

# The current state of caring for family carers in UK hospices

Findings from the Hospice UK  
organisational survey of carer  
assessment and support

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# About Hospice UK

Hospice UK is the national charity for hospice and palliative care. We work to ensure all adults and children living with a terminal or life-shortening illness receive the care and support they need, when they need it.

Our mission is to transform the way society cares for the dying and those around them. We empower individuals and communities to embrace hospice care, and extend its breadth and reach to improve everyone's experience of death, dying and bereavement.

[www.hospiceuk.org](http://www.hospiceuk.org)

# About NIHR CLAHRC GM

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# Introduction

This report summarises the state of carer assessment and support provision across the hospice sector in the UK from the Hospice UK Organisational Survey of Carer Assessment and Support (HUK-OSCAS) 2018. The survey represents stage two of a Hospice UK consultation and survey project. Results are presented in the context of the **10 Recommendations for implementing comprehensive, person-centred assessment and support for family carers providing end of life care**, generated from stage one of the project. The 10 Recommendations are reproduced on page 4.

Compared to other healthcare service providers, the hospice sector is considered to be at the forefront regarding support for carers of patients receiving end of life care. This report shows the current state of the sector, with recommended actions for improving carer assessment and support provision within hospices.

## Intended audience

This report is highly relevant to hospice provision, where family carers often play a pivotal role towards the end of life. The contents will enable organisational leads and practitioners in the hospice sector to consider survey findings in relation to their own organisation's support for carers, celebrate where they are doing well, and develop strategies to address the gaps where carer assessment and support could be improved. The report will also be particularly relevant to commissioners of hospice services.

## Definitions

**Family carers/carers:** We use the NICE definition: 'Carers, who may or may not be family members, are lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management.'

**Community-based services:** Hospice services delivered outside the hospice building – such as hospice at home and community specialist nurses.

**Day/outpatient care:** Hospice services provided within the hospice building (and other clinical settings, e.g. hospital clinics and care homes) for non-residential patients.

**End of life care:** Care delivered in the last year of life (NHS England definition).

**Family support:** Hospice services provided pre- and post-bereavement for family and carers of the patient.

**Inpatient unit:** Care provided to patients and their carers/families within the hospice on a residential basis.

**Person-centred care:** Care that is based on carers' or patients' own definition of their support needs and what would help them, as opposed to a process led by the practitioner.

# Foreword

We are living and dying in an era of an ageing population, multi-morbidity, long term conditions and rapidly changing political, social and economic times. Hospice and palliative care approaches and definitions are being revolutionised. Meanwhile the number of informal family carers in the UK is rising. They have their own needs as ‘co-workers’ (in supporting patients) as well as ‘clients’ in their own right.

I have been a nurse since 1986. But I have been an informal carer and co-worker (alongside my brother and sister) for 16 years – first at a distance, weekends and holidays, and then as a full-time one at home, hospital and nursing home. I am one of those millions of informal carers in the UK and over those years, I have been more visible as a co-worker than as a client in my own right.

And this matters... There are moments in my life which have taken my breath away, unforgettable, magical moments when your life changes forever: When I first met my husband, when I qualified as a nurse, when I got married and when my parents first saw our daughter.

There are other times when the breath is pushed out of you, unforgettable, terrifying moments when you know your life will change forever: When my father had his first stroke, when my mother was diagnosed with Alzheimer’s and when the years ahead as an informal carer stretched before me.

And then there are times when the breath is dragged out of you, unforgettable, unforgivable moments when your life has inextricably changed: When my mother could not remember the name of her husband, when I struggled to juggle money, time and logistics and every day I had to make the decision about whether to be a carer to my mother or mother to my daughter.

That is why this report from the University of Manchester, University of Cambridge and Hospice UK, alongside the previous **10 Recommendations for implementing comprehensive, person-centred assessment and support for family carers during end of life care** is so important.

It enables carers to be visible within health and care systems; validated as people who care as well as people who would benefit from care in their own right. Whilst the report looked at the current state of caring for family carers in UK hospices, it provides a methodological road map and action plan for seeing, assessing, planning and acting upon care for carers, relevant across all settings.

Many of us are or will know people who have been or will be carers. I am sure that I would have been a better carer, daughter, mother and wife if I had been assessed and seen as both a co-worker and client in my own right. I recommend this report to you.

**Dr Sarah Russell RGN, Carer, Daughter, Mother, Wife**  
**Admiral Nurse Professional and Practice Development Facilitator, Dementia UK**  
**Florence Nightingale Foundation Travel Scholar 2018**

# The Hospice UK 10 Recommendations

The Hospice UK 10 Recommendations that formed the basis for the Hospice UK Organisational Survey of Carer Assessment and Support (HUK-OSCAS) 2018 are presented in Table 1. The recommendations were developed in the first part of a Hospice UK consultation and survey project. The survey forms the second part.

**Table 1: Hospice UK 10 Recommendations for the provision of person-centred assessment and support for family carers towards the end of life**

<b>Foundation Recommendations</b>	
<b>Core requirements to facilitate carer assessment and support</b>	
<b>1</b>	<b>Consistent identification of carers within the care setting</b> To ensure services know who patients' main carers are in the first place.
<b>2</b>	<b>Demographic and contextual data on who the carer is and their situation</b> To aid communication with carers and awareness of their circumstances (e.g. full name, contact details, relationship to patient, particular issues).
<b>3</b>	<b>A protocol for assessing carers and responding to the assessment</b> To ensure there is consistent, comprehensive person-centred assessment of carers' support needs and consistent response.
<b>4</b>	<b>A recording system for carer information, separate from patient data</b> To ensure that information on carers is recorded in a defined location for record keeping and future reference (e.g. carer details, assessment outcomes, follow up actions).
<b>Implementation Recommendations</b>	
<b>Recommendations to support and sustain the implementation of carer assessment and support</b>	
<b>5</b>	<b>A process for training practitioners about carer assessment and support</b> To ensure staff are aware of protocols for carer assessment and support and confident about using them.
<b>6</b>	<b>Available time/workload capacity for carer assessment and support</b> To provide the time required to plan, implement and sustain carer assessment and support.
<b>7</b>	<b>Support from senior managers for carer assessment and support</b> To provide leadership and authority to make required changes and ensure dedicated time and capacity as required.
<b>8</b>	<b>Role models/champions for carer assessment and support</b> To provide the facilitation required within teams to embed carer assessment and support.
<b>9</b>	<b>Pathways for communication about carer assessment and support</b> To ensure common purpose and procedures, feedback of staff concerns to managers, shared problem solving and sharing of good practice.
<b>10</b>	<b>Procedures for monitoring/auditing processes and outcomes of carer assessment and support</b> To assess progress towards targets, enable review and communicate activity.

