End of Life Care Public Survey

Macmillan Cancer Support is working with the NHS Sheffield Clinical Commissioning Group and Sheffield Hallam University to deliver a project assessing end of life care (EOLC) in Sheffield. The information you share will help us to provide a fairer service for everyone and commission services that meet the needs of the patients better. We are seeking to understand how EOLC is delivered from a number of providers across Sheffield, including the challenges to providing care as well examples of good practice.

Exactly when EOLC begins will vary for each individual, but typically people become frailer, less mobile, and their symptoms and treatment needs may increase. Whilst each patient and family are individuals and it is therefore difficult to put timescales on this, for the purpose of this survey, end of life care is considered to begin 6-12 months before death and ending for partners/relatives/carers 6-12 months after death during the bereavement period.

We appreciate that it can be a hard subject to talk about, which is why any insight you can give is extremely valuable to us and important in helping improve services for others in the future. **The survey should take around 15 minutes to complete**.

All responses are anonymous and the responses you provide will not be attributed to you. All responses collected will be confidential and used only in general form to provide an overview of care. No personal data will be collected or shared with other parties. Individual responses will be destroyed once the project is concluded and only the summary data retained. By completing the survey you are giving your consent for Sheffield CCG to utilise your responses for the aforementioned purposes.

For any questions about this or the project itself please contact Alex Green (alex.green4@nhs.net).**The survey can be returned to us using Freepost (no stamp required) via:**

FREEPOST NHS SHEFFIELD CCG

1. Are you a patient receiving end of life care or a carer/relative/partner/friend of a patient who has received end of life care?

☐ Patient – *Please go to Page 2*

☐ Carer/Relative/Partner/Friend – *Please go to Page 7*

Patient Experience – Your Condition	
2. Which condition are you receiving end of life care for?	
☐ Cancer	☐ Dementia
☐ HIV/AIDS	☐ Congestive Heart Failure (CHF)
☐ Chronic Obstructive Pulmonary Disease (COPD)	
☐ Other – Please Specify	
3. Do you live with any other long term condition other than the one described in question 2?	
☐ Yes – *Please go to page 3*	☐ No – *Please go to page 4*

Patient Experience – Your Other Long Term Conditions	
This section is to understand how many people receiving end of life care also live with another long term condition and whether this affects the care they receive.	
4. Which of the following long term conditions, outside of the one you are receiving end of life care for, do you have? (Tick all that apply)	
☐ Angina	☐ Asthma
☐ Cancer	☐ Chronic fatigue syndrome/ME
☐ Chronic Obstructive Pulmonary Disease (COPD)	☐ Congestive Heart Failure (CHF)
☐ Chronic Pain	☐ Dementia
☐ Depression	☐ Diabetes
☐ Epilepsy	☐ Hepatitis A/B/C
☐ Haemophilia	☐ HIV/AIDS
☐ Hypertension	☐ Irritable bowel disease (IBS)
☐ Multiple sclerosis	☐ Motor Neuron Disease
☐ Osteoarthritis	☐ Parkinson's disease
☐ Sickle cell disease	☐ Stroke/transient ischaemic attacks
☐ Tuberculosis	☐ Urinary Incontinence
☐ Other – Please Specify	
5. Do you feel your other long term condition(s) cause difficulties in your end of life care?	
☐ No	
☐ Yes – Please tell us more	

Patient Experience – Your Care

In this section we will ask you about the end of life care (EOLC) you are receiving and about your wishes. We understand that this can be upsetting to think about, but any information you can share with us will be valuable in helping to improve services.

6. Please tell us which services you've experienced during your care and how you would assess your experience on a scale of 1 – 5 (tick all that apply):

	Negative Experience 1	2	3	4	Positive Experience 5	No Experience
GP Surgery	O	O	O	O	O	O
Hospital	O	O	O	O	O	O
Care/Residential Home	O	O	O	O	O	O
Nursing Home	O	O	O	O	O	O
NHS 111 (Non-Emergency Call Centre)	O	O	O	O	O	O
Out of Hours Doctor	O	O	O	O	O	O
Community Nursing	O	O	O	O	O	O
Any Other Service	O	O	O	O	O	O

Any additional information you'd like to share about these services:

7. Where is the majority of your end of life care received?

☐ At home	☐ Hospice
☐ GP Surgery	☐ Care home (Residential)
☐ Hospital	☐ Care home (Nursing)
☐ Other – Please specify	

8. How frequently do you receive end of life care?	
☐ Daily (including multiple visits)	☐ Monthly
☐ Weekly	☐ As I require it
☐ Fortnightly	
☐ Other – Please specify	

