Background ‘CODE’ is a 40-item self-completion post-bereavement questionnaire, focused on the last days of life and based on key components of best practice for care of the dying. CODE is a shortened, more user-friendly version of an original validated instrument, ‘Evaluating Care and Health Outcomes for the Dying’ (ECHO-D).

Aim To assess the validity and reliability of CODE by conducting: cognitive ‘think aloud’ interviews; test-retest analysis; and assessing internal consistency and construct validity of three key composite sub-scales—‘CARE’; ‘ENVIRONMENT’; and ‘COMMUNICATION’.

Methods A post-bereavement survey was conducted with 291 next-of-kin (NOK) to patients who died at home in Northwest England from advanced incurable illness. All NOK were invited to complete the CODE questionnaire and also asked if willing to undertake a cognitive interview and/or complete CODE for a second time a month later.

Test-retest reliability was assessed using: percentage agreement; Kappa statistic and Spearman’s correlation coefficient. For each sub-scale, Cronbach’s alpha and item-total correlations were used to assess internal consistency. Confirmatory factor analysis was used to assess construct validity.

Results 72 bereaved relatives (24.7% response rate) returned the completed CODE questionnaire, and 25 completed CODE for a second time. 15 cognitive interviews were undertaken. All interviewees found CODE sensitively worded and easy to understand. Minor revisions were suggested to provide additional clarity.

Test-retest analysis showed all except two questions had moderate or good stability. Although the ENVIRONMENT scale was not perceived as relevant within the home setting, all three sub-scales scales showed good construct validity and internal consistency (Cronbach’s alpha > 0.79).

Conclusions ‘CODE’ represents a user-friendly, comprehensive outcome measure for care of the dying. This preliminary data, despite small numbers, builds on previous work with ECHO-D and provides support for CODE’s validity and reliability. CODE could potentially be used to benchmark individual organisations and identify areas for improvement.