Chapter 3: *Conducting an Audit*

STEP I

Conducting an audit is an umbrella term that encompasses several smaller elements of the survey process. This chapter covers the nuts and bolts of administering a survey. Chapter 4 focuses on preparing and analyzing the data that you collect.

Checklist for administering a survey

- ✓ ***Choose a survey tool***
- ✓ ***Select a sample***
- ✓ ***Make initial contact***
- ✓ ***Train the interviewers***
- ✓ ***Inform & protect respondents***

3.1 Choose a survey tool

The Toolkit of Instruments for End of Life Care contains two survey tools: the Prospective Patient Interview and the After-death Bereaved Family Member Interview.

3.1a Purpose of the interview tools

➢ The **Prospective Patient Interview** was designed to obtain feedback from a patient as he/she is receiving medical care for a life-threatening illness. Two important advantages of a prospective survey are that the data collected can be used to shape the care of the particular patient who responded to the survey and that patient preferences can become the reference point for evaluating the appropriateness of care (Fowler et al 1999).

The Prospective Interview asks patients about the care they are receiving.

This instrument has a set of core questions that pertain to all patients, regardless of the setting of care. In addition, there are modules that have been designed to address "new admission" issues and the special circumstances of home care, long-term care, and hospice settings.

Core/module design

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➢ The **After-death Bereaved Family Member Interview** was designed to gather *retrospective* data on the care that a patient received at the end of life. That is, we are asking the family members for his/her perception of the patient's end-of-life medical care after the patient has died. Given that it is difficult to accurately identify patients who are in the last month/week of life and that many patients are unable to be interviewed, family members can often provide important information about the quality of medical care at the end of life. Although family members cannot know exactly what a patient was feeling or thinking, they can report on what they were told, their own observations, their perceptions of the patient's dying experience, and their own experience with health care providers (Fowler et al 1999).

The After-death Interview asks family members about a deceased loved one's care.

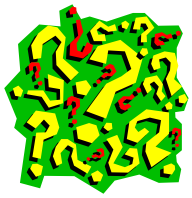
The After-death Interview includes several domains of care (e.g., physical comfort, self-efficacy of the family). You can choose to include all of these domains or to focus on only a few of them. We have prepared versions of the After-death Interview that are specific to *nursing home*, *hospice*, and *hospital* settings. In addition, questions specific to the last month of life are available in a module.

Domain-specific design

3.1b Issues to consider when choosing a tool

As these brief descriptions suggest, every survey tool has its own advantages. The tool you choose will depend on several factors, some of which are likely to be specific to your institution. Two issues to consider are the kind and time frame of the data you want to gather.

- *The kind of information you want to gather*- Do you want to gather information that will guide the care of current patients? Do you want to learn more about the extent to which family members were prepared for and supported in their loved ones' dying process as well as their perspective on the patient's care?



- *The time frame of the data*- Do you want information about quality of care of current patients, regardless of how long they will continue to live? Do you want to know more about quality of care in the last month or week of a patient's life – data that may be difficult to obtain from a

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critically ill patient?

PROSPECTIVE PATIENT SURVEY	AFTER-DEATH FAMILY MEMBER SURVEY
Guidance for care of *that* patient	Family member experiences and perspectives on patient care that provide information to guide the quality of care of future patients
Current patients	Past patients
No specific period in illness progression or life course	Data about a defined period (e.g., last week of life)

Given the difficulties of surveying patients who are close to death, the After-death Bereaved Family Member Interview is generally easier to administer than the Prospective Patient Interview. With an interviewer who is trained and sensitive to bereavement issues, family members are usually very willing to participate in this type of survey.

3.2 Select a sample

Your sample consists of those people who respond to your survey. When selecting your sample, it is important to consider both the *make-up* and *size* of the sample.