Reported in Ewing G and Grande GE. *Providing comprehensive, person-centred assessment and support for family carers towards the end of life: 10 recommendations for achieving organisational change*. London: Hospice UK, 2018.

The full report on the Hospice UK 10 Recommendations can be accessed at:

<https://www.hospiceuk.org/publications>



# Executive summary

The HUK-OSCAS survey aimed to assess provision of carer assessment and support in UK hospices providing services for adult patients in 2018: 57.5% of 200 hospices responded. Service provision was measured in the context of the Hospice **UK 10 Recommendations** (page 4) for ensuring **consistent and equitable access to comprehensive person-centred assessment and support for family carers**.

Findings can only be based on hospices' survey responses and can only 'scratch the surface'. When a recommendation was reported to be met, we cannot assess how consistently or in-depth this was done. For example, a hospice may have a process for formal assessment of carers, as recommended, but if this is only provided to a few carers in practice, then its benefit would be limited. Still, this is the first survey to give an indication of the state of carer assessment and support in UK hospices.

The survey shows that **only one in eight hospices reported having an organisational strategy specific to carers**. In most cases (67%) carers were included as part of the patient strategy. Whilst still valuable, this means that support for carers may always remain an afterthought that is omitted when resources are under pressure. Carer-specific strategies can enable hospices to specify and protect what they aim to do for carers and the resources required to achieve this. **We consider the formulation of a carer-specific strategy a vital first step in improving provision for carers**.

The **Hospice UK 10 Recommendations** (page 4) fall into two groups:

## 1. Foundation Recommendations:

core requirements to facilitate carer assessment and support.

## 2. Implementation Recommendations:

necessary to support and sustain the implementation of carer assessment and support.

## 1. Foundation Recommendations

### 1.1 Findings

#### **Consistent identification of carers (R1):**

most hospices (87%) had a process or protocol for identifying a patient's main carer. However, it would be important to assess how consistently this is being done (i.e. the proportion of all carers being identified).

#### **Recording of demographic and contextual carer data (R2):**

nearly all hospices (95%) collected some data on carers. However, findings also indicated that hospices may mainly record data as contact information in relation to the patient, as opposed to contextual data to understand the carer's situation.

#### **Recording system for carers, separate from patient data (R4):**

Only 18% of hospices always stored carer data separately from patient data, while 39% did so some of the time. Separate carer records for easy reference, access and retrieval are important to enable systematic identification, assessment and support for carers in their own right.

**Protocol for assessing carers and responding to the assessment (R3):** only 37% of hospices used formal assessment, 47% used informal assessment approaches, and 16% did not assess carers. Formal assessment tools used included both those that directly assess what carers need support with, and tools that only indicate that something is wrong, but not what support is required (e.g. measurement of burden). Informal assessment approaches may range from simply asking the carer how they are doing to more meaningful discussions about needs.

## 1.2 Points for Action for Foundation Recommendations

The high level of reported **identification** of carers and recording of carer data within hospices is very positive. However, it is important to **audit how consistently this is done**, and to **what extent the data recorded give staff meaningful information** about the carer's situation.

Very few hospices consistently recorded carer information separately from the patient. Hospices with **separate carer record options** should ensure these are **used consistently**, and **hospices that have no carer record should aim to establish one**.

The level of formal carer assessment was low. It will be **important to increase formal assessment**. It will also be important to **determine what constitutes an 'assessment'** for carers, including how it is recorded, **particularly for informal approaches** currently used, **as these may be inconsistent** and only involve asking 'how are you?'.

## 2. Implementation Recommendations

### 2.1 Findings

Hospices providing formal assessment were more likely to meet the Implementation Recommendations compared to those with informal or no assessment. Given that the survey was cross-sectional, we cannot say that providing formal assessment causes hospices to meet more Implementation

Recommendations, only that the two are related, and that hospices appear to fall into two groups.

Hospices providing formal assessment were more likely to:

- **train** their staff about carers (R5) (79% formal versus 31% not formal)
- include **carer support in job** descriptions (R6) (69% versus 46%)
- have **senior management** with a carer remit (R7) (83% versus 75%)
- have a **carer's champion** within their workforce (R8) (68% versus 49%)
- **communicate** updates around carers (R9) (81% versus 65%)
- **audit/monitor** their carer assessment and support (R10) (57% versus 11%).

### 2.2 Points for Action for Implementation Recommendations

The two groups of hospices lead us to propose two sets of points for action – the first for hospices providing formal assessment, and the second for those using informal approaches or no assessment.

#### Actions for hospices providing formal carer assessment and support

Hospices should further consider increasing **recording** of data on carer assessment and support, outcomes of assessments **for monitoring** progress, and where relevant, establish a **carer champion** and embed **carer support in job descriptions**.

It would further be important to **review current practices for assessment and support**, including the following:

- Does the assessment tool enable **comprehensive assessment** of support needs? Does it help identify what support should be put in place or just indicate that the carer has difficulties (e.g. is distressed, anxious, burdened) that then requires further assessment to indicate what support they need?

- Are there **clear procedures** in place for using the tool to assess carers' support needs and for responding to assessments?
- Is **training** in assessment and support of carers provided for all relevant staff? Is training provided at induction of all new staff? Is refresher training offered?
- Are all carers of patients in your hospice likely to be **offered the opportunity** to be assessed and supported **on an equal basis**?
- Are there **clear communication pathways** for sharing information about carer assessment and support (from management to staff; staff to management; and between staff) or do communication channels need to be established?

#### Actions for hospices not providing formal assessment and support needs

The main recommendation for these hospices is to consider if and how a **formal needs assessment process** might be achieved. With informal processes it can be difficult to define what constitutes an assessment, ensure consistency and equity for all carers, record and assess outcomes, and this may sometimes only involve asking 'how are you?'. Considerations would include the **type of formal tool** to be used and **who would assess and support carers**. It also would be important to review how this would be underpinned by consistent carer identification, information recording and carer records.

It would be important to further consider all the Foundation Recommendations (page 4) for implementation of comprehensive person-centred carer assessment and support:

- how to deliver **training** to relevant staff to assess and support carers
- ensuring **protected time** for completing and responding to assessments
- review or creation of **senior management** leadership roles for carer support
- review or creation of **champion roles** to drive implementation forward
- consideration of **communication** channels for carer information and updates
- how to best **monitor and audit** services provided.

#### Conclusion

The proposed action points in this HUK-OSCAS report are intended to support hospices to enhance their support for carers. With the emerging demographic challenges and the deficit of social and health resources, there is a real need now to identify, assess and support carers as a vital resource.

# Survey aims and methodology

## Background

Carers (family members/friends) provide vital, unpaid support to patients and are central to making care at home possible. With a projected national increase in number of deaths and more care being delivered at home, the role of carers becomes ever more critical. Hospices will need to respond to increases in demand, and their support of carers as key workers is likely to be an important part of meeting the challenges ahead.

