

Chapter 4: *Preparing & Analyzing the Data*



STEP I
continued

Now that you have completed surveys on hand, the task becomes transforming the information you've gathered (i.e., the data) into results that can inform your institution's dialogue about how to improve end-of-life care. This task includes:

1. **preparing the data** for analysis, and
2. **analyzing the data** according to the concerns of your institution.

4.1 *Preparing the data*



What do I do with this pile of completed questionnaires?!?

4.1a **Deciding which completed questionnaires can be utilized for analysis**

One of the advantages of standardized survey interviews (such as the Toolkit instruments) is that the data included in each completed questionnaire should be clear and straightforward. That is, respondents should choose one of a list of available responses for each survey question. Some cases though, may not be so straightforward and may even be ineligible for analysis. Ineligible questionnaires are those that do not include data either for enough or for the key questions necessary for the analysis.

Questionnaires that do not include clear answers for one or more items have "missing data." When the number of pieces of missing data exceeds a predetermined limit as set by the analyst (i.e., *you!*), then the questionnaire cannot be analyzed meaningfully. For the Toolkit, a good rule of thumb is to consider a questionnaire ineligible for analysis if it is missing data for more than one (1) of the key questions for a particular problem score. Since this rule is not set in stone, you may want to increase this number to two (2) missing items for a problem score with more key questions (e.g., Inform and promote shared decision-making).

A questionnaire may also become ineligible if it is missing data for one of the items that your institution finds particularly important. For example, your

Missing too much data

Missing the data of interest

institution may be conducting an audit to determine if patients' pain levels are being relieved within 48 hours of report of pain. If a patient answers all questions except the one about whether his/her pain was relieved within 48 hours, then that respondent's questionnaire would be ineligible for inclusion in your audit of pain relief.

4.1b Coding and entering the data

For a standardized survey, *coding* the data means assigning a number to each possible answer. The number assigned to the answer chosen by a respondent, then, is *entered* into a computer database. It is much simpler for a computer to recognize and analyze numbers (i.e., codes) than words.

Assigning numbers to the data

The Toolkit instruments include the code for each possible answer in brackets [] behind the answer. Note that the same pattern for assigning codes is used with similarly structured questions (e.g., "yes"=1, "no"=5). The computer will keep track of the responses according to *both* the question number and the code of the answer to that question that is chosen by the respondent.

Choosing the numbers to assign as codes

If you are using information from the coversheet, medical records, or some other source, you will need to assign a number to each possible answer (i.e., code the data). In some instances, it may be useful to group possible answers. For example, an institution may want to include in the analysis whether or not a patient currently has a spouse. The coversheet offers 4 categories for marital status, but for the purposes of this analysis "widowed", "divorced", and "single" all mean that no spouse is present. Consequently, "married" could be coded as "1" while "widowed", "divorced", and "single" could all be coded as "0".

If you are including questionnaires that have some pieces of missing data, you will need to assign a code that represents missing data in order to tell the computer that it is missing. The code for missing data must be different from all other codes. For example, the number "99" may identify missing data *if and only if* no other possible answer has the code "99".

Coding missing data

As indicated in the "Instructions for the Interviewer" section of the Toolkit instruments, it is sometimes logical to skip questions for some respondents. For example, a patient who reports no pain should not then be asked about

Coding skipped questions

pain severity. In these cases, a “skip pattern” is appropriate for that respondent. When a question is skipped, the lack of information on that question is not actually “missing data” because the information was not supposed to be supplied in the first place. Consequently, you will need to assign a different code for skip patterns. For example, the number “8” may represent a skip pattern *as long as* “8” does not represent any of the possible responses or missing data.

Once each of the possible responses, missing data, and skipped questions has been assigned a number as its code, then the data is ready to be entered into a computer database. Since the Toolkit Scoring Packet provides a ready-to-use Excel Worksheet and Guide for data entry and analysis (see the Registration Form), we recommend that you use Microsoft Excel as your data entry program. However, you may use other spreadsheet applications or other statistical programs (such as SAS). If you use a program other than Excel, you will need to write the necessary formulas or program coding in the language of the program you choose in order to complete the analysis.