9. Please select your level of agreement with the following statements in relation to your end of life care (EOLC):

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
How often I receive care is appropriate for my needs	O	O	O	O	O
I am given enough information about when and where I'll receive EOLC	O	O	O	O	O
I am given enough information about what my EOLC will involve	O	O	O	O	O
I feel I am treated with dignity, compassion and respect	O	O	O	O	O
I feel I can ask questions or seek advice about my EOLC	O	O	O	O	O
My wishes regarding my EOLC are known and respected	O	O	O	O	O
I am receiving EOLC where I wish to receive it	O	O	O	O	O
It was easy to access EOLC that is appropriate for me	O	O	O	O	O
There is enough support for loved ones, relatives, friends or carers when someone is receiving EOLC	O	O	O	O	O
Staff have the confidence and compassion to be able to talk to patients and those who care for them about death and what happens at the end of someone's life	O	O	O	O	O

Any additional comments:	
10. Have you communicated a preferred place to die?	
☐ Yes	☐ No
11. Overall are you happy with the end of life care provided to you?	
☐ Yes	☐ No
12. Please tell us what is good about the end of life care you are receiving:	
13. What could be improved or done differently?	

Please now go to page 12

The Patient's Condition	
In this section we will ask you about the condition of the person who has received end of life care. We understand that this can be upsetting to think about, but any information you share with us will be valuable in helping to improve services. We know in some cases the patient may have already died and have tried to respect this with the use of multiple tenses in questions.	
14. What is (was) your relationship to the patient?	
☐ Partner	☐ Friend
☐ Relative	☐ Prefer not to say
☐ Carer	
☐ Other – Please Specify	
15. Which condition does (did) the patient receive end of life care for?	
☐ Cancer	☐ Dementia
☐ HIV/AIDS	☐ Congestive Heart Failure (CHF)
☐ Chronic Obstructive Pulmonary Disease (COPD)	
☐ Other – Please Specify	
16. Does (did) the patient live with any other long term condition other than the one described in question 15?	
☐ Yes – *Please go to page 8*	☐ No – *Please go to page 9*

The Patient's Other Long Term Conditions	
This section is to understand how many people receiving end of life care also live(d) with another long term condition and whether this affects the care they receive.	
17. Which of the following long term conditions, outside of the one identified in the previous section does the patient have/has (Tick all that apply)	
☐ Angina	☐ Asthma
☐ Cancer	☐ Chronic fatigue syndrome/ME
☐ Chronic Obstructive Pulmonary Disease (COPD)	☐ Congestive Heart Failure (CHF)
☐ Chronic Pain	☐ Dementia
☐ Depression	☐ Diabetes
☐ Epilepsy	☐ Hepatitis A/B/C
☐ Haemophilia	☐ HIV/AIDS
☐ Hypertension	☐ Irritable bowel disease (IBS)
☐ Multiple sclerosis	☐ Motor Neuron Disease
☐ Osteoarthritis	☐ Parkinson's disease
☐ Sickle cell disease	☐ Stroke/transient ischaemic attacks
☐ Tuberculosis	☐ Urinary Incontinence
☐ Other – Please Specify	
18. Do you feel their other long term condition(s) cause(d) any issues in relation to the patient's end of life care?	
☐ No	
☐ Yes – Please tell us more	

The Patient's Care

This section is to understand about the patient's and your experience of end of life care.

19. Is the patient currently receiving end of life care?

☐ Yes	☐ No

20. Do (did) you live with the patient?

☐ Yes	☐ No
☐ Some of the time	

21. Please tell us which services you or the patient have experienced during their care and how you would assess your experience on a scale of 1 – 5 (tick all that apply):

	Negative Experience 1	2	3	4	Positive Experience 5	No Experience
GP Surgery	O	O	O	O	O	O
Hospital	O	O	O	O	O	O
Care/Residential Home	O	O	O	O	O	O
Nursing Home	O	O	O	O	O	O
NHS 111 (Non-Emergency Call Centre)	O	O	O	O	O	O
Out of Hours Doctor	O	O	O	O	O	O
Community Nursing	O	O	O	O	O	O
Any Other Service	O	O	O	O	O	O

Any additional information you'd like to share about these services:

22. Where is (was) the majority of the patient's end of life care received?

☐ At home	☐ Hospice
☐ GP Surgery	☐ Care home (Residential)
☐ Hospital	☐ Care home (Nursing)
☐ Other – Please specify	

23. How frequently does (did) the patient receive end of life care?	
☐ Daily (including multiple visits)	☐ Monthly
☐ Weekly	☐ As I require it
☐ Fortnightly	
☐ Other – Please specify	