Recent policy documents outlining ambitions for the future of end of life care consider family carers as a foundation that underpins their ambitions for patient provision. This implies that looking after family and friends who care for patients at the end of their lives is critical, but there is a sparsity of information and direction as to how this should be achieved. Formalising what is required to assess and support carers is therefore essential in improving support for this vital, unpaid workforce.

To inform this, the first stage of our project identified the building blocks required to embed carer assessment and support within healthcare organisations, presented in **10 recommendations for implementing comprehensive, person-centred assessment and support for family carers during end of life care.**

Here we report on the second stage of the project, which aimed to assess how well current hospice provision matches the 10 Recommendations and identify any gaps. This was done in the form of a Hospice UK Organisational Survey of Carer Assessment and Support (HUK-OSCAS).

The 10 Recommendations on which the survey was based are summarised on page 4. The first four are **Foundation Recommendations**: core requirements to facilitate carer assessment and support. These recommendations comprise carer identification,

recording of key carer data, a process for formal needs assessment and responding to that assessment, and recording system for carer information separate from patient data.

The remaining six recommendations are **Implementation Recommendations**: actions required to support and sustain carer support within hospices in practice. These recommendations cover staff training, workload capacity, senior management support, provision of carers' champions within hospice staff, regular communication around carer support, and the auditing and monitoring of carer services.

## Survey methodology

HUK-OSCAS was a postal survey sent to hospices within Hospice UK's membership, limited to those providing services for adult patients. One response was sought on behalf of each organisation. Surveys were completed by one or more staff members in each responding hospice. Study packs and reminders for non-responding organisations were sent out between March and June 2018. After this time non-responding hospices were contacted by telephone to request they complete a shortened version of the survey. This shortened survey included 10 questions – one for each recommendation.



## Survey contents

The postal survey questions included:

- general service details (e.g., hospice services provided)
- overall approach to carers (e.g. overall strategy for carers, carer services provided)
- provision related to each recommendation.

## Survey responses

We identified 200 eligible organisations for participation in the study. Of these, 100 provided responses to the full survey. An additional 15 hospices completed the shortened survey over the telephone. Therefore, we received an overall response rate of 57.5%.

Number of respondents for each question will vary depending on whether the organisation responded to the full or shortened survey, and additionally on the number of organisations that chose to skip individual questions. For clarification, we therefore report number of respondents for each question in our findings.

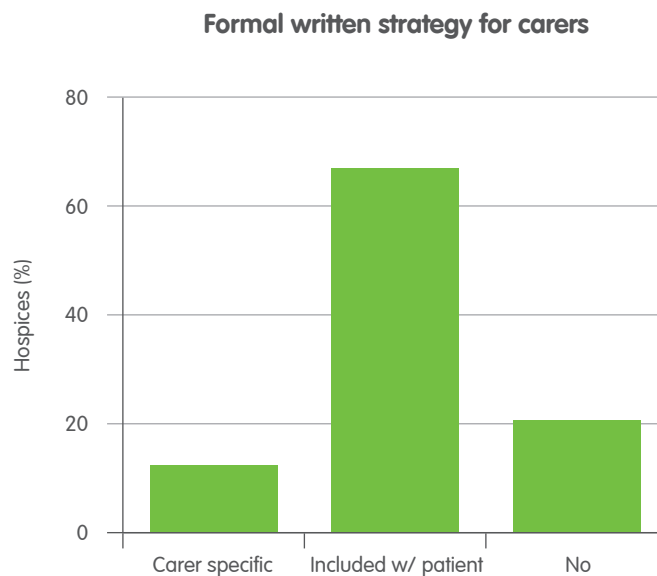
# Results: Responding hospices and general service details

## Survey responders

By country, we received 97 responses from England (58% of all eligible hospices in England), 8 from Scotland (53%), 7 from Wales (50%) and 3 from Northern Ireland (75%).

Of the 100 hospices responding, 93% offered family support, 91% day/outpatient care, 83% inpatient care and 82% community-based services. 63% hospices offered all service categories.

**Figure 1: Approach to provision of formal written strategy for carers (%) by responding hospices (n=96)**



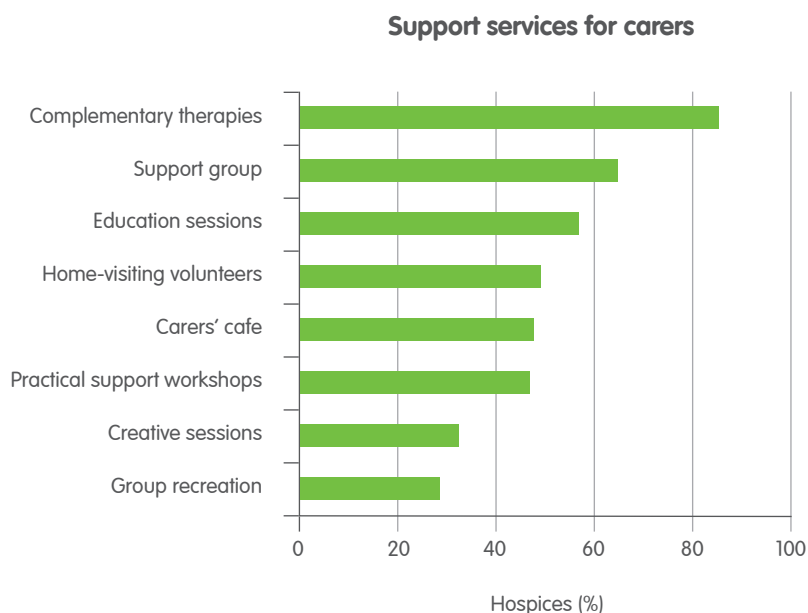
## Overall approach to carer support

As an indication of their overall approach to carers, hospices were asked whether they had a formal written strategy specific for carers. Carer-specific strategies were relatively rare, with 12 of 96 (13%) hospices stating they had this (Figure 1). Carers were most likely to be included within the patient strategy, with 64 hospices (67%) reporting this. 20 hospices (21%) had no strategy for carers.

## Services for carers

Hospices often provide a range of services for carers (Figure 2). Complementary therapies were most frequently provided, with 86% of responding hospices reporting this. Support groups (64%) and education sessions (57%) were also frequently offered. From the options provided, hospices were least likely to provide group recreation, such as walking groups (29%), and creative sessions, for example art and music therapy (33%).

