

Appendix 1 CODE-EM Family Survey Tool

CODE-EM Questionnaire

1	There was enough help with nursing care in the ED, such as giving medicines, changing diapers and helping the patient find a comfortable position in bed.	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
2	The bed area in the ED and surrounding environment was comfortable for the patient.	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
3	The bed area in the ED and surrounding environment was comfortable for the family.	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
4	The bed area in the ED and surrounding environment had adequate privacy for the patient	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
5	Did you have confidence and trust in the ED nurses who were caring for the patient?	Yes, in all of them	Yes, in some of them	No, not in any of the nurses		
6	Did you have confidence and trust in the ED doctors who were caring for the patient?	Yes, in all of them	Yes, in some of them	No, not in any of the doctors		
7	In your opinion, during the patient's stay in the ED, did the patient appear to be in pain?	Yes, all of the time	Yes, some of the time	No, s/he did not appear to be in pain		
8	In your view, did the doctors and nurses in the ED do enough to help relieve the pain?	Yes, all of the time	Yes, some of the time	No, not at all	Not applicable, s/he was not in pain	
9	In your opinion, during the stay in the ED, did the patient appear to be restless?	Yes, all of the time	Yes, some of the time	No, s/he did not appear to be restless		
10	In your view, did the doctors and nurses in the emergency department do enough to help relieve the restlessness?	Yes, all of the time	Yes, some of the time	No, not at all	Not applicable, s/he was not restless	
11	In your opinion, during the stay in the ED, did the patient appear to have a "noisy rattle when breathing?"	Yes, all of the time	Yes, some of the time	No, s/he did not have a noisy rattle to the breathing		
12	In your view, did the doctors and nurses in the ED do enough to help relieve the "noisy rattle" when breathing?	Yes, all of the time	Yes, some of the time	No, not at all	Not applicable, s/he did not have a noisy rattle to the breathing	
13	In your opinion, during the stay in the emergency department, did the patient appear to have difficulty breathing?	Yes, all of the time	Yes, some of the time	No, s/he did not have difficulty breathing		
14	In your view, did the doctors and nurses in the emergency department do enough to help relieve the breathing difficulty?	Yes, all of the time	Yes, some of the time	No, not at all	Not applicable, s/he did not have difficulty breathing	
15	During the time in the ED, the patient's care and treatment was discussed with you and/or the family.	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
16	The healthcare team at the ED explained the patient's condition and treatment in a way you found easy or difficult to understand.	Very easy	Easy	Neutral	Difficult	Very Difficult
17	How would you assess the overall level of emotional support given to you by the ED healthcare team?	Very poor	Poor	Fair	Good	Excellent
18	The ED healthcare team discussed the patient's religious or spiritual needs.	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
19	Were you told that the patient would be likely to die soon?	Yes		No		
19a)	If yes, who told you s/he was likely to pass away soon?	Yes		No		
20	Did a member of the ED healthcare team talk to you about what to expect during the dying process (e.g. what symptoms may arise)?	Yes		No		
20a)	If yes → Was the discussion about what to expect during the dying process helpful?	Yes		No		
20b)	If no → Would a discussion about what to expect during the dying process have been helpful?	Yes		No		
21	In your view, the patient was treated with respect and dignity by the ED doctors.	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
22	In your view, the patient treated with respect and dignity by the ED nurses.	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
23	Overall, in your opinion, were you adequately supported during the patient's stay in ED?	Yes		No		

CODE-EM, Care of the Dying Evaluation - Emergency Medicine; ED, emergency department.

