

Part 1: Questions about you

1. What would you consider to be your main health problem (if any)?

2. If you have more than one main health problem, state what these other health problems are.

3. What was the main health problem that caused you to be admitted to hospital?

4. How did you come to be in hospital (Please cross one box)

- | | |
|--|--|
| <input type="checkbox"/> Emergency-brought in by ambulance | <input type="checkbox"/> Non-emergency - brought in by ambulance |
| <input type="checkbox"/> Planned Procedure | <input type="checkbox"/> Admitted through Emergency department |
| <input type="checkbox"/> Other Planned admission | <input type="checkbox"/> Other (please specify) <input type="text"/> |

Part 2: Your experience in hospital (Please cross one box unless instructed)

This section asks about your experiences in hospital. 'Hospital staff' means all persons from the hospital that you had contact with. 'Support person' means any relative, friend or carer who supported you as a patient.

- | | Yes,
always | Yes,
sometimes | No | I had no
need to ask |
|--|--|--|--------------------------------|---|
| 5. When you had important questions to ask a doctor, did you get answers you could understand? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. When you had important questions to ask a nurse, did you get answers you could understand? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. Sometimes in a hospital, one doctor or nurse will say one thing and another will say something quite different. Did this happen to you? | Yes,
often
<input type="checkbox"/> | Yes,
sometimes
<input type="checkbox"/> | No
<input type="checkbox"/> | No
<input type="checkbox"/> |
| 8. If you had any anxieties or fears about your condition or treatment, did a doctor discuss them with you? | Yes,
often
<input type="checkbox"/> | Yes,
sometimes
<input type="checkbox"/> | No
<input type="checkbox"/> | I didn't have any
anxieties or fears
<input type="checkbox"/> |
| 9. If you had any anxieties or fears about your condition or treatment, did a nurse discuss them with you? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 10. Did doctors talk in front of you as if you weren't there? | Yes,
often
<input type="checkbox"/> | Yes,
sometimes
<input type="checkbox"/> | No
<input type="checkbox"/> | No
<input type="checkbox"/> |
| 11. Did you want to be more involved in decisions made about your care and treatment? | Yes,
definitely
<input type="checkbox"/> | Yes, to
some extent
<input type="checkbox"/> | No
<input type="checkbox"/> | No
<input type="checkbox"/> |



12. Overall, did you feel you were treated with respect and dignity while you were in hospital?
- Yes, always ☐ Yes, sometimes ☐ No ☐
13. Did you find someone on the hospital staff to talk to about your concerns?
- Yes, definitely ☐ Yes, to some extent ☐ No ☐ I had no concerns ☐
14. Were you ever in pain? ☐ Yes ☐ No - **GO TO QUESTION 16**
15. If yes, do you think the hospital staff did everything they could to help control your pain?
- Yes, definitely ☐ Yes, to some extent ☐ No ☐
16. If your support person(s) wanted to talk to a doctor, did they have the opportunity to?
- ☐ Yes, definitely ☐ My family didn't want or need information
☐ Yes, to some extent ☐ Family or friends were not involved
☐ No ☐ I didn't want my family or friends to talk to a doctor
17. Did the doctors or nurses give your support person(s) all the information they needed to help you recover?
- ☐ Yes, definitely ☐ No support person(s) was involved
☐ Yes, to some extent ☐ My support person(s) didn't want or need information
☐ No
18. Did a member of staff explain the purpose of the medicines you were to take at home in a way you could understand?
- ☐ Yes, completely ☐ I didn't need an explanation ☐ No
☐ Yes, to some extent ☐ I had no medicines - **If this answer go to question 20**
19. Did a member of staff tell you about medication side effects to watch for when you went home?
- ☐ Yes, completely ☐ Yes to some extent ☐ No ☐ I didn't need an explanation
20. Did someone tell you about things to watch out for after you went home that might be a cause for concern regarding your illness or treatment?
- ☐ Yes, completely ☐ Yes to some extent ☐ No
21. Did you experience a healthcare incident while you were in hospital? By healthcare incident we mean: "An event or circumstance during health care caused by the hospital which could have or did result in unintended or unnecessary harm to you."
- ☐ Yes - **If "Yes" continue to part 3**
☐ No - **If "No" you have completed the survey thank you. Please return the questionnaire to the 45 and Up Study coordinating centre in the envelope provided or addressed to Patients' Experiences Project, 45 and Up Study, Reply Paid 87269, Broadway, NSW 2007**

ONLY COMPLETE THE NEXT SECTIONS IF YOU HAD A HEALTHCARE INCIDENT.

