**Oxfordshire VOICES survey 2019**

**Views of Informal Carers**

**1. How long had s/he been ill before s/he died?**

***Tick one only*□ S/he was not ill – s/he died suddenly**

**□ Less than 24 hours**

**□ One day or more but less than one week**

**□ One week or more but less than one month**

**□ One month or more but less than six months**

**□ Six months or more but less than one year**

**□ One year or more**

**Care at Home**

**These questions are about care at home –**

**not in a care home**

**3. When s/he was in home in the last three months of life, did s/he get any help at home from any of the services listed below?**

These may have been provided by different organisations, such as voluntary organisations, a private agency or social services.

***Tick all that apply***

**□ A district or community nurse (a nurse who comes to the house and may wear uniform)**

**□ A specialist palliative care nurse, Hospice nurse or MacMillan nurse (a nurse who visits or telephones to talk and advise on medications and other aspects of care. Not usually in uniform)**

**□ Marie Curie night sitting (a nurse who stays with the patient overnight)**

**□ Any other nurse at home**

**2. Did s/he spend any time at home during the last three months of life?**

**If s/he died suddenly with no illness or time for care, please go to question 37.**

**Otherwise, please continue with the questions below.**

***Tick one only***

**□ Yes – go to question 3**

**□ No – S/he was in a care home for the whole 3 months – got to question 12**

**□ No – S/he was in hospital – go to question 24**

**□ Home care worker, home carer, home care aide or home help**

**□ Social worker / support worker**

**□ Community therapist**

**□ Religious leader**

**□ Meals-on-wheels or other home delivered meals**

**□ Hospice at home**

**□ Occupational therapist (OT)**

**□ Rapid Response Team (team of nurses and home care workers who provide care over the short term to allow someone to remain at home and prevent hospital admission)**

**□ S/he didn’t receive any care**

**□ Don’t know**

**□ Something else – please write below**

**4. When s/he was at home in the last three months of life, did all these services work well together?**

***Tick one only*□ Yes, definitely**

**□ Yes, to some extent**

**□ No, they did not work well together**

**□ S/he did not receive any care**

**□ Don't know**

**5. Overall, do you feel that you and your family got as much help and support from health and social services as you needed when caring for her/him?**

***Tick one only***

**□ Yes, we got as much support as we wanted**

**□ Yes, we got some support but not as** **much as we wanted**

**□ No, although we tried to get more help**

**□ No, but we did not ask for more help**

**□ We did not need help**

**6. During the last three months of his life, while s/he was at home, how well was her/his pain relieved?**

***Tick one only***

**□ Does not apply – s/he did not have any pain**

**□ Completely, all of the time**

**□ Completely, some of the time**

**□ Partially**

**□ Not at all**

**□ Don**'**t know**

**Urgent Care Provided Out of Hours**

**7. In the last three months of life, while s/he was at home, did s/he ever need to contact a health professional for something urgent in the evening or at the weekend?**

***Tick one only*□ Not at all – go to question 12**

**□ Once or twice – go to question 8**

**□ Three or four times – go to question 8**

**□ Five times or more – go to question 8**

**□ Don't know – go to question 12**

**8. The last time this happened, who did s/he contact, or who was contacted on her/his behalf?**

***Tick all that apply*□ A GP**

**□ NHS 111/Out of Hours**

**□ District Nurses**

**□ Specialist or Macmillan Nurses**

**□ S/he used a lifeline pendant**

**□ A hospice**

**□ 999**

**9. What happened as a result? Was s/he...**

***Tick one only***

**□ Visited by a GP at home**

**□ Visited by a district nurse at home**

**□ Visited by a hospice nurse at home**

**□ Visited by a hospice doctor at home**

**□ Given medical advice over the phone**

**□ Given another number to ring to get medical advice**

**□ Advised to go to an out-of-hours GP surgery**

**□ Advised to contact the GP surgery when it opened**

**□ Advised to go to an Accident and Emergency department at a hospital**

**□ Something else (please write below)**

**10. In your opinion was this the right thing for them to do?**

***Tick one only***

**□ Yes**

**□ No**

**□ Not sure**

**11. Overall do you feel that the care s/he got when s/he needed care urgently in the evenings or weekends in the last three months of his life was:**