Table S1 Derivation of CODE-EM from original CODE questionnaire

Original CODE™	CODE-EM	Rationale for change
1 There was enough help available to meet his/her personal care needs, such as washing, personal hygiene and toileting needs. Scale: • Strongly agree • Agree • Neither agree nor disagree • Disagree • Strongly disagree	Omit	Not always required during ED stay, shorten survey, point regarding nursing care included in question 2 instead.
2 There was enough help with nursing care, such as giving medicines and helping him/her find a comfortable position in bed. Scale: • Strongly agree • Agree • Neither agree nor disagree • Disagree • Strongly disagree	There was enough help with nursing care in the ED , such as giving medicines, changing diapers and helping the patient find a comfortable position in bed. -Use same scale	Specific to ED stay
3 The bed area and surrounding environment was comfortable for him/her. Scale: • Not applicable, s/he died at home • Strongly agree • Agree • Neither agree nor disagree • Disagree • Strongly disagree	- The bed area in the ED and surrounding environment was comfortable for the patient. - The bed area in the emergency department and surrounding environment was comfortable for the family.	- Specific to ED stay - Modification in scale: remove 1st option - Additional question to assess family's comfort in the ED environment.
4 The bed area and surrounding environment had adequate privacy for him/her. Scale: • Not applicable, s/he died at home • Strongly agree • Agree • Neither agree nor disagree • Disagree • Strongly disagree	The bed area in the ED and surrounding environment had adequate privacy for the patient.	- Specific to ED stay - Modification in scale: remove "NA, s/he died at home" option
5 In your opinion, how clean was the ward area that s/he was in? Scale: • Not applicable, s/he died at home • Very clean • Fairly clean • Not at all clean	Omit	Not a major issue in ED
6 Did you have confidence and trust in the nurses who were caring for him/her? Scale: • Yes, in all of them • Yes, in some of them • No, not in any of the nurses	Did you have confidence and trust in the ED nurses who were caring for the patient? -Use same scale	Specific to ED stay
7 Did you have confidence and trust in the doctors who were caring for him/her? Scale: • Yes, in all of them • Yes, in some of them • No, not in any of the doctors	Did you have confidence and trust in the ED doctors who were caring for the patient? -Use same scale	Specific to ED stay
8 The nurses had time to listen and discuss his/her condition with me. Scale: • Strongly agree • Agree • Neither agree nor disagree • Disagree • Strongly disagree	Omit	As time is often limited due to the fast pace in ED, effective communication by ED staff may be better measured by how much the family was involved and understood i.e., questions 16 and 19 below.
9 The doctors had time to listen and discuss his/her condition with me. Scale: • Strongly agree • Agree • Neither agree nor disagree • Disagree • Strongly disagree	Omit	As above
10 In your opinion, during the last two days, did s/he appear to be in pain? Scale: • Yes, all of the time • Yes, some of the time • No, s/he did not appear to be in pain	In your opinion, during the patient's stay in the ED , did the patient appear to be in pain? -Use same scale	Specific to ED stay
11 In your view, did the doctors and nurses do enough to help relieve the pain? Scale: • Yes, all of the time • Yes, some of the time • No, not at all • Not applicable, s/he was not in pain	In your view, did the doctors and nurses in the ED do enough to help relieve the pain? -Use same scale	Specific to ED stay
12 In your opinion, during the last two days, did s/he appear to be restless? Scale: • Yes, all of the time • Yes, some of the time • No, s/he did not appear to be restless	In your opinion, during the stay in the ED , did the patient appear to be restless? -Use same scale	Specific to ED stay
13 In your view, did the doctors and nurses do enough to help relieve the restlessness? Scale: • Yes, all of the time • Yes, some of the time • No, not at all • Not applicable, s/he was not restless	In your view, did the doctors and nurses in the emergency department do enough to help relieve the restlessness? -Use same scale	Specific to ED stay
14 In your opinion, during the last two days, did s/he appear to have a 'noisy rattle' to his/her breathing? Scale: • Yes, all of the time • Yes, some of the time • No, s/he did not have a noisy rattle to the breathing	In your opinion, during the stay in the ED , did the patient appear to have a "noisy rattle" when breathing? -Use same scale	Specific to ED stay
15 In your view, did the doctors and nurses do enough to help relieve the 'noisy rattle' to his/her breathing? Scale: • Yes, all of the time • Yes, some of the time • No, not at all • Not applicable, s/he did not have a noisy rattle to the breathing	In your view, did the doctors and nurses in the ED do enough to help relieve the "noisy rattle" when breathing? -Use same scale	Specific to ED stay
