

# QUALYCARE-NI Study

## “What enables cancer patients to die at home?”

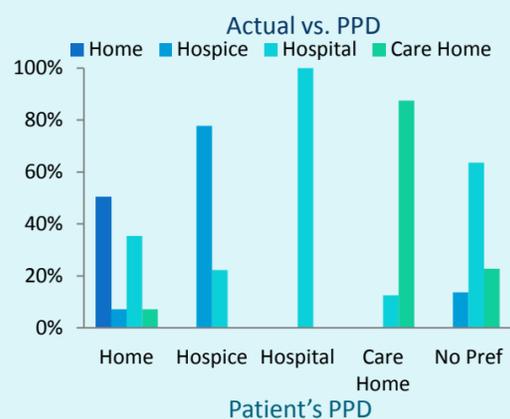
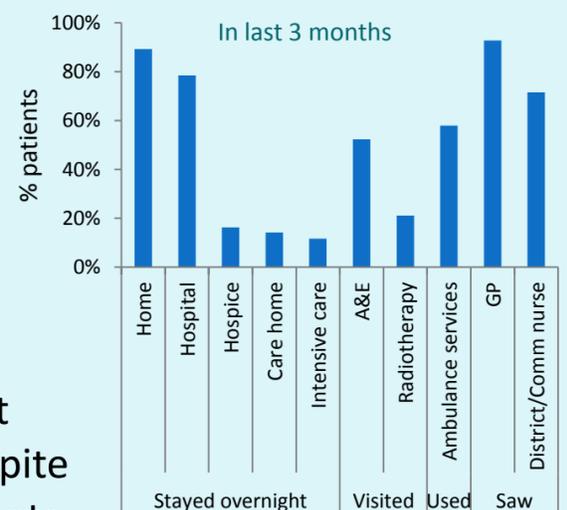
### A study of carers and bereaved relatives

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**Background:** A review[1] of Northern Ireland (NI) cancer patients dying within acute hospitals, identified factors associated with hospital death. However, further work was required to understand factors associated with achieving patient’s preferred place of death (PPD). We surveyed relatives of deceased cancer patients to assess views on care received three months before death, comparing preferences with actual experience.

**Method:** People registering a cancer death in the 4-9 months previously were sent a questionnaire, devised by Cicely Saunders Institute, King’s College London (KCL) for the QUALYCARE London study[2]. Questionnaire data were analysed to identify factors associated with home and institutional deaths.

**Results:** 1495 questionnaires posted out, 465 returned. 52% questionnaires completed by sons/daughters, 25% by spouses. 38% respondents took time off work in 3 months before relative died, 42% after, 32% were retired.



**Last week of life:** 43% spent most of last week at home, 36% in hospital. 71% affected by pain despite medication. 12% had time wasted on appointments. 33% family/patient hadn’t enough information given.

**Place of death:** 41% patients died in hospital, 38% at home. A third who died in hospital were there <1 week (9% <1 day). 53% patients achieved their PPD. 79% patients’ PPD was home. 18% respondent’s preference changed after their

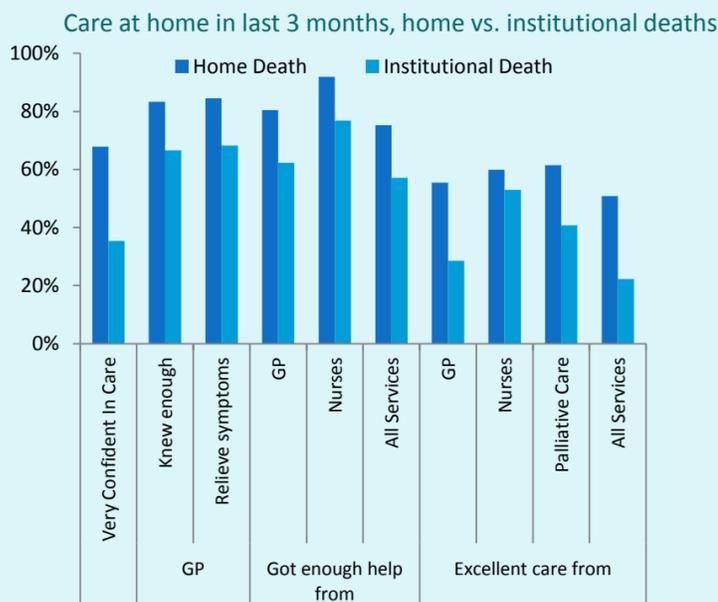
relative died. ¾ respondents were there when the patient died. ¼ dying in hospital had no family/friends with them when they died.

#### Home vs. institutional deaths:

Respondents whose relative died at home reported higher levels of confidence in patient care at home in 3 months before death compared to relatives of those dying in an institutional setting.

**Conclusions:** Preliminary results show high levels of service usage and hospital stay in last three months, 36% unhappy with aspects of care and only half achieving PPD. Respondents reported that for patients dying at home there were higher levels of support from GP and other services whilst the patient was at home, compared with the support provided at home to those who then died in an institutional setting.

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**Support:** 18% patients and 15% family didn’t have a discussion with a health professional that the patient was likely to die because of their illness. 22% didn’t have a health professional to rely on in last 3 months.

**Future work:** Questionnaire data will be linked to N.Ireland Cancer Registry (NICR) database and investigated in terms of

disease factors such as stage of disease, duration of disease and cancer type. The results of the QUALYCARE-NI study will be compared to those of QUALYCARE London.

**References:** 1. Blaney J, et al. Hospital Cancer Deaths—Late diagnosis and missed opportunity. *BMJ Supportive and Palliative Care* August 2011, doi:10.1136/bmjspcare-2011-000036  
2. Gomes B et al. Variations in the quality and costs of end-of-life-care, preferences and palliative outcomes for cancer patients by place of death: the QUALYCARE study. *BMC Cancer* 2010, 10:400.