3.2a Make-up of the sample

WHO *should be in the sample ???*

A crucial step in administering a survey is to identify *who* is going to be in your sample. Some general guidelines apply to both the Prospective Patient Interview and the After-death Bereaved Family Member Interview. That is, the Toolkit surveys were not developed to address the special issues associated with the death of a child or with death by trauma or suicide. Also, children should not be asked to be respondents to this survey. Therefore, we recommend that you do *not* include the following people in your sample:

- patients under 18 years of age,
- family members under 18 years of age,
- patients or family members of patients who died as a result of trauma or suicide.

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In addition to these general guidelines, special considerations arise for each of the two Toolkit interview tools.

➢ **Prospective Patient Interview**- In a survey of dying people, two key decisions are choosing which patients to include in the sample and identifying the point in the course of a patient's disease at which data are to be collected (Fowler et al 1999). Many patients are too ill to be interviewed in the last week of life. Furthermore, identifying who is in the last week of life is a difficult task (Teno & Coppola 1999). Given these difficulties, the table on the following page identifies several alternative trigger points for identifying potential patients to include in your sample.

Trigger points can help identify patient respondents.

Certain triggers may be more useful for specific types of institutions. For example, *hospice or palliative care organizations* may find entry into a service program to be the most useful trigger. On the other hand, *hospitals* may look to life-limiting diagnoses to identify patients who are eligible for the survey. *Nursing homes* may find that guidelines based on expected behaviors near the end of life are the most useful trigger for identifying a sample of patients. Regardless of the trigger you choose, it is important that your criteria for including patients in the sample be reliable on an ongoing basis so that the same trigger can be used to identify the entire sample.

See Trigger Points table on next page.

➢ **After-death Bereaved Family Member Interview**- Selecting family members as potential respondents raises an important issue—*who is the best family member to act as a proxy for a patient's quality of care?* The best proxy respondent is the person who was most fully involved with all phases of the patient's dying experience and who can answer the most questions as an informed person (Fowler et al 1999). As one might expect, the person identified in the discharge records as the family members may or may not be the best proxy respondent for the deceased. We have chosen to use existing data sources to help identify the potential family member to complete the survey. For example, we suggest contacting the person listed as the informant or contact person on the hospital admission paper work. Then, ask that person: *Would you say you are one of the people who knows the most about how [PATIENT] was doing during (his/her) last few weeks of life?*

Who is the best family member to interview?

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Trigger Point ▪ Specific criterion options	**Advantage**	**Disadvantage**
Prognosis ▪ Diagnosis that implies life-limiting prognosis (e.g., pancreatic cancer, metastatic colon cancer)	Can search computer database using DRG as key word	Not helpful criteria for certain diseases (e.g., COPD)
▪ Diagnosis with utilization data (e.g., CHF patient with 2 or more admissions)	Can search computer database	Utilization data reflect practice patterns. Best suited for managed care in which all health events are captured
▪ Computerized model (e.g., APACHE III with cutoff MDS/RAI)	Prognostication systems already in use by many institutions	Uncertainty in prognosis for non-cancer and ICU illnesses
▪ NHO "prognostic" guidelines	HCFA uses these guidelines	Uncertainty in prognosis
Guidelines ▪ Define behaviors which should occur with limited life expectancy	Guidelines can be developed locally	Variation in guidelines limits ability to compare data
Discrete event/circumstance ▪ Entry to service program (e.g., 72 hours after hospice admission)	Yields actionable information about an important event; survey can be modified for a sentinel time period	Some questions are linked to prognosis; some questions may not be appropriate after hospital discharge
▪ Occurrence of a concern or event with a particular patient		Not cost effective; some questions may not distinguish between those with or without an event
Physician ▪ Use of an IHI Team question from breakthrough series "Would you be surprised if your patient died in the next year?"	Simple	Linked to physician behavior; Sensitivity and specificity of question is unknown
▪ MD identification of people with six month prognoses		Linked to physician behavior; extensive research shows concern with this trigger

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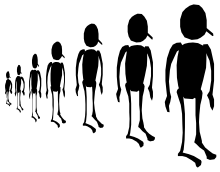
3.2b Size of the sample

A small amount of data collected on a regular basis can provide invaluable information. For the purpose of *quality improvement*, as few as 20 or 30 interviews can provide you with enough information for a baseline assessment. Research projects supported by grant funding, though, will often require larger sample sizes and more extensive planning.