	In your opinion, during the stay in the emergency department, did the patient appear to have difficulty breathing? -Use same scale as above	Additional question, to review the 4 main symptoms (pain/SOB/rattle/agitation) included in our clinical charts.
	In your view, did the doctors and nurses in the emergency department do enough to help relieve the breathing difficulty? -Use same scale as above	As above
16 During the last two days, how involved were you with the decisions about his/her care and treatment? Scale: • Very involved • Fairly involved • Not involved	During the time in the ED, the patient's care and treatment was discussed with you and/or the family. Scale: • Strongly agree • Agree • Neither agree nor disagree • Disagree • Strongly disagree	Specific to ED stay and a more objective measure of communication by ED staff. Rephrased as a statement using a 5-point scale.
17 Did any of the healthcare team discuss with you whether giving fluids through a 'drip' would be appropriate in the last two days of life? Scale: • Yes • No • Don't know	Omit	Not routinely discussed in the ED
18 Would a discussion about the appropriateness of giving fluids through a 'drip' in the last two days of life have been helpful? Scale: • Yes • No • Not applicable, we had these types of discussions	Omit	As above
19 Did the healthcare team explain his/her condition and/or treatment in a way you found easy or difficult to understand? Scale: • Very easy • Fairly easy • Fairly difficult • Very difficult • They did not explain his/her condition or treatment to me	The healthcare team at the ED explained the patient's condition and treatment in a way you found easy or difficult to understand. Scale: • Strongly agree • Agree • Neither agree nor disagree • Disagree • Strongly disagree	Rephrased as a statement using 5-point scale
20 How would you assess the overall level of emotional support given to you by the healthcare team? Scale: • Poor • Fair • Good • Excellent	How would you assess the overall level of emotional support given to you by the ED healthcare team? -Use same scale	Specific to ED stay
21 Overall, his/her religious or spiritual needs were met by the healthcare team. Scale: • Strongly agree • Agree • Neither agree nor disagree • Disagree • Strongly disagree	The patient's religious or spiritual needs were discussed with the ED healthcare team. -Use same scale	We do not have chaplain services in ED, but we can review patient's religious background and offer to allow the family to bring in their own religious support or conduct rituals.
22 Overall, my religious or spiritual needs were met by the healthcare team. Scale: • Strongly agree • Agree • Neither agree nor disagree • Disagree • Strongly disagree	Omit	No routine assessment of family's spiritual needs.
23 Before s/he died, were you told s/he was likely to die soon? Scale: • Yes • No → If 'Yes', who told you s/he was likely to die soon?	Were you told that the patient would be likely to die soon? -Use same scale → If 'Yes', who told you s/he was likely to die soon?	Similar but rephrased as patient may not have died yet in the ED
24 Did a member of the healthcare team talk to you about what to expect when s/he was dying (e.g., symptoms that may arise)? Scale: • Yes • No	Did a member of the ED healthcare team talk to you about what to expect when the patient was dying (e.g., what symptoms may arise)? -Use same scale	Specific to ED stay
25 Would a discussion about what to expect when s/he was dying have been helpful? Scale: • Yes • No • Not applicable, we had these types of discussions	Would a discussion about what to expect when the patient was dying have been helpful? -Use same scale	Same
26 In your opinion did s/he die in the right place? Scale: • Yes, it was the right place • No, it was not the right place • Not sure • Don't know	Omit	Patient may not have died in the ED
27 I was given enough help and support by the healthcare team at the actual time of his/her death. Scale: • Strongly agree • Agree • Neither agree nor disagree • Disagree • Strongly disagree	Omit	Patient may not have died in the ED
28 After s/he had died, did individuals from the healthcare team deal with you in a sensitive manner? Scale: Yes No Not applicable, I didn't have any contact with the healthcare team	Omit	Patient may not have died in the ED
29 How much of the time was s/he treated with respect and dignity in the last two days of life? Please answer for both doctors and nurses Scale: • Always • Most of the time • Some of the time • Never • Don't know	In your view, the patient treated with respect and dignity by the ED doctors. In your view, the patient treated with respect and dignity by the ED nurses. Scale: • Strongly agree • Agree • Neither agree nor disagree • Disagree • Strongly disagree	Same but we have formatted as 2 separate questions. -Using the standard 5-point scale
30 Overall, in your opinion, were you adequately supported during his/her last two days of life? Scale: • Yes • No	Overall, in your opinion, were you adequately supported during the patient's stay in ED ? -Use same scale	Specific to ED