To obtain the Toolkit Scoring Packet, see the [Registration Form](#)

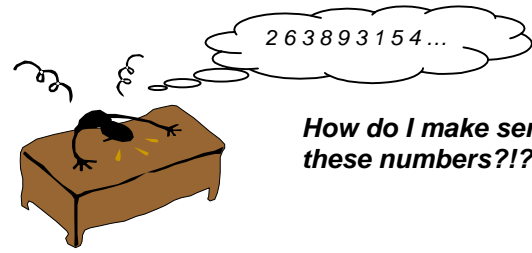
4.1c Cleaning the data

Cleaning the data means verifying that the data has been entered correctly. The accuracy of the data entry process is essential for the quality of your results. To clean the data, remember the following checks:

- ✓ *Check for out-of-range values.* Some data entry packages can be programmed to warn the person entering the data if an out-of-range value has been entered. If your data entry package does not do this, you should check the data for numbers (i.e., codes) that are not possible given coding schemes you have assigned to the potential answers, missing data, and skipped questions.
- ✓ *Check for skip pattern problems.* Look for the code you’ve assigned to skip patterns and check to make sure that skipping that question was appropriate for that case.
- ✓ *Check for duplicates.* The number of records in the data file (e.g., lines on a data entry spreadsheet) should match the number of cases in your final sample of respondents.



4.2 Analyzing the data



How do I make sense of all these numbers?!?

HAPPILY, the computer will “crunch the numbers” for you! In addition, if you are using Microsoft Excel as your data management and analysis program, we will provide you with a pre-formatted Excel Worksheet that will calculate your problem, domain, and scale scores (see the Toolkit Registration Form).

Even though the computer will do the computational work, it is a good idea for you to understand how the problem scores and scale scores are calculated in order to be able to interpret them correctly. Moreover, in addition to computational issues, two questions remain: do the scores accurately reflect the quality of care in your institution, and how does an institution decide whether a problem or scale score needs to be addressed? As a result, this section will address the following:

- a. calculating problem and scale scores,
- b. interpreting the scores,
- c. prioritizing your results.

4.2a Calculating problem and scale scores

Problem scores. The majority of Toolkit survey results will be presented in terms of problem scores. As noted in the “Instructions for Scoring” section included with the instruments, problem scores are a summary of all responses in a specific domain that indicate a less than optimal experience or an opportunity to improve. Any answer that indicates an opportunity to improve is treated as a problem. For example, both a response that a patient received “less than the amount of care needed” and a response that a patient received “more than the amount of care needed” are treated as problems because both responses indicate an opportunity to improve.

What counts as an opportunity to improve?

A *problem score* summarizes the number of opportunities to improve within a specific domain. For example, for a particular problem score that includes 5 questions, your score could vary between 0 and 5. In this example, a score of 0 indicates that respondents reported no opportunities to

What is a problem score?

improve and that your institution is doing very well, while a score of 5 indicates that respondents reported an opportunity to improve on all items.

A *domain score* is the average problem score across the questions included in that score. A domain score is calculated by dividing the problem score by the number of survey questions used to calculate that problem score. Following the above example, a score of 1 in a problem score comprised of 5 questions corresponds to a domain score of 0.20 ($1/5=0.20$). This domain score of 0.20 means that respondents identified an opportunity to improve on one out of five questions.

What is a domain score?

Scale scores. Unlike problem scores, scale scores do not correspond directly with an opportunity to improve. Instead, scale scores reflect the average answer to survey questions whose response categories range from a low response to a high response (e.g., ratings on a scale from “0” to “10” or responses ranging from “not at all” to “very much so”). For example, consider the domain called “Encourage the self-efficacy of the family” in the Toolkit After-death Bereaved Family Interview. The scale score will reflect whether the average bereaved family member felt “very confident”, “fairly confident”, or “not confident” about knowing what to expect or do while their loved one was dying.

What is a scale score?