**Figure 2: Provision of support services (%) by responding hospices (n=100)**



# Recommendation 1

## Consistent identification of carers within the care setting

### Rationale

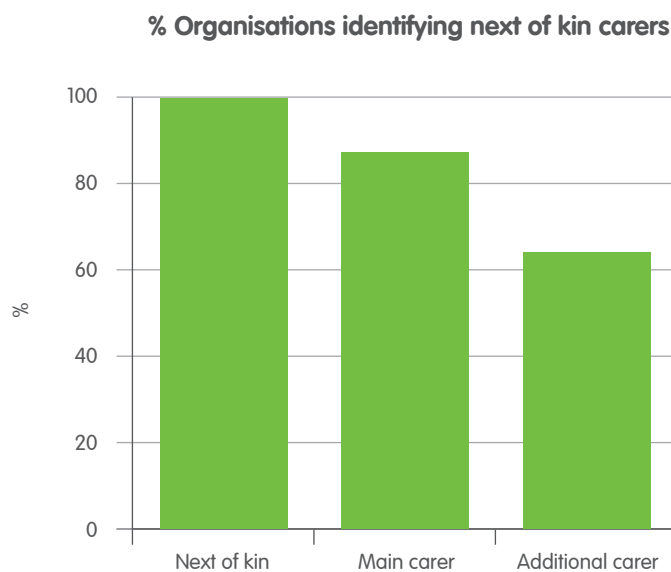
This is the essential first step in facilitating robust services for carers: routinely identifying all of those who may be in need of carer assessment and support. Consistent identification of carers is important for ensuring equity for carers: that every carer an opportunity to access assessment and support within hospices.

### Survey findings

Ninety-nine per cent (99 of 100) of hospices reported routinely identifying next of kin when patients first accessed their services (Figure 3).

Eighty-seven per cent of responding hospices reported having a process or protocol for identifying main carers (100 of 115). By comparison only 64% (64 of 100) reported a protocol/process for identifying additional carers (i.e., those contributing to caring for the patient, but to a lesser degree than the main carer).

**Figure 3: Identification of next of kin (n=100), main carers (n=115) and additional carers (n=100) across responding hospices**



### Key messages

- Most hospices have processes in place for identifying main carers.
- This should serve as the beginning of a record for the carer as someone to be supported in their own right.
- Hospices should consider why they currently identify main carers – is it as the beginning of a process for their possible assessment and support, or primarily to gather emergency contact details for the patient?



# Recommendation **2**

## Demographic and contextual data on who the carer is and their situation

### Rationale

To provide the best support for carers, practitioners should have key data about them readily available. This would include demographic information, and contextual details about the carer's situation, such as whether they have other caring responsibilities and any health issues of their own they may be facing. Carer data should be accessible to practitioners so that records can be easily updated after engagement with hospice staff, akin to that of a patient record. This can also help prevent duplication of work, such as multiple staff broaching an initial assessment of the carer.

### Survey findings

Ninety-five per cent (109 of 115) of hospices reported collecting some data on carers, the highest reported recommendation overall (Figure 4). In terms of the types of data collected, we found that the 94 responding hospices were more likely to collect contact information on the carer's name, telephone number and relationship to patient than contextual information on carer's age, where they lived and role in caregiving (Figure 5).

**Figure 4: % of responding hospices reporting the collection of data on carers**

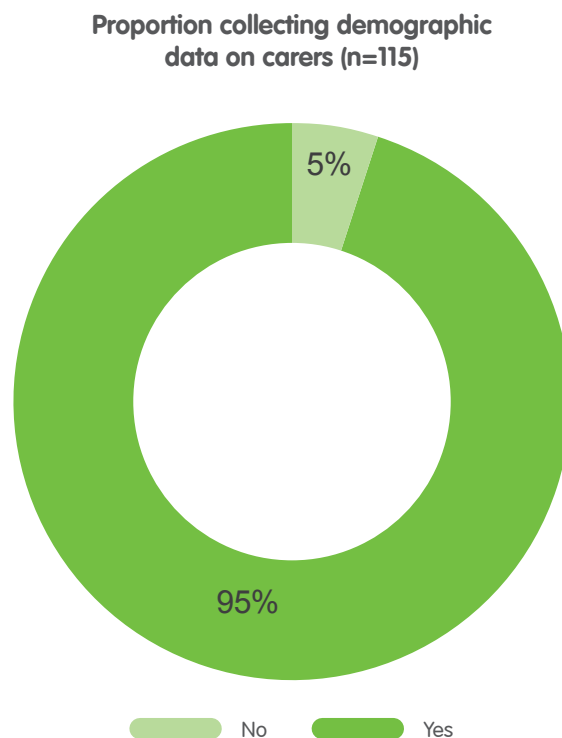
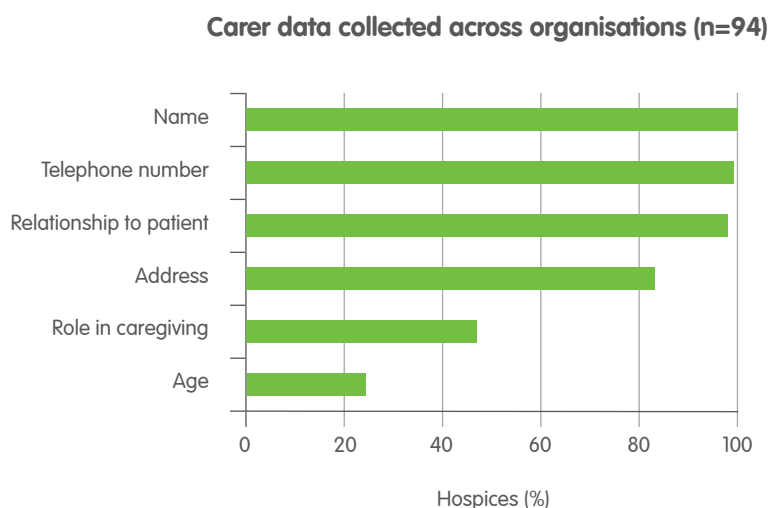


Figure 5: Key carer data collected by hospices (%)



### Key messages

- Most hospices do collect data on carers – an important early step in the process.
- Hospices should reflect on whether carer data are collected as contact information for the patient, or for the carer as a service user in their own right.
- This is strongly related to recommendation four, which considers the storage of these data.

