrow, keyword search, to be able to narrow it to say I only want it if this word is in the title. That would help cut down on a lot of related but not actually on-target results that I get."*

- *"Expert commentaries... I think that there is a lot of really valuable information there but I just wonder if it's sort of in its own silo and whether or not actually a lot of the users who may benefit from it would find it there. Or, if it's a commentary on a specific guideline."*

- *"And then my other comment was just about the annotated bibliographies feature. I think for one aspect of the work that we do is working with people who are actively refining methodologies. That kind of really defined grouping about articles and developing them is really useful."*

Question: Do you trust the information provided by NGC? Why/why not?

All respondents indicated they trust the information provided by NGC. The reasons they

provided for that trust were that NGC identifies the guideline source and date produced, guidelines included in NGC seem to come from identified and authoritative sources, the institutional support of NGC from AHRQ, and effective and evidenced-based criteria used for including guidelines in NGC.

Excerpts from the respondents' statements are below:

- *"YES – I would say because it points to where the information is coming from and it's cited and we know that it is pretty current and it tells when it was last updated."*

- *"One of the things that we always talk about when we're instructing on EBM (evidence-based medicine) and use of EBM, particularly in a clinical setting, is the importance of doing some of your own evaluation. And, so while a lot of guidelines, being secondary literature sources, do a lot of evaluation for us, we are always looking at the different organizations that are producing them and having a good understanding of the criteria for how they are included in NGC. So, I think we as librarians stay on top of that and, for that reason, we can tell our clinicians that don't necessarily have the time to devote to some of that that they can trust the information that is provided in NGC."*

- *"They seem to be authoritative and you can tell who said what when."*

- *"Well, I'll preface this by saying we don't ever make any clinical decisions based on what we find in here so our level of trust doesn't have to be that high. We use it for different purposes. We aren't even passing on information to anybody who's going to be affecting clinical care for it. But, of course we trust it because it's from the Agency for Healthcare Quality and Research."*

Question: Has NGC influenced your approach or ability to identify current/high quality guidelines?

All of the focus group participants stated that NGC has influenced their approach and ability to find guidelines. The primary reason mentioned was that NGC consolidates guidelines into one location with rigorous standards and comparison features. These attributes reduce time spent searching for guidelines and therefore reduce decision-making time in a clinical setting or ease time spent gathering information in a research setting. For these reasons, the respondents indicated that NGC has become an essential research tool. One respondent also mentioned that NGC improves awareness of and focus on guidelines in their institutions.

Excerpts from the respondents' statements are below:

- *"It builds on where else we go and what we're looking for. So, if we find a guideline there, then we're showing a student that it's also available in a different resource. So, I definitely think that NGC has influenced our ability to identify and the way that we*

demonstrate it."

- *"I think it does help us find high quality guidelines, to identify them, and current guidelines."*

- *"I think it speaks highly to the resource that it's just part of our normal work process. It's one of the resources that we regularly use – it's integrated into our work flow."*

- *"I think the whole presence of the NGC has made the emphasis on guidelines much more in the forefront. I think it's given us a better focus and a better awareness of guidelines, so I think it definitely has influenced both the way I work and the way that other people work."*

- *"Because guidelines.gov exists in our sort of going down the list to see what other things exist on a topic, it means that we don't have to go to all of the various individual organizations that may be producing guidelines."*

- *"This ability to have at least this one place that is making this wonderful effort to pull together the guidelines is terrific."*

- *"It's really so valuable, the ability to say, "I think these are the three best choices, but let me make sure this is the right audience and that they're talking about the right clinical question that I'm looking at, to use that comparison utility, to look at the syntheses to see, 'Is my question really answered in these guidelines? Is that really what they're telling you to do? Is that really what my people are trying to treat?' That's really valuable – all of the extra stuff that is there. Like you say, it's not just locating the guidelines; it's all of the extra things that are there."*

Question: Should NGC use other controlled medical vocabularies? If yes, why?

Six respondents report that NGC already uses a comprehensive set of controlled medical vocabularies. One respondent did not answer the question. One respondent stated that additional controlled medical vocabularies should only be added if they enhance the capabilities of the site and are responsive to overall trends in the field, such as in the case of newly formed controlled medical vocabularies or updates to existing systems. Another respondent suggested that new controlled medical vocabularies could be added if they improved functionality. Another suggested implementing the integration of NGC to other databases or resources like PubMed, a comment that triggered agreement among participants. One respondent also suggested ensuring search terms are easy to identify for many different audiences. The criticism in this regard stemmed from difficulty searching for and receiving relevant guidelines from simple language searches instead of medical library-specific terms. Excerpts from the respondents' statements are below:

- *"I would say it's [NGC and current indexing] working the way it is."*

- *"I don't know if there necessarily needs to be more. I don't know if more is necessarily going to be better at this point. I think the ICD-9s are in there right now. ICD-10s, maybe. But, other than that, I don't think there needs to be anything else – if that would contribute positively to the functionality of the site."*

- *"It looks like a pretty comprehensive list of different languages... Maybe, you would want to take some of them out, if anything."*

- *"If there would be either at the level of integration of having when you're searching the MeSH webpage to allow it so say, 'search in guidelines.gov' or have that be part of … instead of just the way…now you can just sort of browse through the various different topics. If, much like PubMed, you could enter the MeSH controlled vocabulary and to build your search that way and to say now that I've selected the subject heading that I'm interested in, search the guidelines database."*

- *"Of those indexing terms that are being presented, if you could search the indexing terms by keyword to come up with the controlled vocabulary that you then want to use to search for the guidelines. That would be helpful at least for the way that I search."*

- *"I was just thinking about guidelines by topic. I think, you know, not only for librarians but for other classes of users, groupings like occupations – or disciplines and occupations – the terminology, I think, just really doesn't resonate. … So, I'm just arguing that it would be useful to review and maybe do some user testing on, like, names of categories under those guidelines by topics so that they're really meaningful to everyone."*

Question: Comments on the redesign. Are there any enhancements you would like to see?

