# Indictors of Quality at End of Life; A Regional Project Spanning Hospice, Hospital and Community Specialist Palliative Care Services in Lanarkshire

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**Abbreviated abstract:** Dying at home is seen as a proxy indicator of good end of life care but it is important to establish that this outcome matches the patient and family preferred place of death (PPD) and is not achieved at the cost of good holistic care. Quality indicators were formulated. Patients' actual place of death and PPD were recorded. Symptom control and supportive communication were rated. Data collection is ongoing in order to assess possible barriers to advance care planning and the achievement of PPD.

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# Previous work, challenge, and approach

- Commissioners of Specialist Palliative Care services wish to have a measure of the success of strategy implementation and service development.

- The blunt measure of increased numbers of deaths at home does not show individual attainment of preferred place of death (PPD) and only measures one aspect of 'a good death'.

- Other indicators of a good death include physical comfort, communication and psychosocial care.

- The collaborative development of Quality Indicators, to inform local and regional understanding of end-of-life care provision, in both specialist and non-specialist palliative care settings is therefore a good starting point to strengthen the quality and safety agenda.

- Data that supports system-level improvements in end-of-life care provision is central to providing better clinical care and informing research, policy reform and service commissioning.

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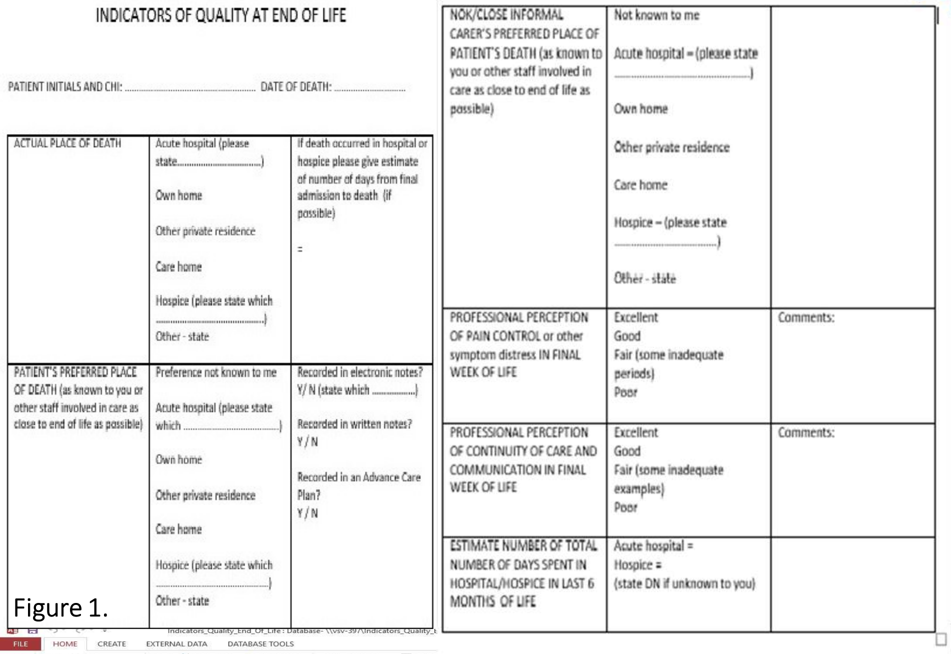
# Techniques and Methods

- Quality indicators were drawn up to posthumously record the actual place of death, the rate of recording of PPD and also to rate symptom control and supportive communication in the last week of life as experienced by the patient and family.

- Initially, a paper version of Quality Indicators was created (Fig.1), however, an electronic database is now accessible by all Specialist Palliative Care (SPC) clinicians (Fig.2). Systems are in place to enable the direct input of data after all deaths under SPC care, with subsequent biannual reports being produced.

- Version 2 of the Quality Indicators report has been simplified, but with extended options to assess barriers to advance care planning and the achievement of PPD.