Part 3: Questions about the healthcare incident

A '**healthcare incident**' is "An event or circumstance during health care caused by the hospital which could have or did result in unintended or unnecessary harm to you." If you had **more than one** healthcare incident while in hospital please answer these questions about the one you thought was the incident that affected you the most



22. On what day of the week did the healthcare incident occur? (please cross one box)

☐ On a weekday (Monday to Friday) ☐ On a weekend day (Saturday or Sunday)

23. At what time did the healthcare incident occur? (please cross one box)

☐ 8am to 5pm ☐ 5pm to 12 midnight ☐ 12 midnight to 8am ☐ Not sure

24. Where did the healthcare incident occur? (please cross one box)

☐ Public hospital ☐ Private hospital ☐ Somewhere else (please say where):

25. Briefly explain what happened to you.

26. What harm resulted from the healthcare incident? (you may cross more than one box)

☐ I started vomiting ☐ I felt very sick
☐ I suffered a fracture ☐ I am permanently disabled
☐ I developed an infection ☐ Other (please say what)
☐ I had some other injury

27. What clinical care did you have as a result of the healthcare incident?
(you may cross more than one)

☐ I had to return to theatre to get the problem fixed
☐ I had to have additional treatment (please say what treatment)
☐ I had to go to the intensive care unit
☐ I had to be referred to another healthcare facility (please say what type)
☐ I had no particular treatment

28. How serious were the effects of the incident? (please cross one box)

☐ No effects ☐ Mild effects ☐ Moderate effects ☐ Severe effects

29. Was the healthcare incident related to treatment for your main health problem?
(please cross one box)

☐ Yes ☐ No ☐ Not sure

30. If No, what was the healthcare incident related to?

31. Did you have to stay in hospital longer because of your healthcare incident?

☐ Yes ☐ No ☐ Not sure

32. When did you first know about the healthcare incident? (please cross one box)

☐ Immediately after it happened ☐ 5 to 7 days after
☐ Within 24 hours after ☐ More than 7 days after
☐ Within 2 days after ☐ Not sure when it happened
☐ 3 to 5 days after



33. Who first noticed the healthcare incident? (please cross one box)

- ☐ You ☐ Your support person ☐ Hospital staff

34. Who first talked to you, or did you talk to first, about the healthcare incident?
(you may cross more than one box)

- ☐ The consultant ☐ A team of doctors and nurses
☐ A nurse ☐ An intern
☐ A nursing student ☐ A medical student
☐ The registrar ☐ Other (please specify)

35. Do you remember what you were told? (please cross one box)

- ☐ Yes, completely ☐ Yes, in part ☐ No

36. If you can recall what you were told completely or in part, briefly explain what you remember being told.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
37. I was relieved to know what happened	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. I was angry	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. I was depressed about what happened to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. I was confident that I was in good hands	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. I was satisfied with how I was treated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. Did you feel that the doctors, nurses and other hospital staff were open and honest with you about the healthcare incident? (please cross one box)					
<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not sure					

43. Please explain your answer:

44. Put in your own words, how did the healthcare incident affect your life?
(e.g. emotionally, financially, in terms of day-to-day living etc.).

Part 4: The Disclosure Process

An **open disclosure process** is the name for open discussion that the hospital organises between a patient and doctors, nurses and other hospital staff to openly give and discuss information about a health care incident.