Six of the seven respondents had positive responses to the redesigned NGC Web site. The other respondent did not respond to the question. One enhancement the focus group participants reported wishing to see in newer versions of the NGC Web site were for AHRQ to review sorting categories when searching and refine search engine parameters to limit irrelevant results respondents reported receiving when searching. Future versions of the NGC Web site could expand capacity to other subject areas related to health but not explicitly clinical guidelines. One respondent mentioned criminal justice and inmate health as a topic that may not be explicitly clinical but may have practice guidelines that it would be useful to include in NGC. Another enhancement the focus group participants discussed was that NGC could further enhance the emphasis on guideline evidence grades. The final enhancement suggested by the focus group participants was to take steps in future versions of the NGC Web site to integrate the NGC content with other guideline resources. NGC could enhance integration with other resources sites

(e.g., PubMed) and improve integration of NGC information and bibliographic citation management software. This theme was discussed throughout the focus group in response to several questions, indicating it was an important theme for the medical librarians in this group.

Excerpts from the respondents' statements are below:

- *"The only thing that I could think of is the first one that was mentioned, which was the downloads to Endnote. For what we do, that would really improve the tool greatly."*

- *"I noticed under the guidelines by topic there are things there like anthropology and education and social sciences. So, I was just kind of curious if really the intent overall is to include guidelines across the academic spectrum or if it is to really only sort of pick those items that relate to medicine in those other fields. And, if so, one area to look at in the future might be criminal justice. They are starting to do a lot more work and some of that will have to do with the health of the inmates."*

- *"The only thing that I would emphasize... is the idea of a grade of some sort, an evidence grade for the guidelines."*

- *"I really have enjoyed the new design. It's much easier."*

- *"I know in our experiences with the physicians that we work with have really appreciated the enhancements."*

- *"I just had this idea because lots of times when I'm in PubMed, I start by searching MeSH then click the buttons and say "Take these terms and search it in PubMed." I wonder if there would be either at the level of integration of having when you're searching the MeSH webpage to allow it so say, 'search in guidelines.gov' or have that be part of ...instead of just the way ... now you can just sort of browse through the various different topics. If, much like PubMed, you could enter the MeSH controlled vocabulary and to build your search that way and to say now that I've selected the subject heading that I'm interested in, search the guidelines database."*

- *"I think the integration [with PubMed] would be really cool if it could be done ...maybe going back and forth both ways."*

Question: Other comments

None of the respondents had any additional comments.

Conclusion

The focus group participants, consisting of medical librarians, were satisfied overall with NGC. The main source of this satisfaction was the ability to search for multiple credible guidelines in

one place. The focus group found NGC was an easy to use and highly accessible tool for conducting this work. The tools and features associated with NGC used to compare guidelines and evaluate evidence and guideline sources were also highlighted as beneficial and important for this audience. The main criticisms from this focus group were based on issues of NGC having the most current guidelines, NGC having a mobile interface that was less easy to use than other guideline resources, and the inability to integrate NGC information with other guideline resources and bibliographic citation management software.

Appendix I: Measure Developer Qualitative Summary

AFYA conducted one-on-one telephone interviews with four measure developers as part of the evaluation. The participants were from the following institutions.

- HealthPartners
- Kidney Care Quality Alliance
- Joint Commission
- University of Toronto

Each interview lasted from 30 minutes to one hour and followed approximately the same format as the focus group.

As part of the introduction for the interviews, key informants were asked if they had completed the NGC evaluation survey; none of the respondents indicated they completed the NGC online evaluation survey.

Question: Respondent use of guidelines and NGC

This group primarily uses guidelines as a starting point for measure development. Guidelines typically contain the most current evidence-based procedures for health practices and conditions. The respondents said that these were good initiation points for developing their medical measures because they can assess best practices and develop measures based on what the guidelines recommend.

Excerpts from the respondents' discussions on these topics are presented below:

- *"I've done a lot of work kind of measuring things and trying to think about how stuff goes better. And I have had a fairly consistent interaction with guidelines as both tools and kind of as a concept as I've gone through that."*

- *"In the process of measure development, we always look for evidence-based measures that are reliant on randomized control trials, meta-analysis type of articles, and existing guidelines. So, as part of our evidence review and literature review process, we look to NGC, initially, actually, to display the existing guidelines on a particular topic. Once we have those guidelines, I then look at the references on which those guidelines were based, so that I can judge the level of evidence."*

- *"I work with a couple of organizations when they need to develop measures for, in particular, upcoming National Quality Forum projects. When they have a call for measures in a given area, a group, an organization, may decide that they want to try to submit some measures into that project to see if they can get endorsed. So they'll contact*

me, and my colleague, to help them develop the measure to appropriate and up-to-date, evidence-based measure as possible. So in that regard, I actually do, because I'm trying to collect the most up-to-date evidence, and the most widely accepted evidence, I do turn to guidelines very frequently, when developing measures. And, to answer your next question, the most common source that I use is the National Guidelines Clearinghouse. I do go to it quite often to see what's out there in a particular area, and then use that to help guide us in our decision-making."