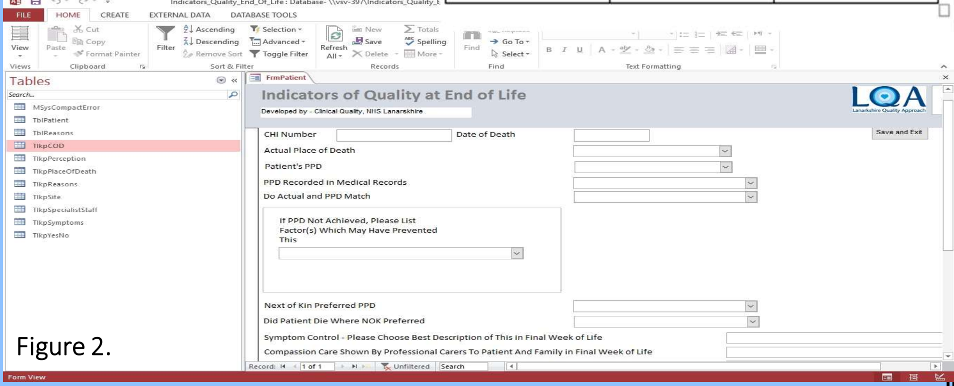
INDICATORS OF QUALITY AT END OF LIFE

PATIENT INITIALS AND CHI: .............................................. DATE OF DEATH: ..............................

| | | |
|---|---|---|
| ACTUAL PLACE OF DEATH | Acute hospital (please state...................................)<br>Own home<br>Other private residence<br>Care home<br>Hospice (please state which ..........................................)<br>Other - state | If death occurred in hospital or hospice please give estimate of number of days from final admission to death (if possible)<br>= |
| PATIENT'S PREFERRED PLACE OF DEATH (as known to you or other staff involved in care as close to end of life as possible) | Preference not known to me<br>Acute hospital (please state which ..........................................)<br>Own home<br>Other private residence<br>Care home<br>Hospice (please state which ..........................................)<br>Other - state | Recorded in electronic notes? Y/ N (state which ..................)<br>Recorded in written notes? Y / N<br>Recorded in an Advance Care Plan? Y / N |

| | | |
|---|---|---|
| NOK/CLOSE INFORMAL CARER'S PREFERRED PLACE OF PATIENT'S DEATH (as known to you or other staff involved in care as close to end of life as possible) | Not known to me<br>Acute hospital – (please state ..........................................)<br>Own home<br>Other private residence<br>Care home<br>Hospice – (please state ....................................)<br>Other - state | |
| PROFESSIONAL PERCEPTION OF PAIN CONTROL or other symptom distress IN FINAL WEEK OF LIFE | Excellent<br>Good<br>Fair (some inadequate periods)<br>Poor | Comments: |
| PROFESSIONAL PERCEPTION OF CONTINUITY OF CARE AND COMMUNICATION IN FINAL WEEK OF LIFE | Excellent<br>Good<br>Fair (some inadequate examples)<br>Poor | Comments: |
| ESTIMATE NUMBER OF TOTAL NUMBER OF DAYS SPENT IN HOSPITAL/HOSPICE IN LAST 6 MONTHS OF LIFE | Acute hospital =<br>Hospice =<br>(state DN if unknown to you) | |

Figure 1.



Indicators of Quality at End of Life

Developed by - Clinical Quality, NHS Lanarskhire

CHI Number
Date of Death
Actual Place of Death
Patient's PPD
PPD Recorded in Medical Records
Do Actual and PPD Match
If PPD Not Achieved, Please List Factor(s) Which May Have Prevented This
Next of Kin Preferred PPD
Did Patient Die Where NOK Preferred
Symptom Control - Please Choose Best Description of This in Final Week of Life
Compassion Care Shown By Professional Carers To Patient And Family in Final Week of Life

Figure 2.