## Recommendation

### 3

## A protocol for assessing carers and responding to the assessment

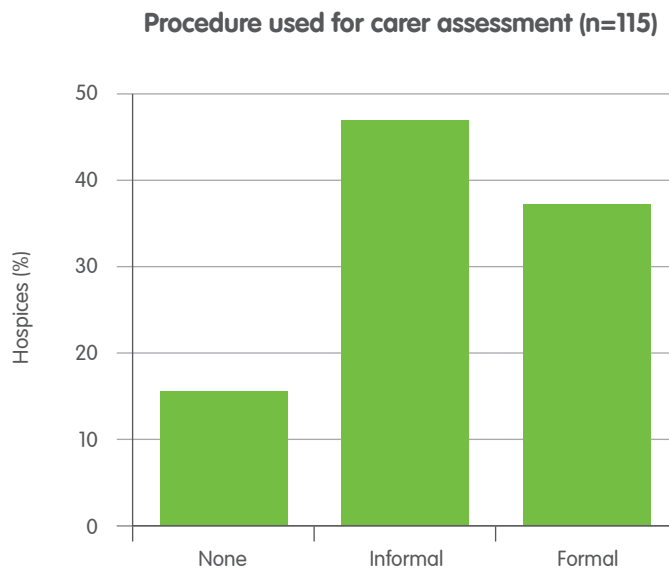
### Rationale

Recommendation three highlights the need for a protocol to establish common, standardised practices for carer assessment. Informal assessment processes might include asking a carer how they are with no further action or the carer being aware that they are being assessed. This may lead to an inconsistent approach, with resulting support being patchy, selective or ineffective. Therefore, to provide the best support for carers, a consistent assessment process using a formal, evidence-based needs assessment tool is recommended, underpinned by a protocol that ensures all carers have an equal chance of offer of assessment.

## Survey findings

To assess the formality of approach to carer assessment, we asked hospices if they provided assessment using a formal tool, informal assessment, or no assessment. Fifty-four of 115 hospices (47%) reported using informal approaches, and 16% (18 of 115) stated that they did not offer carer assessment (Figure 6). The rest, 37% (43 of 115) of hospices reported using a formal assessment tool. Thirty-four provided details of the formal assessment tool used. Some tools directly assessed what support carers needed: the Carer Support Needs Assessment Tool (CSNAT) (n=24); local authority assessment tools (n=3). Other tools indicated whether there is a problem, but without identifying the support required: Zarit burden interview (n=3), Distress Thermometer (n=2), Adult Attitude to Grief Scale (n=2). Three used unspecified in-house tools (n=3).

**Figure 6: Carer assessment procedure used by participating hospices (%)**



### Key messages

- Just over a third of hospices reported using formal carer assessment.
- Hospices providing formal assessment should review 1) to what extent offers of assessment are consistent and equitable; 2) whether tools used provide direct assessment of the support carers need or only indirect indication of problems.
- Hospices using informal approaches to carer assessment or no assessment, should review the feasibility of introducing a formal needs assessment process.

# Recommendation 4

## A recording system for carers, separate from patient data

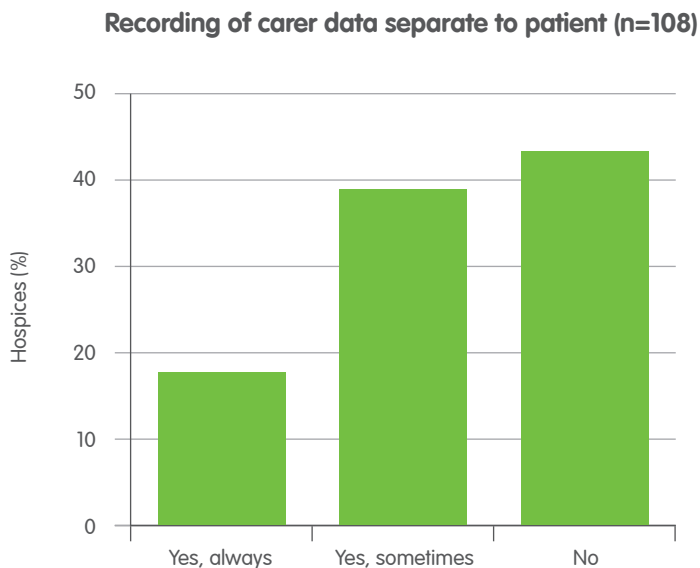
### Rationale

To ensure the carer's position as a person to be supported in their own right, they should have their own record, stored separately from the patient record. This should make carer information more accessible for record keeping, future reference, including monitoring of follow up actions from assessment, and allow staff from across the hospice to be quickly appraised of the carer's situation without duplicating work.

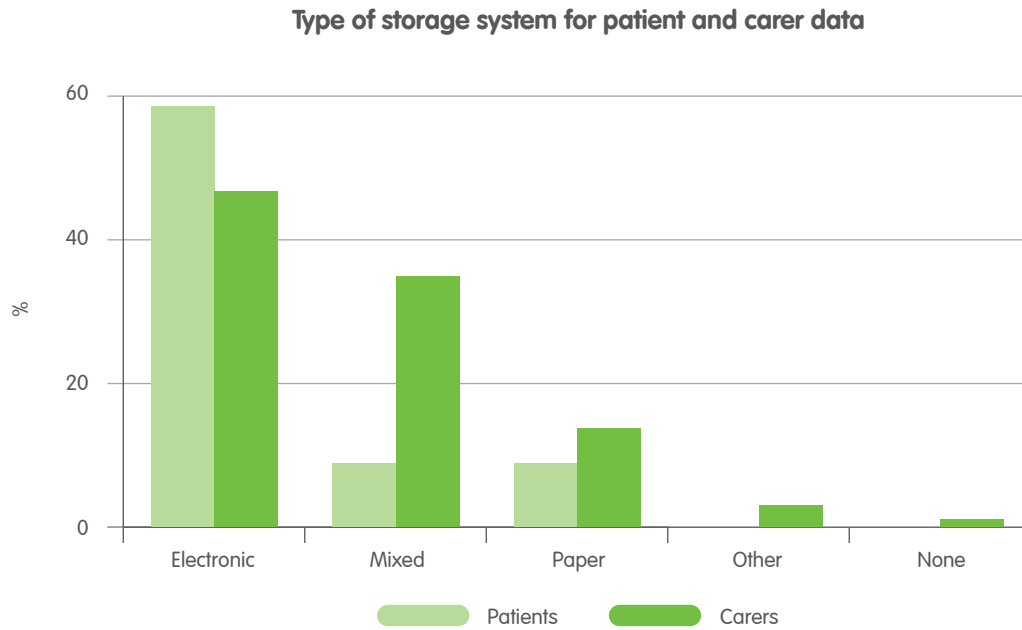
### Survey findings

Overall, 61 of the 108 hospices (57%) that reported collecting carer data, stored carer data separately to patients (Figure 7). However, only 19 hospices (18%) reported doing this all of the time, with 42 (39%) doing this some of the time. Sixty-one of 100 (61%) reported sharing data between services routinely, with a further 33 doing this some of the time (33%). Only 6 hospices reported that they did not share carer data between services. Carer records were less likely to be stored electronically than patient records, with a higher proportion of carer records being stored using mixed or paper-only systems (Figure 8).