- *"They pull together work groups. As I said, they don't have physicians or clinical people on staff, really. They pull together community work groups with the proper stakeholders on the groups. And yes, they come prepared with a lot of literature searches and things like that for the work group."*

- *"Some of the basis behind when we started building our clinical indicators is that they are guideline-based. They're evidence-based and when we develop, if we go down the path of developing a measure, we have guidelines to back them up, and that's what they're built off of."*

- *"My department supports the national reporting, which is HEDIS. It's pretty prescribed, so, you don't debate that. We also, historically we've produced what we call our clinical indicators report... that our state particularly really wants us to kind of stop developing a lot of rogue measures, as they say, and our provider community kind of likes – they don't want our health plan measuring these five things on diabetes and then the next health plan measuring two of those and then four of their own. They kind of wanted to keep it more standard. Prior to that, though, we would develop measures; we will put them in our clinical indicator – and we do still have some in there that are fairly unique in there. The ones that are, a couple of them are the ones, actually, on the clearinghouse site. We have our preventive services measures logged on the clearinghouse site."*

- *"I'm the architect of what's called the Excellent Care for All Act, up here, which was an act passed by our Parliament about a year ago that gave NICE-like powers to one of our agencies here, and also required the production, release – uh, production and release of annual improvement plans by the health facilities, and actually requires boards to tie the CEO compensation to the achievement of those plans... you're going to be increasing the ability of one of our agencies to give guidance. I needed to make a very credible case with the political – government – that this was actually possible. And so being able to go to NGC and say 'Look at all this.' You know, this isn't starting from scratch, was actually pretty valuable."*

- *"We were doing a much different approach to defining clinical indicators, and we wanted to start, really from an evidence-based perspective. So we started in this case,*

actually, looking at different sources of what we consider credible evidence on what could be done better, and one of which was guidelines... developing indicators in sort of pretty highly specialized areas of cancer surgery. We did four different areas. And at the end we actually wanted to know whether consensus panels ended up choosing indicators that were more or less likely to be supported by evidence."

- *"So the first time that we did it, we were actually, we'd developed a series of clinical indicators for different conditions like stroke and so on, in hospitals, and we put together a list of guidelines related to the indicators. And it was nothing more than just a static list that we sent up to all of our hospitals."*

- *"I used it as a reference, just to, when we had a project and we had measures come in, I would go in and double check to see if the measures were consistent with the most up-to-date guidelines that were out there."*

- *"I think we would, to compare. So if we're working on a measure, or maybe we're updating preventive services, our preventive services measure, we might go out and look, what's anybody else doing around this topic, to see how they might match up with us."*

Knowledge about NGC varies from five to nine years, and overall use is lower in this group than in other interview groups and focus groups. The respondents report using NGC only a few times a year. Excerpts from the respondents' discussions on these topics are presented below:

- *"On occasion. You know, it isn't the first place I go, as I say. But sometimes we go out, trying to just peruse what other measures might be out there along a topic line that maybe we're working on."*

- *"I would say probably 25 to 35% of what we need is supplied by NGC... You know, it's because, as I said, no one is required to put anything in NGC... of it might also be the extensive documentation you have to do to send something to NGC. And I know where they're coming from, you know? I talk to the ECRI people all the time and I understand their need for rigor. But their need for rigor translates to somebody else's need for work."*

- *"We're being encouraged in our provider incentive program to pay out using the Minnesota Community Measurement rates, versus going out and duplicating. And so, our preventive services measure, which we still go out and audit ourselves, we don't require them to turn anything – I actually have a staff I send out to do chart audits – we still have that in our provider incentive program, but community measurement's also going down that path, too. They're pulling a work group together now to develop a pediatric preventive measure, particularly in our market. That's where it's all going. You know, we're not kind of out necessarily looking at guidelines anymore and developing, because*

it's viewed as competing with what the state wants us to do, which is use the collaborative."

This group listed a wide variety of other sources they use for guideline research. Other sources include Guideline Advisory Committee, subject area boards and associations, evidence-based care programs, NQMC, specialty Web sites, professional association Web sites, review databases such as PubMed, Cochrane reviews, AMA's PCPI criteria, KDOQI guideline statements, consensus statements or guideline developments from groups, ICSI, and professional associations. One respondent considers NGC to be the "gold standard" of guidelines because of the gathering of other guidelines. Another respondent uses NQMC and AHRQ evidence reviews in addition to NGC. Excerpts from the respondents' discussions on these topics are presented below:

"I would consider National Guidelines as the gold standard outside of the specific organizations that are developing the guidelines in the first place."

"I've used some of their reviews in the past; I've used the NQMC quite a bit, as well. Yeah, any time they have a review that's pertinent to whatever it is I'm researching."

Question: Respondent opinion of NGC

All respondents indicated they trust the information in NGC. Reasons reported for that trust include that NGC is supported by the government and AHRQ, NGC provides links to source materials and press coverage related to each guideline, and NGC associates guidelines with evidence. The major caveat to this trust involves issues with currency of information. One respondent looks at other sites, especially medical associations, in addition to NGC in order to ascertain the most current recommendations and guidelines when developing measures. Another respondent valued the inclusion of foreign guidelines in NGC. Excerpts from the respondents' discussions on these topics are presented below:

- *"It's something that's sponsored by the U.S. government, or, you know, like in the case of NICE, you know, NICE guidelines are developed out of the UK, but because of the fact that it's associated with the U.S. federal government you have – that, by itself gives you some comfort, I guess, that the material that you're gathering from it is credible .... It's a publicly available source, so I like that. It's not some black box that I'm buying into and I'm not sure who else can see it. And then I think finally the fact that where these things come from, a variety of other attributes of these things are very clearly identified."*

- *"I would say 80%. But I have had occasion to look at – you know, identify something in NGC, when I cross-check it at a professional association Web site, the Web site has an updated version that hasn't made it through NGC."*

- *"It provides the links and it seems to be consistently brought up to date with new releases*

and so on, so I feel pretty comfortable using it."