***Tick one only***

**□ Excellent**

**□ Good**

**□ Fair**

**□ Poor**

**□ Don’t know**

**District and Community Nursing**

**If s/he had care in the last 3 months from district and community nurses – go to question 12.**

**If s/he did not, go to question 15.**

**12. How often did the district or community nurse visit (at the most frequent time)?**

***Tick one only***

**□ More than once a day**

**□ Every day**

**□ 2 – 6 times a week**

**□ Once a week**

**□ 2 – 3 times a month**

**□ Less often**

**□ Don’t know**

**13. How much of the time was s/he treated with respect and dignity by the district and community nurses?**

***Tick one only*□ Always**

**□ Most of the time**

**□ Some of the time**

**□ Never**

**□ Don’t know**

**14. Overall, do you feel that the care s/he got from the district and community nurses in the last three months of life was:**

***Tick one only***

**□ Excellent**

**□ Good**

**□ Fair**

**□ Poor**

**□ Don’t know**

**Care from the GP**

**15. In the last three months, how often did s/he see the GP s/he preferred to see?**

***Tick one only***

**□ Almost or almost always**

**□ A lot of the time**

**□ Some of the time**

**□ Never or almost never**

**□ S/he didn’t try to see a particular GP**

**□ S/he didn’t need to see a GP – go to question 20**

**16. How much of the time was s/he treated with respect and dignity by the GPs?**

***Tick one only*□ Always**

**□ Most of the time**

**□ Some of the time**

**□ Never**

**□ Don’t know**

**17. Were you able to discuss any worries and fears you may have had about her/his condition with the GPs?**

***Tick one only***

**□ I had no worries or fears to discuss**

**□ Yes, I discussed them as much as I wanted**

**□ Yes, I discussed them but not as much as I wanted**

**□ No, although I tried to discuss them**

**□ No, but I did not try to discuss them**

**18. Overall, if the GP visited at home during the last three months, how easy or difficult was it to get him/her to visit?**

***Tick one only***

**□ Very easy**

**□ Fairly easy**

**□ Fairly difficult**

**□ Very difficult**

**□ S/he wanted the GP to visit but they would not**

**□ Does not apply, the GP did not need to visit**

**□ Don’t know**

**14. Overall, do you feel that the care s/he got from the GP in the last three months of life was:**

***Tick one only***

**□ Excellent**

**□ Good**

**□ Fair**

**□ Poor**

**□ Don’t know**

**Please feel free to make comments in the space below**

**Care Homes**

**20. Did s/he live or stay in a care home at any time during her/his last three months of life?**

***Tick one only***

**□ Yes s/he was in a care home**

**Please write the name of the care home below:**

**Name:**

**Town:**

**□ No – go to question 24**

**21. How much of the time was s/he treated with respect and dignity by the staff at the care home?**

***Tick one only*□ Always**

**□ Most of the time**

**□ Some of the time**

**□ Never**

**□ Don’t know**

**22. During the last three months of her/his life, while s/he was in the care home, how well was her/his pain relieved?**

***Tick one only***

**□ Does not apply – s/he did not have any pain**

**□ Completely, all of the time**

**□ Completely, some of the time**

**□ Partially**

**□ Not at all**

**□ Don**'**t know**

**23. Overall, do you feel that the care s/he got from the care home in the last three months of life was:**

***Tick one only***

**□ Excellent**

**□ Good**

**□ Fair**

**□ Poor**

**□ Don’t know**

**Last Hospital Admission**

**24. Did s/he stay in hospital at any time during her/his last three months of life?**

***Tick one only***

**□ Yes, please write the name of the last hospital s/he stayed in below:**

**Name:**

**Town:**

**□ No – go to question 29**

**□ Don’t know – got to question 29**

**25. During her/his last hospital admission how much of the time was s/he treated with respect and dignity by hospital doctors and nurses?**