4.2b Interpreting your scores

Often, the results of the survey both will confirm some of what you expected and provide surprises. Once you see the results of your audit, an important question arises. How can you be sure that the numbers accurately reflect the quality of care in your institution?

The work you’ve done up to this point is one assurance that the numbers reflect the quality of care in your institution. (See Chapter 3 of this Guide regarding using the Toolkit instruments and previous sections of this chapter for coding and entering data accurately.) Assuming the nuts and bolts of surveying and computing have been completed carefully, it remains true that numbers (including your problem and scale scores) need to be interpreted in the context of both possible sources of *data bias* and the *commonly held views* about your institution.

Numbers need to be interpreted.



4.2b.i Data bias means that the data gathered reflect only part of the total picture. This can happen when one group of potential respondents is not included in the questionnaires that are eligible for analysis or when one group's views are more pronounced than others' in the eligible questionnaires. Every survey carries potential for data bias. Some sources of bias are eliminated by carefully following the accepted procedures for conducting the survey and computing the scores. Other sources of bias cannot be controlled by the researcher- e.g., the types of potential respondents who refuse to participate in the survey or the types of questions that respondents do not answer. It is important to identify potential sources of bias in your data (even if you could not control them) in order to be able to interpret your results appropriately.

Every survey has the potential for bias.

Check the following characteristics of your data to help determine if your data are biased.

✓ *Completion and response rates.*

A completion rate is the number of questionnaires you included in your analysis out of the total number of *potential* questionnaires. In other words, it is the number of questionnaires your team completed divided by the number of people that theoretically could have been included. A response rate is the number of questionnaires you included in your analysis out of the number of people you planned to interview. In other words, a response rate is the number of questionnaires your team completed divided by the number of people you attempted to contact--whether or not they agreed to participate.



For example, consider the scenario in which your goal is to interview bereaved family members. A total of 100 people died in your institution. Of those 100 patients, 80 had family members that you know of. You attempt to contact those 80 family members. Of the 80 family members, you were able to interview 75. In this scenario, the completion rate is 75% (75/100), and the response rate is 93.75% (75/80).

Example completion and response rates

In general, the lower your completion and/or response rates, the more likely it is that your survey has missed the perspective of one or more groups. In the above example, you don't have information on the quality of care of those persons who did not have a family member available to be interviewed. It is quite possible that the quality of care for those patients was different than the care of those patients who had a family member to report on their experience. There is no way to know for sure.

Missing the perspective of one or more groups creates bias in the data.

Again from the above example, only a small number of persons refused to participate in the survey. This is one piece of evidence that your survey does reflect the experiences of all groups in your institution. If a large number of people had refused to participate, though, you would need to ask yourself if there was a reason for their refusals? Did they refuse to participate because they were particularly unsatisfied with their loved one's medical care or traumatized by the experience? Again, there is no way to know for sure. *In short, the possibility of having missed the perspective of a group of people grows with the number of people who cannot be contacted or who refuse to participate.*

✓ *Possible reasons for refusals to participate (i.e., non-response bias).*

Although you cannot know for sure how people who refused to participate would have answered the questions, it is useful to know who those people are. In other words, you can use the information you have about the people who refused to participate in order to identify those people who are not represented in your data. For example, you may find that those who did not or could not participate were patients within 24 hours of death at the time of contact, patients with a specific illness, patients or family members of a specific racial group, family members who were not also primary caregivers of the patient, family members of patients who were transferred to your institution within 72 hours of death, etc. *Regardless of what category the non-responders may fit into, it is very useful for interpreting your scores to know whose perspectives are not reflected in those scores.*

Who is not represented?

✓ *Reasons for missing data.*

If a high percentage of respondents did not answer a specific question, it is useful to consider why this occurred. Was the question confusing? Did the interviewer encounter a problem reading that question? Was it particularly emotional for respondents? The interviewers may be able to shed light on possible reasons for the missing data. *Exploring potential reasons behind missing data informs your interpretation of your scores by identifying what elements of the domains of care are not included in the scores because that data is missing.*

What kinds of answers are missing?