- *"Unless there's a link that takes you to the full one, it seems to me if you're a health planner or somebody who wants to use that as evidence for something you're doing, you would want to see more than: 'Trust us, we did our work' – you know? The evidence isn't there, I'd want to be led back to where it would be if I was going to present that to any of the medical people here."*

- *"[NGC] will also have foreign guidelines in there, and it's helpful to see where other countries are in the same aspects of care."*

The respondents said that NGC is an easy-to-use, comprehensive, and authoritative guideline resource. Three respondents found the inclusion criteria to be appropriate and one was not asked this question. One respondent emphasized that criteria like this must be based on evidence and trends in the field and believe that this is a characteristic of NGC. Three respondents felt the policy of maintaining guidelines for five years must be considered in the context of the guideline in terms of guideline updates, and new information and evidence. The respondents indicated that other guideline resources they use update quicker, usually every one year or 18 months. Excerpts from the respondents' discussions on these topics are presented below:

- *"We had processes that allowed us to evaluate evidence, and we had processes that allowed us to actually evaluate the evidence that had gone into policy, whether or not the policy was evidence-based enough. And the stuff when it came through or was associated with NGC when I was getting my briefings, there was not concerns raised about the quality or the utility or relevance of the evidence."*

- *"I would actually think it sounds about right, except for the five-year. That seems – things are changing pretty rapidly right now, and I know NQS is using a three-year time to evaluate their endorsed measures, so making that a little more frequent might be a good idea… with the speed with which evidence is changing in most fields right now. I think it's a good idea to keep it a little more up to date."*

- *"It depends on the topic. And it depends on the guideline developer. You know, some guidelines are good for 20 years. Others, you know, should be reviewed every year and updated."*

- *"I don't quite know why they would be five years when, even on the clearinghouse, we're required to review and update our measures annually… And I think ICSI's on an 18-month to two-year cycle of maintenance for their guidelines. So five years does seem like a long time to go between reviews."*

The respondents were asked about the Web site redesign. One respondent found the redesign

easy to use and said that the comparison and synthesis tools were useful. One respondent found the search functions too complex after the redesign and suggested simpler search functions. Excerpts from the respondents' discussions on these topics are presented below:

- *"It was just really easy for me to use. It felt pretty comprehensive, that, you know, if I wasn't seeing something there I didn't have to worry about it as much. And so those two factors were really valuable to me. And you know, as well, I think everyone who's been working on quality for a long time – it's still kind of a hard battle politically, right? And it's surprising that it is, but it is. And so I think the very fact of its existence at times was very useful to me as well. We're just north of you, at the long-unprotected border. We look very closely at what the United States does. And when the U.S. is making an investment in this, that's important. It signals to people it's a good thing."*

- *"One of the issues we've always had, predating the redesign and after the redesign, has been the use of the search engine. The use of the search engine has been problematic, and it certainly is much improved after the redesign; however, I was still having trouble with it... I think that, for the majority of the more casual users of the Web site, that search engine is so sophisticated that it's difficult to use."*

- *"It seems quite usable for me; it's pretty easy to navigate. It could be just that I'm so used to it by now, but it doesn't seem very complicated, and I think people should be able to find what they're looking for quite readily."*

In terms of respondent opinions of possible features, one respondent said an NGC rating system would not be necessary if individual ratings were accessible. Another respondent would like NGC to integrate with search functions in PubMed to connect citations and guidelines, and a third respondent would like NGC integration with other guideline resources. One respondent says that it partially meets needs, indicating issues with currency and the fact that no one is required to put information in NGC as the main deficient areas. Excerpts from the respondents' discussions on these topics are presented below:

- *"I think either you need a simpler search or they need to display results divided into categories. For example, the first ones to come back are the ones directly where your search term is in the title. And they need a little header to say that. Then they need a header following that section to say, these results show your search term anywhere in... in the guidelines... Something a little more tutorial for the person."*

- *"We have our own internal review criteria. And we don't need to take their word for it."*

- *"I can't recall if you can click to connect to, say, PubMed, directly to a citation? But if that is not an available option, that would definitely be useful."*

Question: NGC influence on respondent's work

NGC's influence was mostly related to developing measures. NGC was reported to be used as a starting point either to find evidence related to measures, or to see if other organizations have developed related measures. Two respondents report NGC has reduced the time they spend searching for guidelines. Excerpts from the respondents' discussions on these topics are presented below:

- *"The first is in actually generating the list of indicators to consider. So there's not like really an indicator clearinghouse. So what you have to do is you kind of have to reverse engineer it out of the evidence... as a starting point for developing improvements. ... The other thing is when we try to make sure that an indicator's useful, we look for tools that might help you improve on the indicator... We try to make sure that there's tools that help people on this stuff. And so being able to go and query and see whether or not, you know, if the guideline talks about what should or shouldn't happen to patients, we can draw a line with the indicator."*

- *"Because it's a source people turn to, to make sure that they're up to date when they're developing the measures."*

- *"One of our measures is being used by somebody out – pay-for-performance out in California. So, kind of the reverse of that. Where we've ended up working with a group out there that was interested in our technical specifications and helping them get a measure going that they found on the site that we're doing... on the clearinghouse, right. So they contacted us for some help, that they were working on that measure. ... It worked the opposite way."*

Question: Other comments

Two respondents provided comments at the end of their interviews. One respondent will use NGC for his overall health policy work. Another respondent highlighted the perception that NGC is not a standalone resource. The respondent believes that information in NGC must be checked against information from other sources, including other citations and other guideline publishers who may have more current information.

- *"We look and probably back at NGC, looking for ideas about public and population health interventions and guidelines. And that'll be important to me. I expect it'll be something as I continue to provide advice on policy that I'll point our new agency to look at it and make sure they use it."*

- *"I think one of the tasks ahead for ECRI is figuring out who they are and what their position is. How are they positioning themselves in the healthcare arena? You know,*

without the requirement that things be submitted through them, or some sort of verification that they have to give to something, it just seems as if a number of guideline developers are ignoring them. And I don't know if it's because of a lack of a requirement that they be submitted there, or the rather extensive documentation requirements that they have. I don't know what it is. I just have a certain amount of sympathy for them. I would also say, overall, I trust the NQMC material much more than I do the NGC materials."