45. Was the initial discussion about the healthcare incident organized by the hospital as an open disclosure process? (please cross one box)

- ☐ Yes ☐ No ☐ Don't know



46. Did the hospital staff talk to you about the healthcare incident at the right time for you?
(please cross one box)

☐ Yes ☐ No - it was too early ☐ No - it was too late ☐ Unsure

47. Did you have at least one planned open disclosure meeting about the healthcare incident?
(please cross one box)

☐ Yes - **If "Yes" continue to question 48**
☐ No - **If "No" go to part 5 on page 9**

48. Who initiated the open disclosure meetings? (please cross one box)

☐ Hospital staff - **If this answer go to question 50**
☐ You or your support person - **If this answer go to question 49**
☐ Other (please state who)

49. If the open disclosure meeting(s) was initiated by you or your support person, how was this done? (you may cross more than one box)

☐ I/we requested information from the hospital ☐ I/we sought advice from a lawyer
☐ I/we made a formal complaint to the hospital ☐ Other (Please explain)

50. How many open disclosure meetings did you have? meeting(s)

51. Were you satisfied with the number of open disclosure meetings you had?
(please cross one box)

☐ Yes ☐ No

52. How long after the incident was the first planned open disclosure meeting held?
(please cross one box)

☐ Within 48 hours ☐ 1 - 2 weeks ☐ Within 1 month ☐ Between 1 to 6 months
☐ More than 6 Months (Please state when)

53. Were you given enough time to think and prepare for the open disclosure meeting(s)?
(please cross one box)

☐ Yes ☐ No

54. Who attended the open disclosure meeting(s)?
(please answer for each person by crossing one box beside their name under each of question A and question B)

Hospital doctor

Surgeon

GP

Nurse

Midwife

Pharmacist

Another health care worker

Other (Please specify)

A		B		
Did this person attend?		Was this person previously involved in your care		
Yes	No	Yes	No	Not sure
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

55. Was there anyone else you would have liked to attend the open disclosure meeting(s)?
(please cross one box)

☐ Yes (Please say who)
☐ No



Items 56 to 88 make statements about things that might have happened in the open disclosure process. **Were they true of the open disclosure process you experienced?**

Please show how strongly you agree or disagree by crossing one box for each statement.

Please give an answer for each item	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	N/A
56. I was given the name of a hospital staff member who would act as an ongoing point of contact for the open disclosure process	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
57. I was given options about the time and place of the open disclosure meeting(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
58. I was given options about the staff attending the open disclosure meeting(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
59. I was given the opportunity to have a support person present who was not a hospital staff member	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
60. I was given enough information about what to expect during the open disclosure process	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
61. I was given an apology or expression of regret including the words "I am/we are sorry"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
62. I was given an explanation about the healthcare incident	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
63. This explanation was clear	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
64. Answers were given to me in simple language	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
65. I was given adequate time to talk about my experience of the healthcare incident	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
66. I had an opportunity to ask questions about the healthcare incident	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
67. Clear information was given about the consequences of the healthcare incident	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
68. The open disclosure process made it clear to me how the hospital was going to investigate the healthcare incident	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
69. I was given the opportunity to contribute to the hospital's investigation of the incident	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
70. Hospital staff were willing to share further information as it became available	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
71. I was given information about how the hospital will prevent similar healthcare incidents in the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
72. The information given to me about how the hospital will prevent similar healthcare incidents in the future was clear	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
73. Hospital staff also gave written information about what we discussed in the meeting(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
74. Written information given to me about what we discussed in the meeting(s) was clear	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
75. Hospital staff did not try to avoid the open disclosure	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
76. Hospital staff involved in my care recognised and acknowledged the healthcare incident	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
77. Hospital staff were regretful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



