

Clinical practice at the end of life: can we collect reliable data?

Dear Doctor,

There is considerable interest in undertaking robust research about clinical decision-making at the end of life. As it is likely that some practices may be illegal we are concerned that it may not be possible to collect reliable data.

With this questionnaire we aim to determine the areas where it may be possible to collect reliable data. We are **not** asking about your own practice, merely, whether you would be prepared to give an honest answer to certain types of questions. We have designed this postal survey in a way that ensures that no individual respondent will be able to be identified: your response will therefore be unidentifiable as well as confidential. Similar data are being collected in the UK.

Your response is very important to us

We would be very grateful if you would set aside some time to answer our questions. This should take you no more than 10 minutes. Please try to answer each question. Many of the questions ask only slightly different things.

If you are unable to answer a question because no option corresponds exactly to the answer you wish to give, please try to answer it as best you can. Please return your completed questionnaire in the **FREEPOST** envelope provided. No stamp is needed.

If you have any concerns about this questionnaire you may contact:

Professor Alan Merry on 021 492 297

Or Dr Louise Webster on 09 3797440

Or Dr Magdi Moharib on 021 171 4686

Thank you

IF you are not prepared to answer the questions on the following pages PLEASE would you be willing to tick one of the boxes below and return the questionnaire (FREEPOST envelope).

I am not prepared to complete the questionnaire because:

I don't know whether to trust you

I'm too busy

I'm not interested in your research

Other, please specify.....

.....

To ensure that you cannot be identified, please DO NOT write your name or provide any identifying information anywhere on this questionnaire.

What is your speciality? (e.g. GP, neurology, palliative care).....

What is your grade? (e.g. vocationally registered, registrar)

Are you **female** **male**

Are you a practising member of a faith group? (e.g. Muslim, Hindu, Christian) **Yes** **No**

REMEMBER when answering the following questions, we are not asking about your practice. We are only interested in knowing whether, in a future research study, you would feel able to answer questions honestly. **All questions are hypothetical and your answers will be anonymous.**

Question 1

If the following question was in a legitimate survey:
Can you recall causing the death of a patient by the use of a drug prescribed, supplied or administered by you with the explicit intention of hastening the end of that patient's life?

Would you answer the above question honestly? **Yes** **No**

If the following question was in a legitimate survey:
Can you recall causing the death of a patient by withdrawing treatment with the explicit intention of hastening the end of that patient's life?

Would you answer the above question honestly? **Yes** **No**

Why do you think that you, or other doctors, would NOT be prepared to answer questions such as those above honestly?

Question 2

If asked in a legitimate survey, to which of the following questions do you think that **you** would be willing to give an **honest** answer about your own practice?

Remember we are not asking about your practice, only whether you would be willing to give an honest answer if you were asked these questions.

With reference to the death of a specific patient (i.e. named patient) did you:

Please tick Yes or No in each column for each scenario.

	Yes	No
Withhold or withdraw medical treatment:		
a) taking into account the possibility that this would hasten the patient's death	<input type="checkbox"/>	<input type="checkbox"/>
b) partly to hasten the patient's death	<input type="checkbox"/>	<input type="checkbox"/>
c) with the explicit intention of hastening the patient's death	<input type="checkbox"/>	<input type="checkbox"/>
Intensify the alleviation of pain and suffering:		
a) taking into account the possibility that this would hasten the patient's death	<input type="checkbox"/>	<input type="checkbox"/>
b) partly to hasten the patient's death	<input type="checkbox"/>	<input type="checkbox"/>
c) with the explicit intention of hastening the patient's death	<input type="checkbox"/>	<input type="checkbox"/>

Question 3

	Yes	No
Would your decision to provide an honest answer be influenced by whether:		
a) the patient was competent or incompetent	<input type="checkbox"/>	<input type="checkbox"/>
b) the patient was terminally ill	<input type="checkbox"/>	<input type="checkbox"/>
c) the patient/family had discussed their views with you	<input type="checkbox"/>	<input type="checkbox"/>

Question 4

Again, assuming a legitimate research survey, would any of the following assurances lead you *to answer honestly*? Please tick the box next to any that apply (options continue onto the following page).

- Anonymous written replies possible
- An anonymous internet survey
- An interview with one of the researchers that was given on the condition that it would be anonymised
- If the interviews were undertaken by a registered medical practitioner on behalf of the research team, and an undertaking was given that your response would be anonymised
- If the researchers provided a signed undertaking never to reveal the identity of any of the respondents

- If the researchers promised never to divulge the link between the respondents and their replies even if faced with prosecution
- If you could be reassured that the method made it absolutely impossible to link the identity of the respondents with their responses
- If the survey was endorsed by the GMC
- If the Department of Health endorsed the survey
- If there was a guarantee from some government department, the GMC or the like that the replies would never be used to investigate the practices of any individual respondent

Which of the options above might prove decisive, or are there any other re-assurances you would require?

Thank you for completing this questionnaire.

Please note that because we have no way of identifying whether or not you have returned this questionnaire, you will receive a reminder note along with a further copy of the invitation letter and questionnaire. If you have already returned this questionnaire, please disregard the reminder. We apologise for any inconvenience caused to you, but this method does ensure that your answer will be entirely anonymous and unidentifiable.