H0W MANY** should be in the sample **???

Regardless of the type of project, it is important to consider that the sample you start out with will be different from your final sample because



some people you ask to participate will not be able to do so or will choose not to participate. It is important that you track the number of people that agree and don't agree to participate in the survey so that you can calculate a response rate (see Chapter 4 of this Guide).

3.3 Make initial contact

The manner in which you establish initial contact with patients or bereaved family members has a profound impact on the respondents' right to privacy. Once you have identified patients or family members as potential respondents, we recommend sending them a letter that introduces your project. This letter should identify who is conducting the study, explain the purpose of the study and what respondents will be asked to do, and give potential respondents the opportunity to refuse all further contact from the study team. Providing potential respondents with the opportunity to refuse further contact from the study team is part of protecting their rights (see below) and sometimes is done by supplying a toll-free telephone number they can call to notify the study team of their wishes. Examples of initial contact letters for patients and family members are included on the following pages.

How should we approach people for interviews?

When is the best time to contact family members? Rarely does a family member, friend, or professional caregiver become uncomfortable in remembering the circumstance of the death of someone close (Lynn et al 1997). We recommend that you contact family members anywhere from three to six months after the patient's death. It has been our experience that

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family members will tell you if they are not ready to talk about the death of their family member.

Sample initial contact letter for ***Prospective Patient Interview***

Dear Mr. Gonzalez,

I am writing on behalf of XXX nursing home. Currently, we are working on a project intended to promote the best quality of care for patients and their family members. We are doing this by speaking with residents, such as yourself, who can provide important information about your experience with the medical care received at our facility.

Specifically, we are asking you to participate in our project by agreeing to be interviewed over the telephone. If you decide to agree to an interview, everything that you tell us will be held in the strictest confidence. Some information you provide will be included in your medical chart and will be used to guide your care in the future; however, we will not identify you or describe you in a way that anyone else could identify you in any general reports that may result from this project.

One of our interviewers will phone you in the next few weeks. If you prefer not to participate in this project, you can call us at 1-800-555-xxxx to notify us of your wishes. Upon receiving a call from you, no one from our study team will contact you further about this project.

We are confident that this project will enable us to promote the highest-level quality of care both for you in particular and for other residents more generally. With this goal in mind, we very much hope that you will agree to participate in a telephone interview.

We look forward to talking with you.

Sincerely,

[Study Team Leader]

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Sample initial contact letter for ***After-death Bereaved Family Member Interview***

Dear Mrs. Smith,

I am writing on behalf of XXX Hospital. We are saddened by the loss of [patient's name] and hope that you have been doing as well as possible during this difficult time.

Currently, we are working on a project intended to promote the best quality of care for seriously ill patients and their family members. We are doing this by speaking with people, such as yourself, who can provide important information about a loved one's medical care at the end of life. We would like to learn about your perspective on the experience of [patient's name] at our hospital and your own experience during that time.

Specifically, we are asking you to participate in this project by agreeing to be interviewed over the telephone. If you decide to agree to an interview, everything that you tell us will be held in strictest confidence. We will not identify you or [patient's name] in any reports that result from this project.

One of our interviewers will phone you in the next few weeks. If you prefer not to participate in this project, you can call us at 1-800-555-xxxx to notify us of your wishes. Upon receiving a call from you, no one from our study team will contact you further about this project.

We are confident that this project will enable us to continue to promote the highest-level quality of care for seriously ill patients and their family members. With this goal in mind, we very much hope that you will agree to participate in a telephone interview.

We look forward to talking with you.

Sincerely,

[StudyTeam Leader]

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3.4 Inform and Protect Respondents

Each respondent has the right to grant informed consent, to refuse participation, as well as to privacy and confidentiality.

3.4a Informed consent. Although the specific procedure for informed consent varies by institution, all informed consent procedures should include at least these three components.

Purpose of study. Always tell the potential respondent the purpose for conducting the survey.