**Figure 7: Hospices by current practice of storing carer records**



**Figure 8: Storage systems used by responding hospices for i) patient and ii) carers**



### Key messages

- A low proportion of hospices reported regularly storing carer data separately to patient data, with 43% not doing this at all.
- Many hospices use inconsistent systems for storage and may wish to review processes in order to develop uniform processes.
- Further exploration with hospices that are safely creating electronic carer records would be valuable to understand their protocols for confidentiality and access.

# Recommendation 5

## A process for training practitioners about carer assessment and support

### Rationale

To deliver carer support confidently, consistently and effectively, staff should be appropriately trained, particularly when using formal needs assessment processes. Training for new staff and refresher training sessions are also important to maintain competency and consistency in assessment processes.

### Survey findings

Fifty-six of 115 hospices (49%) stated that they trained staff in carer assessment and support (Figure 9). Hospices providing formal assessment were most likely to train their staff, with 79% (34 of 43) reporting this. By comparison, training was only offered by 37% (20 of 54) of hospices offering informal assessment and 11% (2 of 18) of hospices who said they offered no assessment.

Social workers, social work assistants and nurses were most likely to be trained in carer assessment and support (Figure 10).

Most hospices provided one-off training as opposed to refresher training. Thirty-three of 41 responding hospices (81%) trained their staff once, whilst 13 of 16 (81%) trained volunteers once.

**Figure 9: Provision of training (%) in carer assessment report in responding hospices**

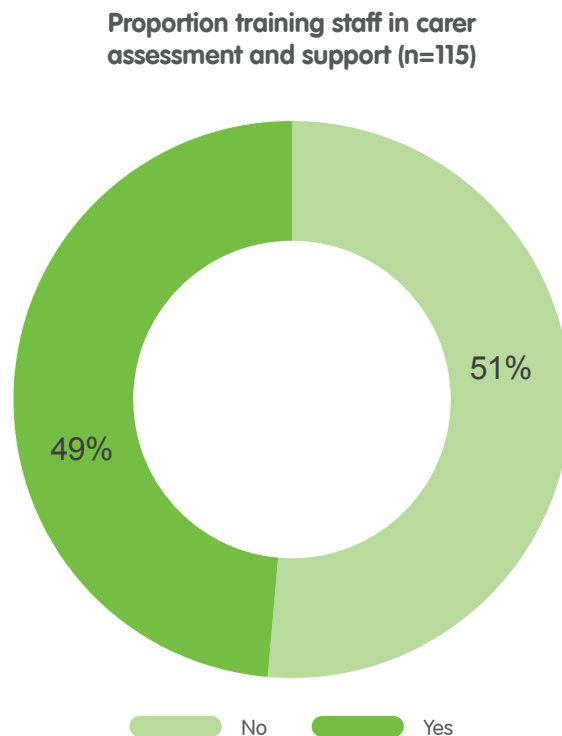
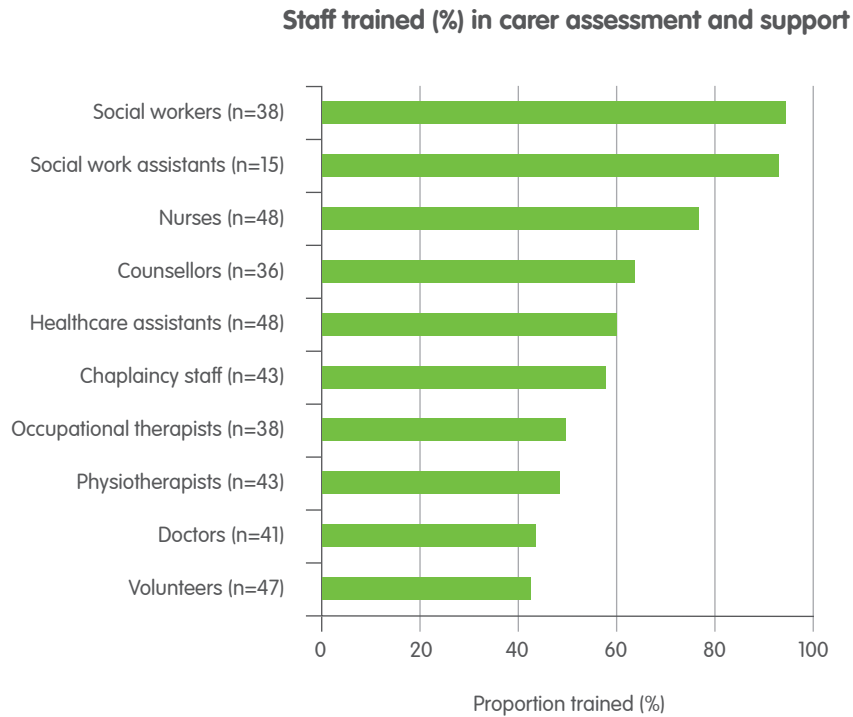


Figure 10: Training in carer assessment and support by job role (%)



### Key messages

- Less than half of hospices were training staff in carer assessment and support.
- Refresher training is crucial for maintaining competency, but is not commonplace.
- For hospices providing or implementing formal carer assessment, staff training in assessments is an important step.
- For hospices not offering formal assessment, some training to raise awareness about carers' needs and concerns is essential.

# Recommendation **6**

## Available time/workload capacity for carer assessment and support

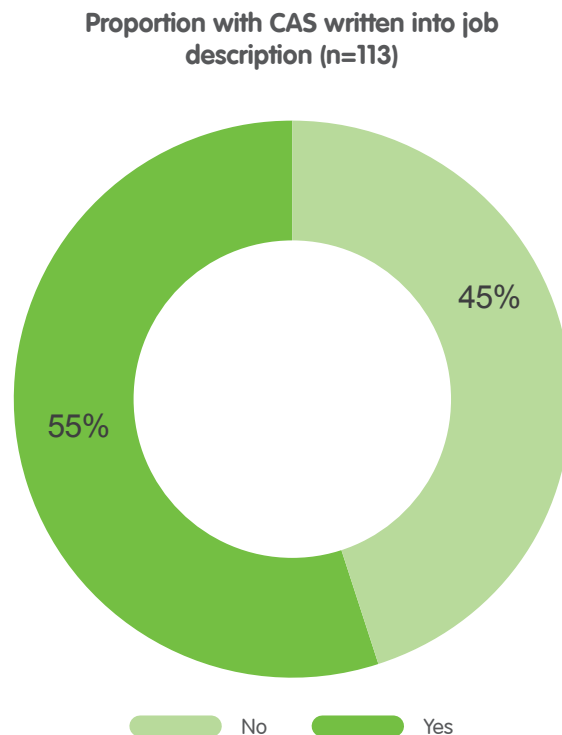
### Rationale

To implement carer support as part of everyday practice, it is important that relevant staff have protected time to complete this work. Formalising assessment and support of carers as part of routine duties requires its inclusion in job descriptions where applicable.

