

# Hospice UK Activity Survey

## 2026 questions

The following are the questions that have been included in this years Activity and Demographic survey and accompanying data points that will require values.

**THIS IS GUIDANCE, NOT THE ACTUAL SURVEY** – please visit the Member Data Portal to submit your data

<https://data.hospiceuk.org/>

### 1. Activity

Hospice Type: Adults/Children/Both

Country: (England, Scotland, Wales or Northern Ireland)

#### **Which Services do you provide**

Select all in the list that apply

Total number of regulator registered and/or licensed beds as of 31 March 2026

Total number of regulator registered and/or licensed beds as of 31 March 2025

*Bed Day / Night Potential Capacity based on Registered Beds alone is a **calculated** field based on the total number of registered inpatient beds*

Bed Day / Night Actual Capacity – This may be different from the calculated value if you have less than the registered beds open.

Total Occupied Bed Days / Nights is used to generate an occupancy value and must be less than the Bed Day / Night Actual Capacity

Are all of your inpatient beds specialist palliative care: Yes/No.

Selecting **No** will make further bed type options visible, Step up step down / enhanced, CHCFT, Winter pressure, Long-term conditions including frailty, Rehabilitative palliative care / respite care, After death care and, Other. Please provide Length of stay for all that apply.

Length of Stay (days): Mean | Median | Max | Min

Time from Admission to Death (days) for inpatients only: Mean | Median | Max | Min.

You will only be required to provide data for the following if you indicated them as services you provide.

*Total Contacts - Outpatients / Day Care*

*Total Visits - Specialist Community (consultant, CNS, ACP)*

*Nursing / Care Home Visits Only - Specialist Community*

*Total Visits - Non-specialist Community (nurse, AHP, HCA, carer, volunteer)*

*Total Visits - Domiciliary Care or, in Scotland, Home Care (specifically commissioned service)*

*Total Visits - Hospital Inpatient (consultant, CNS, ACP)*

### **Referrals and Discharges**

#### **Number of patients by source of referral (on first entry into any hospice service this year):**

Hospital; District Nursing; GP; Care Home; Family; Transitioned between children/adult services; Not differentiated in patient records; Another Hospice; Other; Not recorded

#### **Number of patients by where they are discharged to (from all hospice services this year):**

Died; Hospital; Care Home; Home (own or family member's); Transitioned between children/adult services; Another hospice; Not differentiated in patient records; Other; Not recorded

## **2. Carers and Loved Ones**

*Defined as no. of counselling sessions / support appts / therapies for people other than the palliative patient themselves; including continued bereavement and support*

Total Contacts – Care for Carers / Loved Ones

*Defined as unique carers or loved ones (of palliative patients past and present) who accessed at least one hospice service, including bereavement, in the contract year (must entail at least one material, meaningful contact with a clinician or care worker, i.e. not just administrative call)*

Total Unique Carers / Loved Ones (All Services)

*If you can separate out unique carers / loved ones who accessed your bereavement services from those who accessed any of your other services in the previous question, please put that sub-total here (this is a sub-section of the total in the previous question and should already be included in the previous question)*

Total Unique Carers / Loved Ones (Bereavement Only)

## 3. Demographics

Defined as unique palliative patients who accessed at least one hospice service in the financial year: including those already actively accessing at least one hospice service at midnight on 1st April at the start of the contract year plus those who began accessing at least one hospice service during the contract year up to midnight on 31st March, either as a brand new patient or re-referred (must entail at least one material, meaningful contact with a clinician or care worker, i.e. not just administrative call). Complete all relevant demographic fields.

**Totals are automatically validated against Total Unique Patients.** *This is important to bear in mind as validation throughout this section will be triggered if you exceed the total unique patients values.*

**Total Unique Patients:** value

### Patient Age Range Distribution

**Numbers of patients - Age Range:** Neonatal; 26–44; 45–64; 65–74; 75–84; 85+; Not recorded

### Patient Ethnicity

**Numbers of patients – Ethnicity:** Asian / Asian British; Black / Caribbean / African; Mixed / Multiple ethnic groups; White; Other ethnic group; Prefer not to say (person asked but declined); Not recorded (person not asked)

### Religion

**Numbers of patients – Religion:** Buddhist; Christian; Hindu; Jewish; Muslim; Sikh; Other religion; No religion; Prefer not to say (person asked but declined); Not recorded (person not asked)

### Patient Sexual Orientation

**Numbers of patients - Sexual Orientation:** Bisexual; Gay or Lesbian; Straight / Heterosexual; Other sexual orientations; Prefer not to say (person asked but declined); Not recorded (person not asked)

### Sex and Gender

**How does your clinical system record sex and gender identity?** - Select appropriate option

**Number of patients - Sex:** Female | Male | not recorded

**Numbers of patients - Gender Identity:** Gender identity the same as sex registered at birth; Gender identity different from sex registered at birth; Prefer not to say (person asked but declined); Not Recorded (person not asked)

**Numbers of patients - Gender Identity different from sex registered at birth:** Stated non-binary; Stated trans man / male; Stated trans woman / female; Stated other gender identity; Not stated

## Primary Diagnosis

**Numbers of patients - Primary Diagnosis / Life Limiting Condition:** Cancer; Non-Cancer; Not recorded

**Numbers of ADULT patients - Cancer Primary Diagnosis (ICD10 / SNOWMED codes),** this is a list of options for Cancer diagnosis, provide data for any that apply.

**Numbers of ADULT patients - Non-cancer (not oncology) Primary Diagnosis (ICD10 / SNOWMED codes),** this is a list of options for Non-Cancer diagnosis, provide data for any that apply.

## Living Alone

**Numbers of patients - Living Alone:** Yes; No; Not recorded; Prefer not to say (person asked but declined); Not recorded (person not asked)

# 4. Other Information

Clinical Records System: Pick from list

Patient-centered outcome measures collected: Yes; No; Don't know

If Yes, Which Measures do you collect: Phase of illness, AKPS, IPOS, CPOS; Barthel; Other - becomes visible. Select all from the list that apply.

Where recorded, what percentage of patients are in which phase of illness when entering hospice care for the first time? (%)

Stable | Unstable | Deteriorating | Dying