



NSAP Audit Tool 2

Patient Interview

This interview instrument is designed to be used by specialist palliative care services as part of the National Standards Assessment Program. The survey provides evidence that can be used to support the self-assessment against the Standards for Providing Quality Care for all Australians.

Audit tool 2 – helpful information

Purpose:

to obtain feedback from a patient as he/she is receiving care for a life-limiting illness and clinically relevant information which can be used to shape the delivery of care based on patient preferences.

Sample size:

a final sample of between 20 and 30 interviews should be aimed for. (Services may need to select a larger number in the initial sample because some patients you choose will not be able to participate or will choose not to participate)

Sample selection:

details on sample selection are available in section 4 of the NSAP Guide.

Disclaimer and Acknowledgements

This survey tool has been derived from the previous Patient Interview survey tool developed by Brown University as part of the Toolkit of Instruments to Measure End of Life Care. It has been adapted by Palliative Care Australia for Australian circumstances.

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This project is funded by the Australian Government Department of Health and Ageing under the National Palliative Care Program.

Instructions for the interviewer

- When conducting this interview, read only lowercase text aloud to the respondent.
- Instructions for interviewers are provided throughout the questionnaire in CAPITAL LETTERS. Words appearing in capital letters are meant to guide the interviewer and should not be read aloud.
- Instructions written in lowercase letters are meant to guide the respondent and, therefore, should be read aloud to the respondent.
- It is important to read questions in their entirety and exactly as written.
- Question numbers should not be read to the respondent.
- At times, the name of the institution in which the patient received his/her medical care should be inserted. You should be prepared with this information before beginning the interview.
- Many of the survey questions consist of two parts: i) a question about an aspect of end-of-life care, and ii) a question that provides the response categories and asks the respondent to choose one those categories (e.g., see Question 4) In such cases, read aloud to the respondent both parts of the question as written. It is important to read all of the answer choices before pausing for a response.
- Answer categories are written in CAPITAL letters. Answer categories should not be read aloud to the respondent unless they appear in lowercase letters as part of the question (e.g., see Question 4).
- For yes/no questions, the answer categories should not be read aloud. As a result, the answer categories for yes/no questions are not written into the question.
- After a respondent chooses an answer category, clearly mark the box that corresponds to that answer. For write-in and open-ended answers, mark the corresponding box and record the information as stated by the respondent.
- Based on the answers to certain questions, it sometimes is logical to skip subsequent questions. For example, a respondent who reports that the patient did not have trouble with breathing should not then be asked about treatments for trouble with breathing. In such cases, you will see an arrow after an answer category with an instruction that tells you what question to go to next. If a respondent chooses one of these answer categories, mark the corresponding box and then move on to the question number indicated after that answer category.

EXAMPLE: Q7. While receiving palliative care, did [PATIENT] have trouble breathing?

YES

NO → GO TO QUESTION 11

ACTION: If the respondent chooses "NO", mark the box corresponding to "NO" and then skip to question 11. The answer categories for questions 8, 9 and 10 will be left blank.

- Sometimes a respondent will say that he or she does not know the information needed to answer a question. If "DON'T KNOW" is listed as a response category for that question (e.g., see question 5), then mark the corresponding box and follow any instructions indicated after the "DON'T KNOW" category. If "DON'T KNOW" is not listed as one of the response categories for that question, then mark the box corresponding to "NO ANSWER" and follow any instructions indicated after the "NO ANSWER" category.
- For all questions asked of the respondent during the interview, record the respondent's answer, even if that answer does not correspond with information from the medical record.
- Be sure to familiarise yourself with the survey questions before conducting interviews.
- If your facility requires informed consent, adapt or replace the supplied Informed Consent Statement and read it to the respondent before starting the survey.

INTRODUCTION

BEGIN BY READING THIS INTRODUCTION TO RESPONDENT

Hi, (Ms/Mrs/Mr) [NAME], my name is [YOUR NAME]. Would it be all right if I asked you some questions about your care since you have been in [SITE OF CARE]? I am working with [SITE OF CARE] to try to find out what patients think about the care that they have been provided, so that [SITE OF CARE] knows what it is doing well and what could be improved. Is this a good time for us to talk?

- YES → **CONTINUE WITH INTERVIEW → GO TO THE INFORMED CONSENT SECTION**
- NO → **ASK THE RESPONDENT WHEN WOULD BE A GOOD TIME FOR YOU TO CALL BACK;
SET A DATE AND TIME FOR THE RETURN CALL**

INFORMED CONSENT STATEMENT

IF NECESSARY MODIFY THIS INFORMED CONSENT STATEMENT BASED ON YOUR OWN INSTITUTION'S REQUIREMENTS.

To make sure you have all the information about the study, I am going to read you a few sentences.

Your participation in this interview is, of course, voluntary. Regardless of whether you choose to participate or not, it will not affect you or your care in any way.

Your answers will be kept completely confidential to the extent of the law. The information from this study will not be presented or published in any way that would allow you to be identified. Your answers will be combined with the answers of other people for statistical analysis. Your answers will not be shared with your health team.

It is important that your answers be accurate. Take your time and be sure to ask me if you are not sure what a question means or what kind of answer is wanted. It is very important that you answer as honestly and as accurately as you can. If there is any question you would rather not answer, just tell me and I will skip it.

Do you have any questions about who is doing the study or anything else about the study?

Do you agree to participate in the study?

- YES → **CONTINUE WITH INTERVIEW – GO TO QUESTION 1**
- NO → **THANK INTERVIEWEE AND CONCLUDE INTERVIEW**

INTERVIEW

I would like to start with how you are feeling by finding out about symptoms you may have.