### Survey findings

Sixty-two of 113 (55%) hospices stated that staff had carer assessment and support written into job descriptions (Figure 11). Hospices implementing formal assessment were most likely report this (29 of 42, 69%), compared to those using informal processes (29 of 53, 55%) and those offering no carer assessment (4 of 18, 22%).

**Figure 11: Hospices (%) with carer assessment and support written into job descriptions**



### Key messages

- If staff do not have capacity for carer assessment, it may be less likely to be routinely offered/become part of everyday practice.
- The inclusion of carer support in job descriptions is an important initial action, but is meaningful only if it translates into capacity, competency and activity for completing carer assessment and support.



# Recommendation 7

## Support from senior managers for carer assessment and support

### Rationale

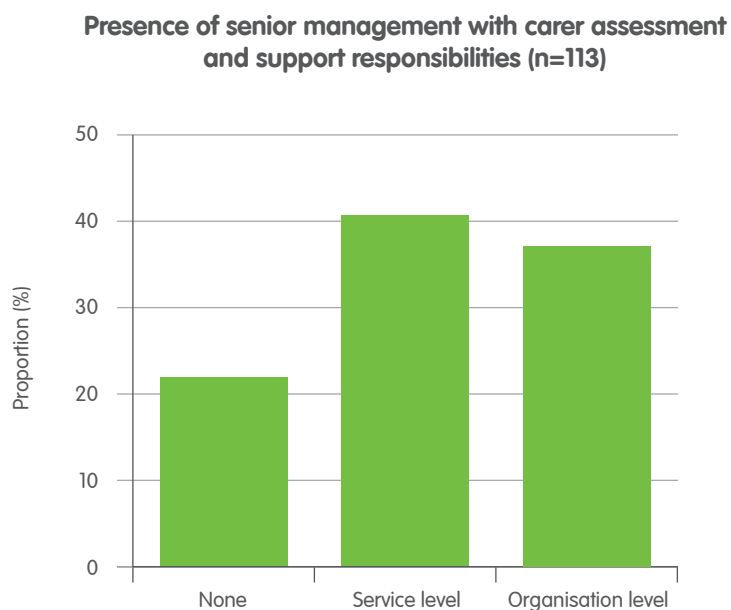
Senior management commitment to providing carer assessment and support – either across the whole hospice or at service-level – is required to implement and sustain carer support across services.

### Survey findings

Most hospices reported having senior management with a remit for carers, with 41% (46 of 113) having this at service-level, and a further 37% (42 of 113) organisation-wide (Figure 12).

Services offering no formal assessment were least likely to report senior management with a carer remit (8 of 18 hospices).

**Figure 12: Reported presence of senior management with carer remit in responding hospices**



### Key messages

- Senior management support for carer assessment and support was widely reported – the highest of the implementation group of recommendations.
- Senior management support for carer assessment varies amongst hospices, and the remit and responsibility of carer-focused managers should be regularly reviewed.

# Recommendation 8

## Role models/champions for carer assessment and support

### Rationale

In addition to having senior management support, this recommendation highlights the importance of having front-line carers' champions with a remit to improve support for carers. The value of carers' champions for carer assessment and support is that, as frontline staff, they are credible practitioners who can create a positive culture around carer provision, cascade training and provide exemplars for practice, problem solving and peer support.

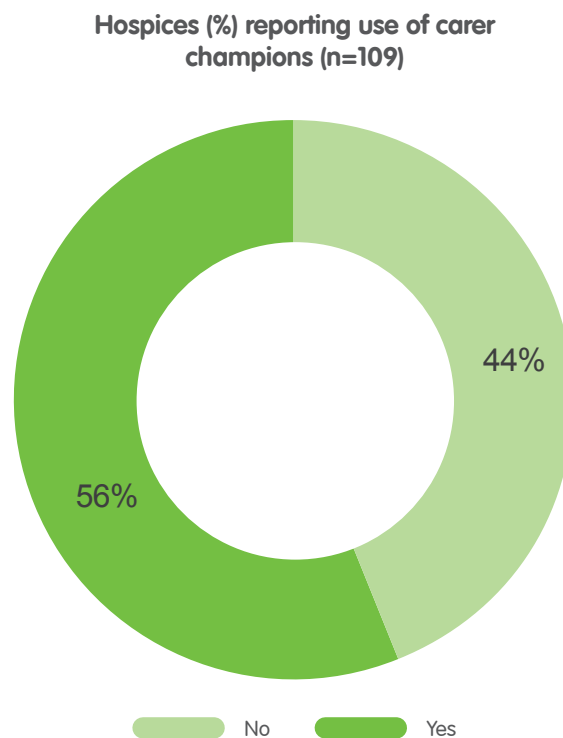
### Survey findings

Sixty-one of 109 responding hospices (56%) reported having carers' champions, in some form, within their staff (Figure 13).

As with the other recommendations in this implementation category, those providing formal assessment were most likely to report meeting this recommendation. Twenty-eight of 41 hospices providing formal assessment (68%) said they had carers' champions, compared to 29 of 51 (57%) hospices using informal approaches and 4 of 17 (24%) hospices providing no assessment.

Hospices were more likely to have a senior manager with a carer's remit (78%, see previous recommendation) than carer's champions (56%).

**Figure 13: Use of carer champions (%) across participating hospices**



## Key messages

- Overall hospices are more likely to have senior management with a remit for carers than carers' champions. This suggests that carer support is potentially more likely to be 'top-down' than 'bottom-up' amongst our responding hospices, whereas a balance of both is needed.
- Those without formally appointed carers' champions could consider if people within their organisation are already fulfilling these roles – in part or wholly – but are not currently labelled as carers' champions.
- Where this role does not exist at all, hospices should consider whether to create a champion role and how best to implement it.
- Investment in a formal hospice champion role rather than sole reliance on individual enthusiasm is likely to ensure greater continuity when staff move on.

# Recommendation

## Pathways for communication about carer assessment and support

### Rationale

Pathways for communication about carer assessment and support ensure common purpose and procedures, feedback of practitioners concerns to managers and sharing of good practice. This requires two-way communication between managers and practitioners, and between and within practitioner teams, for instance at regular staff and care governance meetings.