Please give an answer for each item

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	N/A
78. Hospital staff treated me with respect	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
79. Hospital staff were good at listening to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
80. I was offered appropriate support to deal with the healthcare incident immediately after it	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
81. Hospital staff offered ongoing support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
82. I was given the option of arranging additional meetings if I have further questions in the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
83. The conclusion of the open disclosure process was mutually agreed between me and the hospital staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
84. The hospital met its responsibility to me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
85. I am satisfied with the hospital process for advising me about the healthcare incident	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
86. I would be willing return to this health service for future care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
87. I am satisfied with the outcome of the open disclosure process	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
88. I have felt involved in how health professionals communicate with me since the healthcare incident	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

89. What did you like about the meeting(s)?

90. What did you not like about the meeting(s)?

91. Is there anything you would like to change about the way the meeting(s) was conducted?

92. Are there any other comments you would like make about open disclosure?

93. How do you think the open disclosure process could be improved for patients and support persons?



94. Did you receive offers of any of the following for support after the incident?
(you may cross more than one box)

- | | |
|---|---|
| <input type="checkbox"/> Social Worker | <input type="checkbox"/> Nurse |
| <input type="checkbox"/> Patient advocate/support group | <input type="checkbox"/> Psychiatrist |
| <input type="checkbox"/> Psychologist | <input type="checkbox"/> Other (please state who) |

95. Did you need any of the following as a result of the healthcare incident?
(you may cross more than one box)

- | | |
|--|---|
| <input type="checkbox"/> Financial support | <input type="checkbox"/> Employment assistance |
| <input type="checkbox"/> Psychological support | <input type="checkbox"/> Other (please specify) |

Questions 96 and 97 are about your general views on open disclosure as a policy.

96. Do you think that open disclosure is useful for acknowledging healthcare incidents to patients and their families? (please cross one box)

- ☐ Yes ☐ No ☐ Not sure

97. Please indicate how useful you found open disclosure as an approach to acknowledging healthcare incidents to patients and their families? (you may cross more than one box)

- ☐ A useful approach to find out what happened
☐ A useful approach for the health professional responsible to apologise
☐ A useful approach for the patient and family to put blame on the person responsible
☐ Not a very useful approach for asking questions
☐ Not very useful because the people responsible did not apologise
☐ I did not find the open disclosure process useful
☐ Other (please specify)

Part 5: Complaints you made about your care and treatment while in hospital

A formal complaint is made when a person asks the hospital to investigate a grievance and to make a formal response.

98. Did you talk to anyone about making a formal complaint about your treatment while in hospital? (please cross one box)

- ☐ Yes (please say who)
☐ No

99. Did you make a formal complaint to the hospital or another body while you were in hospital? (please cross one box)

- ☐ Yes
☐ No
☐ Not sure

100. If you made a formal complaint did you receive a response? (please cross one box)

- ☐ Yes
☐ No
☐ Still waiting
☐ Not applicable

101. Did you make a formal complaint **after you were discharged** from hospital?
(please cross one box)

- ☐ Yes - If 'Yes' go to question 102
☐ No - If 'No' go to question 103



102. Who did you make the complaint to? (you may cross more than one box)

- | | |
|--|---|
| <input type="checkbox"/> Local doctor | <input type="checkbox"/> Health ministry |
| <input type="checkbox"/> Health Care Complaints Commission | <input type="checkbox"/> Local Member of Parliament |
| <input type="checkbox"/> Hospital | <input type="checkbox"/> Other (please specify) |

103. Why didn't you make a complaint? (you may cross more than one box)

- ☐ I was told what happened by the doctors treating me
☐ Everything was explained during open disclosure
☐ I thought nothing would come of it
☐ I felt too sick
☐ Other (please specify)

104. Did you consult a solicitor or lawyer about the healthcare incident you experienced?
(please cross one box)

- ☐ Yes
☐ No
☐ Not sure

105. Did you make a claim for medical negligence? (please cross one box)

- ☐ Yes
☐ Still considering
☐ No

106. If No, why not? (cross all that apply)

- ☐ Open disclosure gave me the answers I needed
☐ I thought it would be too expensive
☐ I was advised that there was no case
☐ I thought it would be too stressful
☐ Other (please say what)

107. Please use this space to make any further comments or to raise issues that have not been covered.