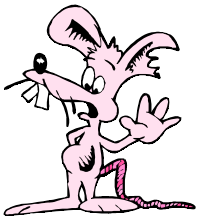
Procedures, risks, and benefits. Each potential respondent must be informed of the procedures that will be followed and any discomforts, risks, or benefits associated with participation.

Contact information. Potential respondents must also know how to contact someone other than the interviewer who can provide additional information about the study.

All respondents have rights.

An informed consent statement should be included at the beginning of each interview. Such a statement is included in each of the Toolkit instruments (link to informed consent statement in Afterdeath interview).

3.4b Refuse participation. Just as potential respondents have the right to know about the nature of a study, they also have the right to refuse to participate without fear of intimidation or negative consequences. In addition, they have the right to refuse to answer any question on the survey and may end the interview at any time. It should be clearly stated to every potential respondent that no aspect of his/her medical care will be impacted by a refusal to participate in this study.



3.4c Privacy and confidentiality. Respondents need to be assured that their records and responses will remain confidential. They have the right to know how their responses will be presented (e.g., as part of an overall group result with no personal identifiers). In addition, need to know that all identifying information will be kept under lock and key during the analysis of the data, and that it eventually will be destroyed.

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At this point in time, many health care settings do *not* require that quality improvement projects seek approval of an institutional review board (IRB). An IRB typically is associated with a research institution and has the responsibility of ensuring that the process of gathering data will not harm the participants in any way. Projects that will be published in a scientific journal or that are being supported by a grant typically need to apply for approval by an IRB. *Regardless of the type of project or whether IRB approval is required, it is important to remember that all respondents have rights!*

Do we need institutional approval to conduct an audit?

3.5 Train the interviewer(s)

The Toolkit instruments are *standardized survey interviews*. This means that the instruments use a pre-defined question-and-answer format to gather information. The questions are carefully prepared in advance, and the answers are mainly closed-ended (i.e., the tool provides a set of possible responses from which respondents must choose). Given this, the role of the interviewer is to read the prepared questions word-for-word to the respondent, and the role of the respondent is to choose an answer from the set of responses offered by the interviewer.

This sounds simple, but there are many opportunities for confusion and "messy" data that is difficult to analyze.

Since the Toolkit surveys have been designed to be administered by an interviewer, it is important for the quality of your study that all interviewers follow the same general guidelines for conducting standardized survey interviews. The survey tools themselves include instructions for how to proceed with the interview, but the guidelines below will help interviewers put on the "interviewer hat."

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3.5a Set the stage for a successful interview

Setting up the interview interaction is *crucial* for the success of the interview. To set the stage effectively, the interviewer needs to explain the purpose of the interview, foster a conducive relationship, and set the standard.

i. Explain the purpose of the interview to the respondent before beginning to ask the survey questions. It is important that the respondent understand the reason that he/she should care about the interview. Even though the respondent received an initial contact letter, it is useful to tell the respondent again which institution is conducting the research and that the goal of the project is to promote the highest quality of care for seriously ill patients and their family members.

Why should the respondent care about the interview?

ii. Foster a conducive relationship between the respondent and the interviewer. In general, the relationship should be warm and professional. The respondent needs to be able to respect the interviewer and know that he/she can be trusted to be accepting and nonjudgmental. This may require some practice, especially if the interviews are being conducted over the telephone.

iii. Set the standard for the respondent and the interviewer. Many respondents may not have been interviewed before, which may make them uncomfortable about the process. Consequently, it is important to tell the respondent what he/she can expect from the interviewer and how it is appropriate for her/him to respond. For example, an interviewer using a Toolkit survey may want to begin by saying that the type of survey being administered requires that the interviewer read each question verbatim and that the respondent choose one of the responses offered by the interviewer.

The respondent needs to know what to expect during the interview.