***Please answer for both Doctors and Nurses***

***Doctors Nurses***

**□ Always □ Always**

**□ Most of the time □ Most of the time**

**□ Some of the time □ Some of the time**

**□ Never □ Never**

**□ Don’t know □ Don’t know**

**26. During her/his last admission how well was her/his pain relieved?**

***Tick one only***

**□ Does not apply – s/he did not have any pain**

**□ Completely, all of the time**

**□ Completely, some of the time**

**□ Partially**

**□ Not at all**

**□ Don**'**t know**

**27. Did the hospital services work well together with her/his GP and other services outside of hospital?**

***Tick one only***

**□ Yes, definitely**

**□ Yes, to some extent**

**□ No, they did not work well together**

**□ Don’t know**

**28. Overall, do you feel that the care s/he got from hospital staff in that admission was:**

***Please answer for both doctors and nurses***

***Doctors Nurses***

**□ Excellent □ Excellent**

**□ Good □ Good**

**□ Fair □ Fair**

**□ Poor □ Poor**

**□ Don’t know □ Don’t know**

**Last Hospice Admission**

**29. Did s/he stay in a hospice at any time during her/his last three months of life?**

***Tick one only***

**□ Yes, please write the name of the last hospice s/he stayed in below:**

**Name:**

**Town:**

**□ No – go to question 33**

**□ Don’t know – got to question 33**

**30. How much of the time was s/he treated with respect and dignity by the hospice doctors and nurses?**

***Please answer for both Doctors and Nurses***

***Doctors Nurses***

**□ Always □ Always**

**□ Most of the time □ Most of the time**

**□ Some of the time □ Some of the time**

**□ Never □ Never**

**□ Don’t know □ Don’t know**

**31. During the last three months of her/his life, while s/he was in the hospice, how well was her/his pain relieved?**

***Tick one only***

**□ Does not apply – s/he did not have any pain**

**□ Completely, all of the time**

**□ Completely, some of the time**

**□ Partially**

**□ Not at all**

**□ Don**'**t know**

**32. Overall, do you feel that the care s/he got from hospice staff in that admission was:**

***Tick only one***

**□ Excellent**

**□ Good**

**□ Fair**

**□ Poor**

**□ Don’t know**

**Experiences in the last two days of life**

**33. During her/his last two days of life was s/he:**

***Tick only one***

**□ At home all the time**

**□ In a care home all the time**

**□ In hospital all the time**

**□ In a hospice all the time**

**□ Other – please write in the space below:**

**34. How much of the time was s/he treated with respect and dignity in the last two days of her/his life?**

***Please answer for both Doctors and Nurses***

***Doctors Nurses***

**□ Always □ Always**

**□ Most of the time □ Most of the time**

**□ Some of the time □ Some of the time**

**□ Never □ Never**

**□ Don’t know □ Don’t know**

**35. Please look at the following statements and tick the answer box that corresponds best with your opinion about the help s/he received in the last two days of life:**

***Tick one for each question (a – c)***

1. **There was enough help to meet her/his personal care needs (e.g. toileting needs)**

**□ Strongly agree □ Agree**

**□ Neither agree nor disagree**

**□ Disagree □ Strongly disagree**

**□ Does not apply □ Don’t know**

1. **There was enough help with nursing care (e.g. medicines)**

**□ Strongly agree □ Agree**

**□ Neither agree nor disagree**

**□ Disagree □ Strongly disagree**

**□ Does not apply □ Don’t know**

1. **The bed area and surrounding environment had adequate privacy**

**□ Strongly agree □ Agree**

**□ Neither agree nor disagree**

**□ Disagree □ Strongly disagree**

**□ Does not apply □ Don’t know**

**36. During the last two days, how do you assess the overall level of support given in the following areas from those caring for her/him?**