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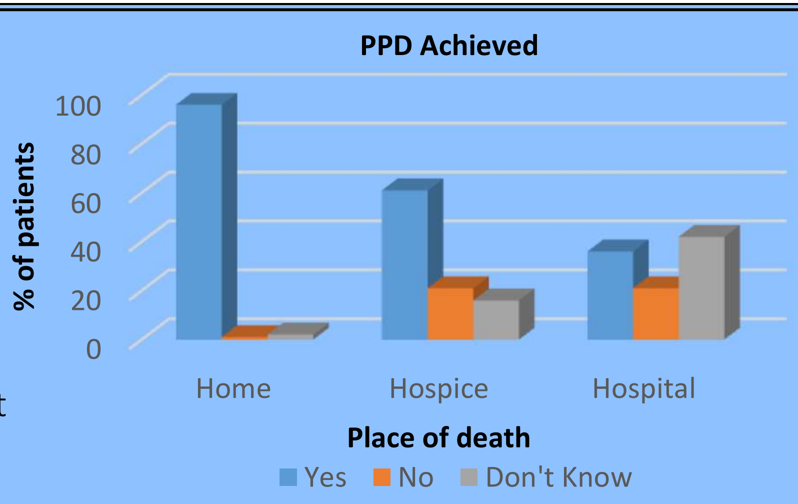
# Results and Conclusions

## Results

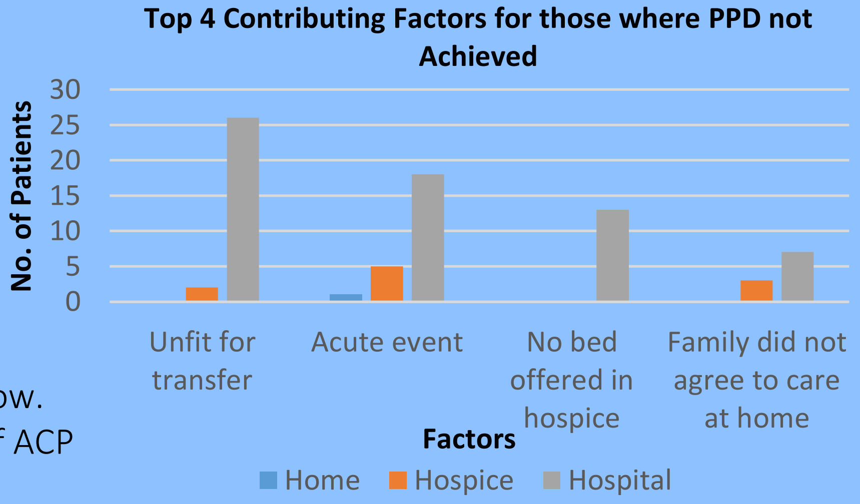
- Initially, 359 patients' records were reviewed over 9 months.
- Patients at home with SPC input showed the highest matching of PPD with actual place of death and the highest subjective rating of comfort and psychological care. Patients with more difficult symptoms may have been admitted to hospice or hospital for that reason.
- The hospital deaths had the highest number of patients where the PPD was not known. Most of the unwanted deaths in hospital were attributed to 'not fit for transfer' or 'acute event' which, along with the lack of knowledge of PPD prior to the death, suggests that advance care planning and discussion around choices at end-of-life is often left too late.
- Of interest, PPD was unknown (usually due to delirium) or not achieved (usually due to a sudden decline or family reasons) in a significant proportion of hospice patients, showing that discharge home to die is not always possible even with a full palliative care team involved.

## Conclusion

- The electronic recording system allows data to be entered directly and reported regularly. Extended use outwith patients under SPC care could follow.
- It is hoped that this project will identify areas with room for improvement of ACP discussions, discharge planning and symptom control, ultimately leading to more patients receiving high standards of care in their preferred place of death.



PPD Achieved



Top 4 Contributing Factors for those where PPD not Achieved

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