Background: An aim of the National End of Life Care Strategy (2008) was to improve dignity and respect in end of life care (EoLC). The VOICES survey was commissioned in 2011 as the first national post-bereavement postal survey, a key component of which was to assess dignity and respect at the end of life. The aim of this study was to explore changes in dignity and respect perceived by bereaved relatives over the five-year period that the VOICES survey was commissioned.

Methods: Aggregate data from VOICES post-bereavement surveys (2011–2015) was obtained from the Office of National Statistics. Information about dignity and respect was extracted and dichotomised into satisfied (‘always’ and ‘most of the time’) and unsatisfied (‘some of the time’ and ‘never’). A chi-squared test for trend was used to analyse changes over time in dignity and respect, for each of seven categories of health care professionals.

Results: There were 1,072,067 responses to the VOICES surveys over 5 years (average response rate 44.4%). Improvements in perceived dignity and respect from 2011 to 2015 were found with respect to five categories of health care professional: GPs (0.7% improvement in satisfaction to 60.9%, p=0.016); hospital doctors (1.7% improvement to 85.0%, p=0.0036); hospital nurses (5.2% improvement to 80.6%, p<0.0001); hospice doctors (0.8% improvement to 95.3%, p=0.0003); hospice nurses (1.9% improvement to 95.2%, p=0.0001). District/community nurses showed a 1.4% decrease in satisfaction to 92.6% (p<0.0001). Care home staff showed no change (p=0.2).

Conclusions: The data has demonstrated a general trend of improvement with regard to dignity and respect experienced from healthcare professionals. District/community nurses showed a decrease in dignity and respect however, this could be attributed to a regression to the mean or due to their high baseline, therefore this would not be cause for concern. The low satisfaction demonstrated with GPs should be investigated.

Method: A systematic literature review of published research from 2000 to 2018 using Medline and PubMed databases, in line with PRISMA guidelines. A thematic matrix analyses approach was adopted. Studies were quality assessed using the QualSyst tool.

Results: Of the 115 studies identified, 19 studies reported on qualitative findings of the GSF implementation in the community setting. All 19 studies collected data from staff members and 4 studies also included patients and/or relatives. The GSF was felt to facilitate improved written and verbal communication in both nursing care homes and primary care teams, and to enhance methods of teamworking. 16 of 19 studies reported increased uptake of a palliative care register to identify end-of-life patients. Barriers to use of the GSF included a lack of sustainability due to high staff turnover, as well as an increased workload and difficulties in discussing end-of-life care with relatives.

Conclusions: These findings support the use of the GSF in improving the quality of end-of-life care through collaborative working and increased communication across healthcare teams. Further studies are required to understand attitudes of patients and relatives. Challenges for policy makers include ensuring end-of-life care tools are both sustainable and flexible according to local population and workforce needs.