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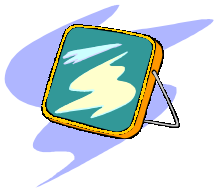
3.5b Strive for neutrality



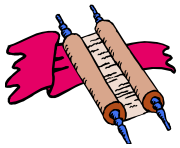
One of the interviewer's goals is to *avoid* influencing the answers chosen by the respondents. Two rules of thumb for remaining neutral are to avoid volunteering personal information and to avoid value judgments.

i. Interviewers should *avoid* volunteering personal information to the respondent. Personal information about the interviewer can sway the respondent's view of what answers the interviewer might consider appropriate or "correct". The goal of the interview is to learn the respondent's views, not what the respondent thinks that the interviewer wants to hear. If a respondent asks the interviewer for his/her opinion during the interview, the interviewer can tell the respondent that the goal is to learn what the *respondent* thinks about certain issues and that they can talk about the interviewer's opinions *after the interview*.

The goal is to record the respondent's perspective.

ii. Interviewers should *avoid* value judgments regarding the respondent's answers. It may be tempting for an interviewer to encourage the respondent by agreeing with or complementing him/her as a form of feedback to a response. This kind of value judgment should be avoided since it may bias further responses. For example, a patient reports that his/her pain was alleviated within the first 48 hours of admission to hospice. In an attempt to encourage the respondent, the interviewer comments "that's good". Even though alleviation of pain may be a "good" outcome, the patient may now feel pressure to avoid the appearance of contradiction by painting a positive picture of his/her experience with hospice during the remainder of the interview. The goal is to obtain an accurate response to each question *from the perspective of the respondent*.

3.5c Probe for an appropriate response



At times, the meaning of a question or an answer may need to be clarified. When this occurs, it is very

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important that the interviewer probe in such a way as to *avoid* influencing or suggesting an answer. Interviewers should follow the **"three Rs"** below to ensure that they do not influence the respondents' answers.

Re-read

i. If a respondent asks the interviewer to clarify the question, the interviewer should re-read the question and possible responses in full. If the respondent needs further clarification, the interviewer should instruct him/her to choose an answer based on his/her best judgment about the meaning of the question. The interviewer should *not* interpret the question for the respondent.

Repeat

ii. If the interviewer needs clarification about the respondent's answer, the interviewer should explain to the respondent that the way to answer is to choose one of responses listed and then should re-read the *entire* list of possible responses. The interviewer should require that the respondent choose one of the listed responses. Some interviewer's may be tempted to interpret the respondent's words, saying "I think you mean X, is that right?" Such interpretation should be *avoided*, since this may influence the respondent's actual answer.

Record

iii. If a respondent is unsure which response to choose even after the interviewer has repeated the question and possible responses, the interviewer should record verbatim all relevant information given by the respondent. The decision as to which response this information points to will be made during the analysis process—not during the interview.

The main idea regarding probing for an appropriate response when conducting a standardized survey is to ***stick to the script!*** The interviewer can repeat questions and answer categories and can explain to the respondent the need to choose an answer category; however, the interviewer should *NOT* interpret a respondent's words or assume the meaning of a respondent's words.

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3.5d Attain consistency across interviewers

Most standardized survey interview projects entail more than one interviewer. Since the goal of the project often is to compare respondents' answers, standardization of responses is crucial. Attaining this standardization requires that interviewers are consistent in how they approach the interview and handle unexpected problems. Two tips for attaining consistency across interviewers are to utilize a common introduction and to practice with each other.

i. <u>A common introduction to and explanation of the interview process</u> can go a long way in attaining consistency across interviews. Standardizing the words the interviewers use to "set the stage" (see above) helps to ensure that each respondent approaches the interview with the same understanding and expectations of the interaction.

ii. <u>Practice, practice, practice</u> with each other! Mock interviews between interviewers not only offer practice for each interviewer but also develop common approaches to the interviewing process. Interviewers can learn from each other the most effective ways to strive for neutrality and to probe for an appropriate response (see above). In addition, interviewers who play the role of respondents can help to anticipate potential questions and problems that may arise. Videotaping and reviewing mock interviews can be a useful learning tool as well.