***Tick one for each question (a – e)***

1. **Relief of pain**

**□ Excellent □ Good □ Fair**

**□ Poor □ Does not apply □ Don’t know**

1. **Relief of symptoms other than pain**

**□ Excellent □ Good □ Fair**

**□ Poor □ Does not apply □ Don’t know**

**(c) Spiritual support**

**□ Excellent □ Good □ Fair**

**□ Poor □ Does not apply □ Don’t know**

1. **Emotional support**

**□ Excellent □ Good □ Fair**

**□ Poor □ Does not apply □ Don’t know**

**(e) Support to stay where s/he wanted to be**

**□ Excellent □ Good □ Fair**

**□ Poor □ Does not apply □ Don’t know**

**Circumstances surrounding her/his death**

**37. Did s/he know s/he was likely to die?**

***Tick only one***

**□ Yes, certainly**

**□ Yes, probably**

**□ Probably not**

**□ No, definitely**

**□ Not sure**

**38. In your opinion, did the person who told her/him s/he was likely to die break the news in a sensitive and caring way?**

***Tick only one***

**□ Yes, definitely**

**□ Yes, to some extent**

**□ No, not at all**

**□ Don’t know**

**□ Does not apply, they didn’t know s/he was dying**

**□ Does not apply, they didn’t tell her/him**

**39. Were you contacted soon enough to give you time to be with her/him before s/he died?**

***Tick only one***

**□ Yes**

**□ No**

**□ I was there already**

**□ It was not clear that s/he was going to die soon**

**□ I couldn’t have got there anyway**

**40. Where did s/he die?**

***Tick only one***

**□ In her/his own home**

**□ In the home of a family member or friend**

**□ In a hospital ward (please write the name of the hospital below)**

**□ In an Accident and Emergency department (please write the name of the hospital below)**

**□ In a hospital Intensive Care Unit**

 **(please write the name of the hospital below)**

**□ In a hospice (please write the name below)**

**□ In an ambulance (please write where the ambulance was on route to below)**

**□ Somewhere else (please write below)**

**41. Did s/he say where s/he would like to die?**

***Tick only one***

**□ Yes – go to question 42**

**□ No – go to question 44**

**□ Not sure – go to question 44**

**42. Where did s/he say that s/he would like to die?**

***Tick only one***

**□ At home □ In a hospice**

**□ In a care home □ In a hospital**

**□ S/he said s/he didn’t mind**

**□ Somewhere else (please write below)**

**43. Did healthcare staff have a record of this?**

***Tick only one***

**□ Yes**

**□ No**

**□ Not sure**

**44. Do you think s/he had enough choice about where s/he died?**

***Tick only one***

**□ Yes**

**□ No**

**□ Not sure**

**□ S/he died suddenly**

**45. On balance do you think s/he died in the right place?**

***Tick only one***

**□ Yes**

**□ No**

**□ Not sure**

**46. Were you or her/his family given enough help and support by the healthcare team at the actual time of her/his death?**

***Tick only one***

**□ Yes, definitely**

**□ Yes, to some extent**

**□ No, not at all**

**□ Don’t know**

**47. After s/he died, did staff deal with you or her/his family in a sensitive manner?**

***Tick only one***

**□ Yes**

**□ No**

**□ Don’t know**

**□ Does not apply, I didn’t have any contact with the staff**

**48. Looking back over the last 3 months of her/his life was s/he involved in decisions as much as s/he would have wanted?**

***Tick only one***

**□ S/he was involved as much as s/he wanted**

 **to be**

**□ S/he would have liked to be more involved**

**□ S/he would have liked to be less involved**

**□ Don’t know**

**49. Looking back over the last 3 months of her/his life were you involved in decisions as much as you would have wanted?**

***Tick only one***

**□ I was involved as much as I wanted to be**

**□ I would have liked to be more involved**

**□ I would have liked to be less involved**

**□ Don’t know**

**50. Were any decisions made about her/his care that s/he would not have wanted?**

***Tick only one***

**□ Yes**

**□ No**

**□ Don’t know**

**51. Overall, and taking all services into account, how would you rate her/his care in the last three months of life?**

***Tick only one***

**□ Outstanding**

**□ Excellent**

**□ Good**

**□ Fair**

**□ Poor**

**□ Don’t know**

**52. Since s/he died, have you talked to a health or social care professional or someone from a bereavement service, about your feelings about her/his illness and death?**