24. Please select your level of agreement with the following statements in relation to the patient's end of life care (EOLC):

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
How often the patient receive(d) care is (was) appropriate for their needs	O	O	O	O	O
I (and/or the patient) are (were) given enough information about when and where they'll receive EOLC	O	O	O	O	O
I (and/or the patient) are (were) given enough information about what their EOLC will involve	O	O	O	O	O
I feel I (and the patient) are (were) treated with dignity, compassion and respect	O	O	O	O	O
I feel I (and/or the patient) can (could) ask questions or seek advice the patient's EOLC	O	O	O	O	O
The patient's wishes regarding their EOLC are (were) known and respected	O	O	O	O	O
The patient is (was) receiving EOLC where they wish to receive it	O	O	O	O	O
It was easy for the patient to access EOLC that is (was) appropriate for their needs	O	O	O	O	O
There is enough support for loved ones, relatives, friends or carers when someone is receiving EOLC	O	O	O	O	O

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Staff have the confidence and compassion to be able to talk to patients and those who care for them about death and what happens at the end of someone's life	O	O	O	O	O

25. Has (did) the patient say where their preferred place to die is?

☐ Yes	☐ No

26. Did the patient die in their preferred place?

☐ Yes	☐ No
☐ Not applicable	

27. Overall are you happy with the end of life care provided to the patient?

☐ Yes	☐ No

28. Please tell us what is good about the end of life care you are receiving:

29. What could be improved or done differently?

Please continue to page 12

Demographic Information	
The following questions are to try and help us identify any inequalities in care received at the end of life. You do not have to answer these questions but the information gathered will help to ensure that access to end of life care services is equal for everyone in Sheffield. No information gathered will be personally attributed to a respondent.	
30. What is your postcode?	
31. Which gender do you identify with?	
☐ Female	☐ Male
☐ Prefer not to say	
☐ Other – Please specify	
32. Is your gender identity different to the sex you were assumed to be at birth?	
☐ Yes	☐ No
☐ Prefer not to say	
33. What is your age	
☐ Under 18	☐ 55-64
☐ 18-24	☐ 55-69
☐ 25-34	☐ 70+
☐ 35-44	☐ Prefer not to say
☐ 45-54	
34. What is your ethnic group?	
☐ Asian British	☐ Mixed/Multiple Ethnic Groups
☐ Asian Other	☐ White
☐ Black British	☐ White Other
☐ Black Other	☐ Prefer not to say
☐ Other – Please specify	
35. What is your religion?	
☐ Buddhism	☐ Sikhism
☐ Christianity	☐ Agnostic
☐ Hinduism	☐ No religion
☐ Islam	☐ Prefer not to say
☐ Judaism	
☐ Other – Please specify	

36. What of the following options best describes your sexual orientation?	
☐ Heterosexual / straight	☐ Gay
☐ Lesbian	☐ Bisexual
☐ Prefer not to say	
☐ Other – Please specify	

37. What is your legal marital or civil partnership status?	
☐ Single	☐ Divorced
☐ Married	☐ Formerly in a registered civil partnership which is now dissolved
☐ In a registered civil partnership	☐ Widowed
☐ Separated, but still legally married	☐ Surviving partner from a registered civil partnership
☐ Separated, but still in a registered civil partnership	☐ Prefer not to say
☐ Other – Please specify	

38. Do you consider yourself to be disabled? *(The equality act 2019 states that a person has a disability if: 'a person has a physical or mental impairment, and the impairment, and the impairment has a substantial and long-term adverse effect on their ability to carry out normal day to day activities')*	
☐ Learning disability/difficulty	☐ Hearing
☐ Physical or mobility	☐ Visual
☐ Long-standing illness or health condition	☐ Prefer not to say
☐ Mental health condition	
☐ Other – Please specify	

39. Do you look after, or give any help or support to family members, friends, neighbours or others because of either long-term physical or mental ill-health / disability, or problems related to old age?	
☐ No	☐ Yes, 50 or more hours a week
☐ Yes, 1-19 hours a week	☐ Prefer not to say
☐ Yes, 20-49 hours a week	
☐ Other – Please specify	

Thank you for taking the time to complete this survey, the information provided will be used to help shape end of life care services in the future. If you'd like to discuss anything about this project in more detail please contact Alex Green (alex.green4@nhs.net). We'd also be keen to hear about people's experiences in more depth on a 1 to 1 basis.

Please return by post, no stamp required, to:

FREEPOST NHS SHEFFIELD CCG