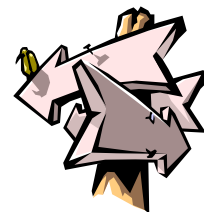
4.2b.ii Identifying commonly held views about your institution is important in the process of quality improvement. Audit results may confirm or contradict the common beliefs about quality of care in an institution. If the problem and scale scores contradict commonly held beliefs about your institution, then two possibilities arise.

1. The numbers are biased in some way and, therefore, do not reflect the complete picture. In this case, you should explore the sources of bias discussed above. If you feel the results are biased, repeat the survey on another sample.
2. Second, the scores are accurate. In this case, it is possible that the commonly held views reflect bits and pieces of anecdotal evidence whereas the audit scores reflect a more complete picture. Alternatively, it is possible that expectations for end-of-life care among patients, family members, and/or care providers are somewhat different than the standard of care proposed by the survey.

Regardless of the reason, if commonly held views contradict the audit results, the reasons behind this should be explored in order to understand the meaning of the audit results in the context of your institution.

4.2c Prioritizing your results for action

Patient and family member surveys can raise many compelling and important issues. How do you decide which issues to address or to focus on first? As the central person(s) conducting and summarizing the results of the audit, you will need to choose which areas you believe should be your initial focus for quality improvement. The following suggestions can help you with these decisions.



What should we tackle first?

⇒ Ranking problems by magnitude. The most straightforward method of prioritizing is to rank issues in order of the size of the problem and to focus first on those that are the greatest.



⇒ Comparing results against outside norms or benchmarks.

A common method of prioritizing is to select issues that compare unfavorably with national, regional, or local norms or with benchmark institutions. This allows you to focus on areas of comparative weakness. Currently, we are conducting surveys that will establish national benchmarks based on the Toolkit instruments.

⇒ Comparing of results within your organization. Comparison within organizations facilitates networking among units or departments and sharing of information about effective practices. Internal competitiveness may also fuel improvement efforts.

⇒ Ease of action. Many organizations focus initially on the issues that most easily present solutions. By demonstrating successful interventions, this prioritization method can rally support for more difficult improvement efforts later to come.

⇒ Comparing results over time. Comparing survey results over time provides a powerful analytic tool for prioritizing because it identifies trends. Following trends allows you to focus on correcting aspects of performance that are slipping over time. To determine accurate trends, though, sample sizes for each survey period must be large enough to achieve stable results.



⇒ Comparing results with predefined goals. One way to rationalize priorities is to set threshold or target goals prior to the survey. You would then focus on issues where performance does not meet these goals. This method is particularly effective when there is clear consensus on what those goals should be.

⇒ Correlating specific and overall measures. In some organizations, it is clear which overall summary measures are most important. For example, an overall rating of the quality of care that is delivered might be the most important indicator of quality for a hospital. Correlating patient responses to specific questions with the overall rating of the quality of care helps to focus attention on a specific issue that, in turn, can improve the overall measure.



⇒ Correlating results with other problems. Some problems may be “markers” for a constellation of other problems. Analyzing how problems relate to one another (i.e., correlate with each other) can help to identify and focus attention on these marker problems and possibly identify the source of the broader issues that need to be addressed.

⇒ Maintaining areas of excellence. An organization may also want to maintain excellence in areas where it is already perceived to be doing well. This approach can provide a clear and positive focus for clinical and administrative staff.

Now that you have completed Step I (conducting the survey, analyzing the data, and choosing your priority areas for improvement), it is essential that members of senior management and other colleagues “get on board”. You’ve already done a significant amount of work to identify an opportunity to improve; applying the principles and tools of quality improvement requires a facility-wide commitment. Chapter 5 will walk you through Step II of the Quality Improvement Model– *Engage Stakeholders and Define a Goal.*



STEP I



STEP II

Reference List

The Picker Institute. *Designing a Patient Feedback System to Meet Your Needs*. May, 1996.

CAHPS 2.0 Survey and Reporting Kit. *Chapter 4: Selecting a Sample, Conducting Your CAHPS Survey, and Analyzing Your Data*. AHCPR, October, 1999.