- *"It certainly is not a standalone resource. I would say it's probably about on a par with the others... I couldn't just use what's there without either double checking it or looking at other sources... Or looking for an updated version."*

Conclusion

This group of measure developers primarily uses guidelines as a source that contributes evidence and information to the measures. They report that guidelines provide information about what the medical field is looking at in terms of topics and associated best practices. The evidence used to support these best practices is useful for the measure developers as they develop indicators and/or quality measures for what indicates effective and quality health care. Due to the nature of their use, this group uses guideline resources, especially NGC, less frequently than other healthcare groups. These measure developers must evaluate a large range of evidence when developing measures, and guidelines are only one source of this evidence. Therefore, many of their comments indicate that they use guidelines in association with myriad other evidence sources.

Appendix J: Policymaker and Researcher Qualitative Summary

AFYA conducted one-on-one telephone interviews with six policymakers and/or researchers for the evaluation. The participants were from the following institutions.

- AcademyHealth
- California Department of Health Care Services
- Centers for Medicare and Medicaid Services, Director, Coverage & Analysis Group
- Johns Hopkins Bloomberg School of Public Health
- West Virginia Offices of the Insurance Commissioner

Each interview lasted from 30 minutes to one hour and followed approximately the same format as the focus group.

As part of the introduction for the interviews, key informants were asked if they had completed the NGC evaluation survey; none of the respondents indicated they completed the NGC online evaluation survey.

Respondent Use of Guidelines and NGC

This group of respondents primarily uses guidelines for evidence reviews, establishing and updating new policies, and research that informs clinical practice. Respondents indicated that they use guidelines for both individual clinical practice and in teaching settings. The respondents also indicated that they use NGC specifically for medical decision-making. Types of decision-making discussed in the interviews were Medicare, personal referrals, coverage decisions, evidence synthesis, quality improvement, and service delivery. Another theme that emerged from the interviews was how the respondents use guideline research to orient them as to what physicians are addressing and what is happening in the field. Excerpts from the respondents' discussions on these topics are presented below:

- *"There's a section of the published decision memoranda for Medicare and national coverage determinations that includes the space for us to list evidence-based guidelines that may bear on the topic under review. So we literally just either list them there with a brief summary of what the guideline says, or something along those lines."*

- *"I think any time that we are revisiting policy or trying to establish new policy, or which there's a report of an update. Some things are noncontroversial, and they're pretty routine. Immunizations is pretty standardized. But many other things like cancer screening tests are more controversial."*

- *"They're certainly one of the tools of evidence-based medicine. I don't think you can look at policy without – among other things besides – looking at systematic reviews and literature reviews. You cannot move ahead with anything on a specific policy without having reviewed, as far as I'm concerned, National Guidelines Clearinghouse. So, I'm familiar with it and have had guidelines, have worked on guidelines that have been posted on it. So I think it's an invaluable resource for all policymakers, particularly medical directors, and certainly Medicaid medical directors, so it's absolutely essential that one looks at and compares different guidelines."*

- *"I also, just in my personal practice, if I'm confronted with treatment of a patient who has something that I haven't really treated in quite a while, and I'm trying to figure out what the standard of care is, I have a few resources I go to. I usually use the Web site tool UpToDate to check on what the current standard is for management of something. But quite often I will look to see what the strength of evidence is by going to the National Guideline Clearinghouse and actually entering the condition name and then seeing if there are guidelines that are specific to it. So, those are some examples of the things that I do."*

- *"In my policy role at Medicaid, we are constantly approached about new therapies, diagnostics, other interventions, referrals that are being requested, and... one of the checks on the checklist, whenever we have a request, is to simply look at the guidelines that might govern something... The good thing about the AHRQ National Guideline Clearinghouse is that it's pretty comprehensive. You can find a lot of things there."*

- *"I teach at the university, and one of the things I'm responsible for at the medical school is teaching the evidence-based medicine portion of the training for third-year medical students. So, when I'm doing that, I talk to them about the value of guidelines and how guidelines and evidence are developed. . And I use the NGC as a model... Because they can go there and find guidelines for a wide range of topics. And not only do they find guidelines that are from U.S. sources, but they find things that come from the NICE program in England, things that are generated all over Europe and other parts of the world... The other reason I use it is that it has a pretty nice scoring system, it's kind of a consistent scoring for evidence – the strength of evidence."*

- *"I really work on the research end for policy development, so guidelines in specific are very important. They're a very important foundation to the information that I gather and present to Dr. …. I think that the National Guideline Clearinghouse, I think those guidelines are an important resource pool that I use in the research that I do."*

- *"I direct the part of CMS that makes national coverage decisions for the Medicare program Part A and Part B – the traditional Medicare program... We're the people who*

actually review the evidence and write the policies."

- *"My research is focused on clinical practice guidelines, so, for my research purposes I use them frequently... What I am interested in is how do we make guidelines – are guidelines relevant to people that don't just have the disease that's the primary focus of the guideline, in older patients... all of my research is really around people with multiple chronic conditions."*

- *"When we look at the guidelines, we look not only is it about the clinical topic, but is it also about a population that's generalizable to ours... does it meaningfully inform our work in some way. Sometimes it can be informative simply as background information. Sometimes the guideline will have something more specific that we might reference."*

- *"On occasion I'll use it if somebody, you know, whether it's a family member or somebody else calls up and says, 'Hey, I have X.' You know, what should I do with X?"*

- *"There are many guidelines out there that are simply based on sort of an experts' consensus in the face of a generally weak evidence base. It generally lets us know what physicians are doing or thinking, without necessarily shedding light on whether what physicians are doing or thinking is clearly evidence-based or not. So part of it is kind of background setting – ah, this is what people, in general, do. Sometimes if it's a particularly strongly written one, it might be more persuasive, if it really does get into the evidence more."*

The frequency with which each respondent used NGC depends on subject matter and work tasks. Respondents generally reported that they use guidelines and NGC heavily when updating a more controversial practice or dealing with a controversial condition. In these cases, respondents felt it was helpful to see what evidence is available and what research has been done in terms of best practices. Excerpts from the respondents' discussions on these topics are presented below:

- *"I think any time that we are revisiting policy or trying to establish new policy, or which, there's a report of an update. Some things are noncontroversial, and they're pretty routine. Immunizations is pretty standardized. But many other things like cancer screening tests are more controversial. So it comes up not infrequently – probably several times, several times a quarter would not be unusual. Right now I'm at a higher policy level; I'm in the director's office. I report to the director. And within our department, in the policymaking branch, they probably use the guidelines on a weekly basis. But it comes to, I may use it – because they've already referred to the NGC – I may not directly go in as frequently myself. But as a department, it's used, I'm sure, on a weekly basis."*

- *"I think it does play an important role in quality, because I alluded to that in my own use*

of guidelines. I think that's – should be the principle use – is that it improves the quality of care. And anything that pulls together, helps people access the available information, is important to be able to drive quality. … Because increasingly, I think we – we, meaning the medical profession – is understanding the importance of systems-based practice, meaning thinking about defined populations, caring for a population, thinking about it not only on a one-on-one level, but also looking at population, taking a population health perspective. And that's really what quality metrics are about. You look at individual care that's good and bad, but overall you're looking at rates. So, what percentage of the population – what percentage of eligible women received a mammogram. How many people with high blood pressure were checked in the last year; how many people who have diabetes had a hemoglobin A1C in a previous year. So you are thinking about defined populations and so I believe that academics are very familiar with National Guidelines Clearinghouse. I think medical directors, people in population health roles and health plans are; I hope that every state and local governmental entity that deals with health care is also well versed, but, that's a hope."

- *"It's part of what we look at. I don't know that it influences healthcare policy decisions so much, because we're always going back to the primary evidence itself, essentially the clinical trials. It's more of a – if we're seeing something that's markedly different from what's out there in the guidelines, then it might suggest, hmm, I wonder if it's just, you know, that the populations are different, or on a more technical basis, the assessment questions themselves are a little bit different, or what. So I mean, we don't really use them to drive policy. We use them more simply as part of our process by which we develop policy."*

- *"I mean, we've looked at all the relevant guidelines on a particular topic – that it has improved quality, because we're able to compare and say this is what the current thinking is in the practice community, this is what the best understanding of the literature says should be done. I'm very – suspicious is the wrong word – but I'm very, I take a very critical eye towards guidelines that are completely homegrown. The advantage of National Guideline Clearinghouse, as you know, guidelines that are on there, as you said, have met the publication criteria. You know you're going to get certain information. I think it's perfectly fine for guidelines to be customized for an individual practice community, an individual practice or hospital, and for there to be a consensus, understanding there's variations based on populations and available resources. I'm fine with that, but, as a starting point, you want to make sure that it's evidence-based and that you have the information to be able to evaluate the guideline itself. And I think that's what NGC provides a unique service. At least, as I said, I can't name a competitor."*

- *"It has helped us make a decision on whether to cover or not to cover a certain service. We make those decisions for coverage in our Medicaid system. If we're asked to cover*

something that has very little evidence, or something that has one guideline, and the guideline is not all that helpful, we may choose to wait and see what happens on that... There have been times that we've been asked to cover something for a population that was much larger than the population really described in the guideline. And so, that's enabled us to say, we're only going to cover it in this particular situation."

- *"I think the obvious thing is that if you use it, and you use it more often as you get familiar with it, then you are introducing a bit more of an evidence-based style of practice, and I think that seems to be the national direction in health care, is to rely more heavily on evidence in making decisions about things. So, I think that that aspect of it has definitely influenced us, and it's influenced my own personal practice, because sometimes you learn things and you see things, but you see them in an anecdotal way rather than in a real objectively studied method. And so, once you get used to reading the evidence on things, it changes your practice."*

All the respondents indicated that NGC is a well-known guideline resource. Two respondents report that they have known of NGC for as long as 10 years. The frequency with which the respondents use NGC varies as their work demands. One respondent only uses basic search functions. Two respondents report finding the guideline comparison functions useful and beneficial.

The respondents also indicated using other guideline and evidence resources in their work. Two respondents use other AHRQ products in their work, particularly the synthesis resources. Other guideline resources the respondents reported using include specialty medical societies, USPSTF, Medline, PubMed, IOM, Cochrane resources, NCCN, Official Disability Guidelines, CMS, and FDA. Excerpts from the respondents' discussions on these topics are presented below:

- *"I think the synthesis functions, whether here or elsewhere, systematic reviews – it's become almost impossible for any one person to keep up on the literature. You just cannot do kind of a random PubMed search because as we've discussed and as you alluded to, you have to have standards of criteria and grade studies, so you can't just say, oh, I found five studies and then try and pull it together. It's become much more rigorous, intensive, and laborious, all of the above. So, these things that synthesize, pull it together, come to a conclusion, guidelines, and for that matter, systematic reviews, other things that pull things together are great help, in general."*

- *"I like looking at the AHRQ Web site in general when I have a question and search through it, so, I've at some point used many of those – what you mentioned – certainly, U.S. Preventive Services Task Force. But I like to look periodically on there. In fact, I'm working with our analysis group and they've looked at the quality measures, because we want to adopt some of those. So we've used a number of those. So the answer is yes, we*

try and use AHRQ in general, the Web site, and try and find, whether it's a clearinghouse or, as you say, evidence review, to help out."