Interviewing seriously ill patients and bereaved family members presents specific challenges for interviewers. Both the health and emotional status of the respondent need to be considered. Undoubtedly, interviewers will encounter different degrees of acceptance and/or grief among patients and family members. Mock interviews can prepare interviewers to approach respondents with compassion while still meeting the objectives of the survey.

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3.5e Pay attention to respondents' stories

As this chapter emphasizes, the Toolkit instruments are survey instruments that require interviewers to collect precise, accurate answers to specific questions. Following the above guidelines is the *primary task* of the interviewer. Since interviewers do administer the instrument, though, the possibility arises that respondents may begin to expand on their specific answers with stories or examples that help to fill-in the picture of their experiences. In addition, the open-ended questions at the end of the toolkit interviews offer the opportunity for respondents to elaborate on or add to the issues addressed in the structured interview.

Even though the primary goal of the interview is to obtain specific responses to pre-defined questions, respondents' stories can be quite useful when presenting the results of your project. People's stories can foster a powerful and contagious excitement about the need for changes in care practices. For this reason, interviewers should pay attention to respondents' stories. If an interviewer finds a story particularly enlightening or compelling, he/she should record that story in the following manner:

People's stories are powerful motivators for change.

i. ***Wait until the interview is over before asking the respondent to elaborate on the story!*** During the standardized survey interview, the interviewer should be sure to ***stick to the script***.

ii. It may be helpful for the interviewer to make a note on the coversheet or interview guide as a reminder to go back to the respondent's story after the standardized interview is complete.

iii. After the standardized interview, the interviewer should tell the respondent that he/she is particularly interested in the story about "X" and ask the respondent for his/her permission to record that story.

Remember to get permission to record data not included in the original survey.

iv. If the respondent agrees, then the interviewer should ask the respondent to repeat the details and record the story verbatim (as much as possible).

v. If the respondent does not agree to have his/her story recorded, then the interviewer should move on and not press the issue.

All respondents have rights.

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vi. Informing and protecting respondents' rights applies to their stories just as much as it does to their answers to survey questions.

vii. When presenting a story as part of your results, never attach a respondent's name to a story or describe a respondent in such a way that anyone would be able to guess whose story you are telling.

3.5f Revisit the interview process throughout the project

Although following the guidelines for conducting a standardized survey interview is crucial for ensuring the quality of the information you gather, no set of guidelines can prepare an interviewer for all possible interview situations. Given this, it is useful to gather the interviewers involved in your project at least once after the interviewing portion of your project has begun. During these sessions, the interviewers can exchange stories about interview situations (protecting the confidentiality of the individual respondents, of course) and share successful techniques. This also presents an opportunity for interviewers to check that their techniques and approaches to the interview are consistent. These sessions are very helpful for encouraging interviewers to continue to wear the "interviewer hat."

(citation for section 3.5: Fowler & Mangione 1990)

FREQUENTLY ASKED QUESTIONS

Why are the Toolkit surveys designed to be administered by an interviewer over the telephone?

As part of the work in creating the survey, we asked focus group participants about the mode of administration. Bereaved family members felt that the survey should not just be mailed out to them, but rather they wanted a person who could speak to them and refer them to bereavement services if needed. However, the majority of hospices in the United States use a self-administered survey. Future work shall modify the survey for self-administration.

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Can we conduct our own telephone interviews?

To avoid the biases inherent in conducting interviews with patients in your own institution or with family members of patients who died in your institution, it is always recommended that a person not directly involved in the care of the patient conduct the interview.

What are the other modes of data collection?

In addition to being administered by an interviewer over the telephone, surveys can be: 1) administered by an interviewer in-person; 2) self-administered and returned to the study team; or 3) administered via a computer program. Sometimes people use a mixture of these modes to minimize the percentage of people who refuse to participate in the survey.

Can you use the same instrument with all modes of administration?

No. Each mode of administration requires an instrument tailored to that mode. It is possible, though, to write questions so that the results can be compared across modes of administration. We will be producing a self-administered version of the Toolkit instruments, which will be comparable to the interviewer-administered version.

Will this survey be translated into other languages?

Yes, future work will translate the survey into Spanish.

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