omit = question not to be included in our study; In bold = changes in wording of the question; The patient is referred to as the "patient" rather than s/he or him/her to suit our local language use. CODE™, Care of the Dying Evaluation; ED, emergency department.

Table S2 Summary of pilot study responses on the questionnaire

Questions	Yes	No	Open question results	Actions on the questionnaire revision
1. Were the questions easy to understand/wording was clear? 1a. If no, which questions? 1b. How can this be improved?	30 (100%)	0 (0%)		No actions
2. Did the questions make you feel emotionally distressed? 2a. If yes, which questions? 2b. How can this be improved?	7 (23.3%)	23 (76.7%)	<p>Q13, Q19</p> <p>Q13: One participant noticed that his mother was struggling to breathe when he arrived at the ED. He also noticed that the space in ED was constrained, but felt it was understandable. Hence, he thought that these could be improved. (Subject ID NPP002, male)</p> <p>Q19: One participant felt that the word 'die' carries a strong meaning. He suggested to change to something more neutral (i.e., worsen). (Subject ID NPP007, male)</p> <p>General comments:</p> <p>Two participants commented that the questionnaire was generally difficult to answer as the topic was on death at a point in time when their loved ones were actively dying. Overall, the questions made them feel emotionally distressed.</p> <p><i>"No particular question, emotionally distressed in general in view of current situation"</i> (Subject ID KPP013, male)</p> <p><i>"(Emotionally distressed) in general, as this concerns life and death"</i> (Subject ID NPP011, male)</p>	Revise the wording in Q19
3. Were any of the questions irrelevant? 3a. If yes, which questions? 3b. How can this be improved?	7 (23.3%)	23 (76.7%)	<p>Q5, Q6, Q7, Q18, Q19, Q20</p> <p>Q5 & Q6: One participant commented that she came to the hospital with confidence in staff/professionals and thus, should not be asked these questions. (Subject ID CPP001, female)</p> <p>Q7: One respondent felt that he was unable to tell if his grandfather was in pain as he (patient) was unconscious. He thinks that if there were no symptoms, the family would not have sent the patient to the ED, thus he felt that we could tailor the questions accordingly. (Subject ID NPP004, male)</p> <p>Q18 (Subject KPP004 chose "Neutral"): "Doctor did not raise this question at all" (Subject ID KPP004, male)</p> <p>Q18 (Subject KPP006 did not choose any answers): One participant felt that this question was irrelevant and may also be insensitive. (Subject ID KPP006, female)</p> <p>Q19 & Q20: One respondent mentioned that these two questions seemed to be overlapping. (Subject ID KPP001, male)</p> <p>Q20: Participant felt that this question was irrelevant as he was already aware of dying process beforehand. (Subject ID KPP003, male)</p>	No actions
4. What are your thoughts on the length of this survey? 4a. If too long, which questions should be taken out?	Just nice: 27 (90.0%)	Too long: 3 (10.0%)	<ul style="list-style-type: none"> <i>"Not sure, slightly too long."</i> (Subject ID KPP007, female) 	No actions
5. Was the survey conducted at an appropriate timing? 5a. If you feel the timing was inappropriate, what would be a better timing? (Other options e.g. should be done later in the ED/after the patient's demise/a week later, etc)	20 (66.7%)	10 (33.3%)	<ul style="list-style-type: none"> <i>"Probably best later"</i> (Subject ID CPP002, male) <i>"At least 1 day after demise"</i> (Subject ID KPP003, male) <i>"1-2 days after admission to ward"</i> (Subject ID KPP006, female) <i>"Unsure"</i> (Subject ID KPP008, female) <i>"(The timing) would depend on the condition of the patient."</i> (Subject ID NPP003, female) One respondent felt that the stay in ED was not long enough and a more appropriate time would be after the patient had "completed" the stay (i.e. admitted to inpatient ward). (Subject ID NPP004, male) <i>"There is no 'good' time. It all depends on individuals' coping."</i> (Subject ID NPP011, male) <i>"A week later would be more appropriate."</i> (Subject ID NPP012, male) 	No actions
6. Any other feedback you would like to share with us?			<ul style="list-style-type: none"> One participant suggested that there should have been a place for the body other than the mortuary while waiting for undertaker. (Subject ID CPP001, female) <i>"Range of choices should be shortened."</i> (Subject ID KPP001, male) For Question 19, one respondent commented that "Yes or No" does not answer the question as the attending doctor did not explicitly state imminent demise but merely explained in terms of higher probability of death. (Subject ID KPP004, male) <i>"Might be too long for others in this situation"</i> (Subject ID KPP008, female) <i>"The timing of conducting the survey can be quite subjective. But for family, it was appropriate. Waiting time for bed is too long."</i> (Subject ID NPP001, female) <i>"Length of survey might be subjective; depends on the state of mind of the interviewee. Waiting time for bed is unbearable."</i> (Subject ID NPP003, female) One participant felt that the survey should be conducted at a time when it's "not too early or too late". (Subject ID NPP005, female) 	No actions

ED, emergency department.