- *"If something is fairly new, and there's a lot of attention being paid by a certain specialty group, we always check to see if they have recommendations in regard to that condition."*

- *"It gives me a sense of what's out there, and I will look, and sometimes there's things that I'm already well aware of pop up, and nothing new, but I don't accept that – I don't stop at that point and say, well, NGC is comprehensive; therefore, this is all I have to do. Then I start looking in other directions."*

- *"I've kind of gotten myself onto a path of using things a certain way, and I have a feeling that it has more capacity than I'm taking advantage of. So, I probably need to take the time and familiarize myself with more of the tools. But I think generally I'm very pleased with all of it, get a lot of use out of it."*

- *"It gave me just the exact information that I would not have found otherwise."*

- *"The way that they lay out the guideline comparisons is just, to me, excellent. And that's not a feature that I have seen in any of the other resources or tools that we use."*

Respondent Opinion of NGC

The respondents felt that NGC was a good resource for finding guidelines. They felt it was easy to use and comprehensive. One respondent said it was his primary guideline searching resource. One respondent said it saves him time when searching for guidelines. All respondents perceive the inclusion criteria to be appropriate and they did not encounter any inappropriate guidelines. One respondent reported trusting the information in NGC. Two respondents found the NGC Web site redesign to be helpful and easy to use. Excerpts from the respondents' discussions on these topics are presented below:

- *"Well, NGC is in my view kind of a one-stop shopping. I'm hoping that every relevant guideline will probably be there on any given topic. Because most societies want to post to NGC and have something that's evidence-based in that repository. NGC, if you were drawing a Venn diagram, is clearly at the center of where one has to research on any particular medical policy issue, in my view. And then other areas are peripheral or supplementary, like U.S. Preventive Services Task Force, because it only covers a portion of medical practice. Professional societies are also narrow, because they cover their domain of medicine. And so NGC – I don't think there's any competitor that I can think of that provides the one-stop shop."*

- *"I think it's equal in quality. Sometimes it's easier, because it's a little more accessible. I like the outline format of it. Once you get used to the format that they use, which is more*

outline than text, I think it's pretty simple to use, and it's also quick. If you're in a situation where the legislature wants you to come over and talk about the wisdom of some type of therapy or something that they're curious about, it's a quick way to get a summary. And I like that part of it. Some of the others, especially the private carriers, much more complicated. I like the Cochrane database, too, and I like going there and looking. But they're different. They're not the comprehensive list that the clearinghouse is."

"It spans across the breadth of evidence. So I feel like I'm getting a full picture, and then if I need to go off and look at a particular piece of evidence, or an article, or – I, even, as a nurse, I use the patient education materials quite often. It's kind of a starting point, or whatever, to I guess, kind of familiarize myself with where we're at with this."

One respondent felt that the search functions could be simplified and that NGC could link to the full articles or evidence that support the guideline. Excerpts from the respondents' discussions on these topics are presented below:

- *"I think to the extent that there are more lay users of it, the likelihood that my mother can figure out whether a guideline is rigorous or not based on the methodology is essentially nil. So I guess if I had to pick one, my preference would be to be more inclusive as a philosophy but to identify certain ones, you know, whether it's sort of the metaphorical gold star in the corner, or whether it's something else. If there were particular criteria by which the better ones could be identified, especially when there are conflicting ones, it could be helpful to say, you know, yeah, you have seven guidelines on this, and they're a little bit all over the map, and here's one that seems to make a more definitive statement. And maybe that's a good thing. This one, for various reasons, is better than the others."*

- *"The only thing I can think of, and it's been awhile since I've looked at it, to the extent that the guideline itself may have a bibliography, what I would love to have is full-text access to an entire bibliography through the NGC Web site, so that I wouldn't then have to go looking for stuff, realizing that copyright permissions and all that sort of stuff may make that impossible. But you know, if the Singapore Health Ministry or the Scottish Health Ministry or someone else has a guideline with a bibliography, I would love it if every one of those were live links to full-text articles."*

Three respondents reported that including guidelines for five years is appropriate, but dependent on the subject area of the guideline, research in the area of the guideline, and evidence support for the guideline. One respondent suggested that it would be interesting to keep old guidelines for research purposes. Excerpts from the respondents' discussions on these topics are presented below:

- *"I thought they looked appropriate, and I would just say that they need … to be relooked*

at on an ongoing basis, because our view of what constitutes evidence-based medicine will change over time. And so, right now, I mean, I think they're reasonable criteria. But the fact is that in the real world, evidence-based medicine – Number one, not everyone even believes that it is the end-all, be-all, and it isn't. So, there's medical politics, there's regular politics in capitol – in state Capitols and also in the nation's Capitol. So, one has to appreciate there's a broader context, so I think the, as I said, I think the inclusion criteria make sense, but one should just continue to – I would encourage AHRQ to – periodically re-evaluate in the same way that they re-evaluate guidelines and have a five-year kind of threshold."

- *"There are probably guidelines in NGC that aren't particularly useful for me. But that may simply be because I'm looking at a particular topic, and for whatever reason the guideline just doesn't necessarily answer my question."*

- *"…There's some sort of I guess an issue about research about guidelines themselves. Has anybody done a systematic review of guidelines and have they said that sort of the sell-by date for a guideline is five years, and then it's stale on the shelf? And are there criteria by which certain guidelines are more likely to change than others? I mean, for example, is a cancer guideline more likely to be superseded than a cardiology guideline, or a sexually transmitted disease guideline? Or are screening guidelines more or less likely to become obsolete versus a treatment guideline or something else, or a pediatric guideline versus a geriatric guideline? I mean, I don't know that anybody's systematically studied it, so five seems to be a reasonable, seat-of-the-pants, arbitrary number."*

- *"Five years is a long time, but it's – the problem is it's situation dependent. In some areas, modalities like colon cancer, new things are being looked at and so, five years is way too long. In other areas where there's not – there's been innovation, but not quite as much radical change, say Pap smears, five years may be OK. A priori, I don't know if there's a magic number, say three or four or five. I think five is kind of a backstop, to make sure that they can look at all the guidelines."*

- *"I guess it would be kind of interesting to create a historical file of guidelines that have expired, been updated, or never were renewed. But I don't know how much use it would get. I mean, it'd be more of a curiosity than anything."*