***Tick only one***

**□ Yes**

**□ No, but I would have liked to**

**□ No, but I did not want to anyway**

**□ Not sure**

**If you feel that you would like to talk about your feelings or discuss painful memories brought back by completing this questionnaire please contact:**

**Cruse Bereavement Care Oxfordshire**

**01865 245398**

**admin@oxfordcruse.co.uk**

**Information about you both**

**53. What was your relationship to her/him? Were you her/his:**

***Tick only one***

**□ Spouse/Partner**

**□ Son/Daughter**

**□ Brother/Sister**

**□ Son-in-law/Daughter-in-law**

**□ Parent**

**□ Other relative**

**□ Friend**

**□ Neighbour**

**□ Staff in care home**

**□ Warden (sheltered accommodation)**

**□ Someone else (please write below)**

**54. What is your age?**

**□ Prefer not to say**

**□ 18 – 19**

**□ 20 - 29**

**□ 30 - 39**

**□ 40 - 49**

**□ 50 - 59**

**□ 60 - 69**

**□ 70 - 79**

**□ 80 - 89**

**□ 90 +**

**55. Are you:**

**□ Male**

**□ Female**

**□ Prefer not to say**

**56. Please could you indicate which ethnic group you belong to:**

***Tick only one***

**□ Prefer not to say**

**□ White - British**

**□ White - Irish**

**□ White – Gypsy or Irish Traveller**

**□ White – Any other white background**

**□ Mixed – White and Black Caribbean**

**□ Mixed – White and Black African**

**□ Mixed – White and Asian**

**□ Mixed – Any other mixed background**

**□ Asian/Asian British - Indian**

**□ Asian/Asian British - Pakistani**

**□ Asian/Asian British - Bangladeshi**

**□ Asian/Asian British – Chinese**

**□ Asian/Asian British – Any other Asian background**

**□ Black/Black British - African**

**□ Asian/Asian British - Caribbean**

**□ Asian/Asian British – Any other Black background**

**□ Arab**

**□ Any other ethnic group**

**57. Please could you indicate which ethnic group the person who died belonged to:**

***Tick only one***

**□ Prefer not to say**

**□ White - British**

**□ White - Irish**

**□ White – Gypsy or Irish Traveller**

**□ White – Any other white background**

**□ Mixed – White and Black Caribbean**

**□ Mixed – White and Black African**

**□ Mixed – White and Asian**

**□ Mixed – Any other mixed background**

**□ Asian/Asian British - Indian**

**□ Asian/Asian British - Pakistani**

**□ Asian/Asian British - Bangladeshi**

**□ Asian/Asian British – Chinese**

**□ Asian/Asian British – Any other Asian background**

**□ Black/Black British - African**

**□ Asian/Asian British - Caribbean**

**□ Asian/Asian British – Any other Black background**

**□ Arab**

**□ Any other ethnic group**

**58. Was s/he:**

**□ Male**

**□ Female**

**□ Prefer not to say**

**59. What was her/his age when s/he died?**

**□ Prefer not to say**

**□ 18 – 19**

**□ 20 - 29**

**□ 30 - 39**

**□ 40 - 49**

**□ 50 - 59**

**□ 60 - 69**

**□ 70 - 79**

**□ 80 - 89**

**□ 90 +**

**60. What was her/his religion?**

**□ Prefer not to say**

**□ No religion**

**□ Christian (all denominations)**

**□ Buddhist**

**□ Hindu**

**□ Jewish**

**□ Sikh**

**□ Muslim**

**□ Any other religion (please write below)**

**Thank you for taking the time to complete this questionnaire. Please return it using the pre-paid envelope provided**

Please use the space below if there is anything else you would like to say about the care provided.

This questionnaire is anonymous: if you wish to discuss anything further, please contact the relevant organisation (e.g. GP practice, hospice) directly.