INTERVIEWER: FOR QUESTION 1A, RECORD THE TWO SYMPTOMS IN THE BOX IN THE TABLE BELOW. FOR EACH SYMPTOM, ASK QUESTIONS 1B- 1D, INCLUDING THE ALTERNATIVE ANSWERS IN THE ELLIPSES. FILL IN THE RESPONSES TO QUESTIONS 1B TO 1D IN THE TABLE BELOW.

Q1A. In the past two days, which two symptoms have been the most bothersome for you?

RECORD RESPONSE IN COLUMN A IN TABLE BELOW.

Q1B. How often do you have [SYMPTOM]? Occasionally/about half of the time/
most of the time/all of the time?

RECORD RESPONSE IN COLUMN B IN TABLE BELOW

Q1C. How severe is the [SYMPTOM]? Not at all severe/moderately severe/extremely severe?

RECORD RESPONSE ON COLUMN C IN TABLE BELOW

Q1D. How much does [SYMPTOM] distress or bother you? A little bit/somewhat/
quite a bit/very much?

RECORD RESPONSE IN COLUMN D IN TABLE BELOW.

A. BOTHERSOME SYMPTOMS	B. HOW OFTEN?	C. HOW SEVERE?	D. HOW BOTHERSOME?
1.1	<input type="checkbox"/> Occasionally <input type="checkbox"/> About half of the time <input type="checkbox"/> Most of the time <input type="checkbox"/> All of the time	<input type="checkbox"/> Not at all severe <input type="checkbox"/> Moderately severe <input type="checkbox"/> Extremely severe	<input type="checkbox"/> A little bit <input type="checkbox"/> Somewhat <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much
1.2	<input type="checkbox"/> Occasionally <input type="checkbox"/> About half of the time <input type="checkbox"/> Most of the time <input type="checkbox"/> All of the time	<input type="checkbox"/> Not at all severe <input type="checkbox"/> Moderately severe <input type="checkbox"/> Extremely severe	<input type="checkbox"/> A little bit <input type="checkbox"/> Somewhat <input type="checkbox"/> Quite a bit <input type="checkbox"/> Very much

INTERVIEWER: IF RESPONDENT DID NOT MENTION PAIN AS A BOTHERSOME SYMPTOM, GO TO QUESTION 4. IF RESPONDENT DID MENTION PAIN, ASK QUESTIONS 2-3 BELOW: BEFORE ASKING THE QUESTIONS BELOW YOU SHOULD EXPLAIN THAT ANY REFERENCE TO THE "MEMBERS OF THE PALLIATIVE CARE TEAM" INCLUDES THE DOCTORS, NURSES OR ALLIED HEALTH PROFESSIONALS WHO PROVIDED CARE TO THE PATIENT. IT DOES NOT INCLUDE THE PATIENT'S GP.

Q2. Has a member of the palliative care team talked with you, in a way that you can understand, about treating your pain?

- YES NO

Q3. Have you received too much, too little, or just the right amount of medication for your pain?

- TOO MUCH
 TOO LITTLE
 RIGHT AMOUNT
 N/A

The next questions are about the medical care that you are receiving at [SITE OF CARE].

Q4. For symptoms other than pain, how much help has the palliative care team provided to keep you comfortable - less than was needed, about the right amount or more than was needed?

- LESS THAN WAS NEEDED
 RIGHT AMOUNT
 MORE THAN WAS NEEDED

Q5. Have you had any feelings of anxiety or sadness while under the care of [SITE OF CARE]?

- YES
 NO → SKIP TO Q7

Q6. How much help in dealing with these feelings have you received from the palliative care team - less than was needed, about the right amount or more than was needed?

- LESS THAN WAS NEEDED
 RIGHT AMOUNT
 MORE THAN WAS NEEDED

Q7. How much information has the palliative care team provided you about your medical condition - would you say less information than was needed, just the right amount, or more than was needed?

- LESS THAN WAS NEEDED
 JUST THE RIGHT AMOUNT
 MORE THAN WAS NEEDED

Q8. Has there ever been a decision made about your care without enough input from you or your family?

- YES NO

Q9. Do you have specific wishes or have you made plans about the types of medical treatment you want or don't want?

- YES NO

Q10. Have you and the palliative care team made plans to ensure that your wishes for medical treatment will be followed?

- YES
- NO

Q11. Have you had any medical procedure or treatment that was inconsistent with your previously stated wishes?

- YES
- NO

Q12. How often have you been treated with respect by those who were taking care of you - always, usually, sometimes, or never?

- ALWAYS
- USUALLY
- SOMETIMES
- NEVER

Now I'd like to ask about your overall opinion of your care. For the next few questions, please use a scale for 0 to 10 where 0 means the worst care possible and 10 means the best care possible.

PLEASE CIRCLE RATING PROVIDED BY PATIENT.

Q13. How well has the palliative care team communicated with you and your family about your illness and the likely outcomes of care?

0 1 2 3 4 5 6 7 8 9 10

Q14. How well has the palliative care team provided medical care that respects your wishes?

0 1 2 3 4 5 6 7 8 9 10

Q15. How well has the palliative care team made sure that your symptoms are controlled to a degree that was acceptable to you?

0 1 2 3 4 5 6 7 8 9 10

Q16. How well has the palliative care team provided emotional support for you and your family and friends?

0 1 2 3 4 5 6 7 8 9 10

And now an overall rating...

Q17. On a scale of 0 to 10, where 0 means the worst care possible and 10 means the best care possible, what number would you give the overall care that you have received?

0 1 2 3 4 5 6 7 8 9 10

CONCLUDING STATEMENT:

Those are all of the questions I have for you. I really appreciate you taking the time to participate in this survey. Please know that your responses will be used to help ensure that [NAME OF FACILITY] provides the highest quality of care to all patients and their family members. Thank you again.

CONCLUDE INTERVIEW