NGC Influence on Respondent's Work

The respondents were asked how NGC influenced their work. One respondent uses guidelines as part of background research, but states that this work does not really drive policy decision work. For this respondent, the usefulness of the guideline depends on the robustness of evidence. Another respondent indicated that guidelines help orient quality improvement efforts since they

describe the most current best practices. A third respondent indicated that guidelines are part of new information that must be accounted for in the field when conducting policy work or clinical practice. The final respondent found the NGC helpful when conducting policy work due to AHRQ's authority and credibility, and review and synthesis work. Excerpts from the respondents' discussions on these topics are presented below:

- *"I think it's been influential, but I think it's been most important as an intermediate step in the development of other published material that describes the guidelines. So, as an example, we've mentioned UpToDate a couple of times. When you use UpToDate as a resource, there are frequently links to guidelines associated with topics that you're reviewing on UpToDate. And so there will be references to things like that. I think the NGC is for most active providers kind of a – kind of out of their reach; they don't go there very often and don't use it very often, but they benefit from it because those who are writing critical reviews and making clinical recommendations are getting their information there and elsewhere, that goes into those overview documents."*

- *"It really depends on the robustness of the guideline. I mean, there are many guidelines out there that are simply based on sort of an experts' consensus in the face of a generally weak evidence base. It generally lets us know what physicians are doing or thinking, without necessarily shedding light on whether what physicians are doing or thinking is clearly evidence-based or not. So part of it is kind of background setting – ah, this is what people, in general, do. Sometimes if it's a particularly strongly written one, it might be more persuasive, if it really does get into the evidence more."*

Other comments

Two respondents provided comments at the end of their interviews. One respondent emphasized the necessity to ensure NGC continues and the other respondent reported his students found NGC to be comprehensive and useful. Another respondent was asked to provide any further comments about his policymaking work. He stated that NGC is in a reasonable place given the mandate of AHRQ and what other healthcare groups are doing.

- *"I would simply say that I've had a few medical students come to me and tell me they were thrilled to learn about it, that they ran into unusual conditions and didn't know there was even a guideline for how to manage it. Recently one of the medical students came up to me and said, you told me about this guideline clearinghouse, and he said: I thought I would test you; I had a patient who had an anal fissure that was difficult to treat. And he said, I didn't know where to go look for a guideline, so I went there. And he said, do you realize I found three guidelines and all kinds of information?"*

- *"I suppose one of the things – and this is probably not something that AHRQ wants to get into – obviously there are times when guidelines differ, for a variety of reasons. And, I*

don't know that AHRQ wants to get in the business of critically reviewing competing guidelines, because then it essentially becomes an AHRQ guideline, which, obviously, they got deauthorized at one point from making guidelines. I don't know that they want to go there. So I think for what it is, and given the constraints around sort of AHRQ's authority, and the rest of that, that what they have right now seems a reasonable place to be. I don't know if they know, if they really have a way of telling, out of their own users, how many of these might actually be patients versus how many are physicians who are using it to guide the care of a specific patient, versus how many are people like me, versus how many people are healthcare researchers. And I don't know whether, you know, something like one of AHRQ's other activities, the U.S. Preventive Services Task Force, where I think – it may just be that I never look at it on NGC, so maybe it's there – but the issue of: Would you have a different interface or a different search or a different whatever for a patient or a member of the public versus what you would if you're someone who, you know, doesn't need to have all of the background explained to them and just wants to get to the meat of a recommendation and doesn't need, or wouldn't benefit from, some summary of the background of the disease itself or some other summary. I don't know because I've never looked, as to whether the NGC has that function on it or not."

Conclusions

This group of stakeholders generally uses guidelines to inform practice or policy work, or their research efforts. The members of this group appear to be involved to certain extent in all of these activities. This makes them uniquely positioned to comment on NGC. Due to their work in this regard, they report that NGC is an important resource due to the ease of use, the comprehensive nature, and the support it provides as an authoritative source. This group is also in a unique position to critique inclusion criteria, since its members are both using guidelines and influencing policies based on that information. The critiques they offered were a call for a quicker turnover in evaluating guidelines and ensuring that all the guidelines in NGC are as current as possible and based on the most current evidence.

Appendix K: Organizations Represented in the Evaluation

Guideline Developer Organizations
American Academy of Otolaryngology
American College of Chest Physicians
American College of Emergency Physicians
American College of Physicians
American College of Radiology
American Society of Clinical Oncology
Cancer Care Ontario, Program in Evidence-based Care
Cincinnati Children's Hospital Medical Center
Endocrine Society
Infectious Diseases Society of America
Institute for Clinical Systems Improvement
John Hartford Foundation
Kaiser Permanente Southern California
Michigan Quality Improvement Consortium
Milliman Care Guidelines
Renal Physicians Association
Scottish Intercollegiate Guidelines Network
University of Michigan Health System
Veterans Health Administration
Washington State Labor and Industries, Worker's Compensation
Other Stakeholders Represented
A. Alfred Taubman Health Sciences Library, University of Michigan
AcademyHealth
California Department of Health Care Services
Centers for Medicare and Medicaid Services
Cincinnati Children's Hospital Medical Center
Department of Health and Human Services (HHS) – Office of the Assistant Secretary for Planning and Evaluation
Duke University
Health Sciences Library, University of Colorado Denver
Health Sciences Library, University of North Carolina at Chapel Hill
Healthcare Quality Consultant, Kidney Care Quality Alliance
HealthPartners
Johns Hopkins
Joint Commission
Medical Library, Children's National Medical Center, Washington, D.C.
National Institutes of Health (NIH), National Heart, Lung, and Blood Institute (NHLBI)
NIH National Library of Medicine (NLM)
Office of the National Coordinator for Health IT (ONC)
Partners HealthCare
Partners Healthcare System
Stanford University
The Oregon Evidence Based Practice Center, Oregon Health and Science University
University of Alabama at Birmingham
University of Georgia, Department of Epidemiology and Biostatistics
University of Toronto
Vanderbilt University, Department of Biomedical Informatics
Veterans Health Administration (VHA)
West Virginia Offices of the Insurance Commissioner