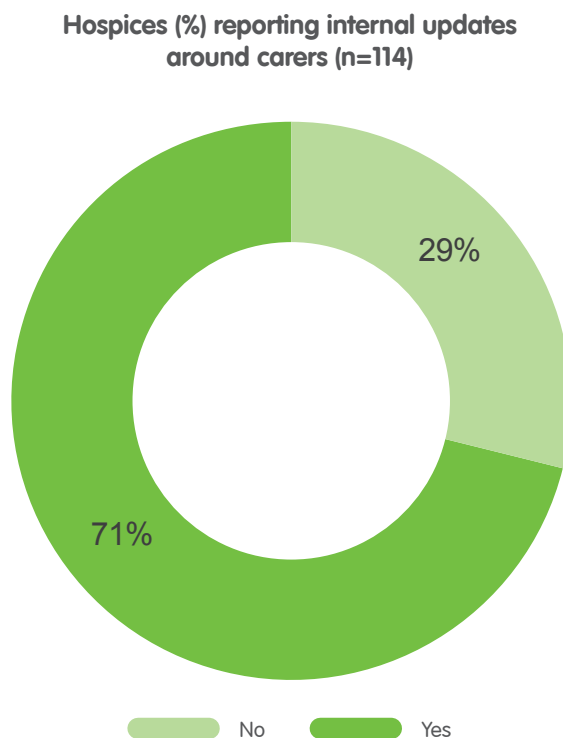
### Survey findings

Communication was commonplace amongst hospices participating in the survey, with 81 of 114 (71%) stating that this happened in their organisations (Figure 14).

Ninety-nine hospices detailed the direction of communication in their organisations. Forty-three (43%) reported two-way communication around carers, 17 (17%) reported top-down (management/leads to staff) communication only, and 6 (6%) reported bottom-up (staff to management/leads) only. Thirty-three (33%) reported no communication pathways around carers.

Feedback from service users (i.e, the carers) is also vital when designing and evaluating services. Eighty-three of 97 hospices (86%) reported having processes for carers to give feedback on services, suggesting that this is commonplace.

Figure 14: Provision of updates around carers (%) in responding hospices



### Key messages

- Communication around carers occurs in the majority of hospices. The frequency and nature of communication varies between organisations.
- A strategy for communication around carers should form part of organisational action plans to formalise where, when and via which method(s) this communication should occur.
- Where communication either does not happen or occurs only one way, this process should be reviewed to encourage consistent two-way communication in the future.
- Carer feedback is an important part of evaluation both of general care and carer support and should inform reviews of existing practice and improvements.

# Recommendation 10

## Procedures for monitoring/auditing processes and outcomes of carer assessment and support

### Rationale

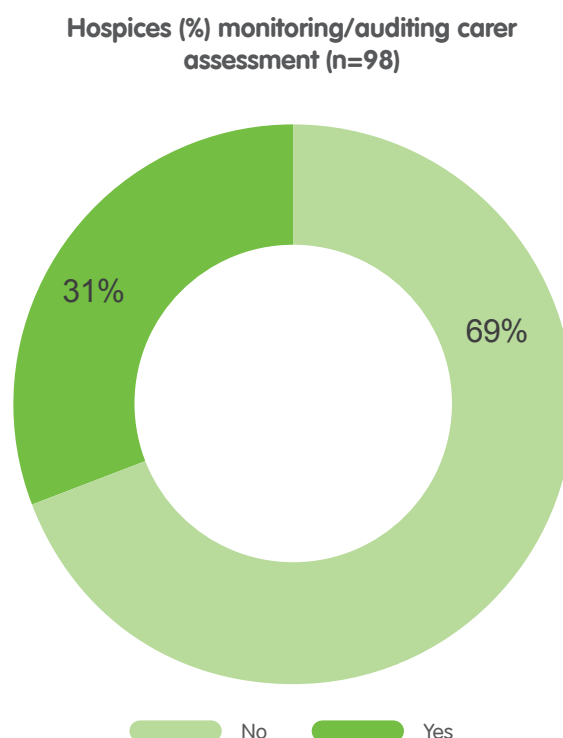
Hospice carer services should be regularly evaluated to assess whether they are appropriate and effective in meeting their goals in relation to carers. Processes for monitoring and auditing carer support services enable a measurement of progress towards targets (such as the proportion of carers undergoing a full needs assessment process out of overall number of carers), identifying problems and highlighting areas for future service development. This also provides hospices with the opportunity to demonstrate the impact of the work they currently do and highlight where added service provision is required, which can be crucial when applying for external funding.

### Survey findings

Of all recommendations, the monitoring/auditing of carer assessment and support was being met by the lowest number of participating hospices, with 30 of 98 stating that they did this (31%). Hospices providing formal assessment were most likely to monitor/audit processes and outcomes, with 24 of 42 (57%) hospices reporting this compared to 6 of 53 (11%) hospices using informal approaches to support carers (Figure 15). We also enquired about types of data collected.

Of the services that did undertake monitoring/ audit, most collected data on number of carers seen (21 of 24 hospices; 81%); but some also considered details of support given (14; 54%) or details of identified need (13; 50%).

**Figure 15: Monitoring/auditing of carer support processes and outcomes (%) in responding hospices**



## Key messages

- The relatively low rate of monitoring/auditing of carer services indicates that many hospices are missing an opportunity to assess and demonstrate the activity and benefits of the work they provide for carers. This could impact on the perceived value of current provision.
- Evidencing carer support can also be important for regulatory inspections (e.g., the five key questions asked by Care Quality Commission during inspections).
- Appropriate planning of future services relies on evidence (such as data on unmet need) to support decision-making.
- Analysis of formal assessments of carer support needs could provide a wealth of data into key carer concerns for organisations.

# Ongoing support and practice development

As a result of both this report and the report **Providing comprehensive, person-centred assessment and support for family carers towards the end of life**, Hospice UK will facilitate the development of:

- A peer support network to share good practice through a carers 'Community of Practice' facilitated via Project ECHO.
- An annual learning event at Hospice UK for the Carers Community of Practice.

- Dissemination of the report via:
  - » Executive Clinical Leads in Hospice and Palliative Care (ECLiHP)
  - » ehospice: an international collaboration between several national and regional palliative care organisations, each of which manages an edition covering their country or region. Hospice UK publishes the UK edition – <https://ehospice.com/uk>
  - » Hospice Leaders Briefing
  - » Hospice UK website

# Further reading

- Ewing G & Grande G (2018) Providing comprehensive, person-centred assessment and support for family carers towards the end of life 10 recommendations for achieving organisational change. Hospice UK Available at: <https://www.hospiceuk.org/publications>
- Carer Support Needs Assessment Tool: <http://csnat.org/>
- National Institute for Health and Care Excellence (2019) *End of life care for adults: service delivery*. [NICE guideline, NG142]. NICE Available at: <https://www.nice.org.uk/guidance/ng142>
- Payne S & Morbey H (2013) *Supporting family carers: report on the evidence of how to work with and support family carers to inform the work of the Commission into the Future of Hospice Care*. London: Help the Hospices Available from: <https://www.hospiceuk.org/publications>
- Penny A (2019) *Care after caring: supporting family carers facing and following bereavement*. National Bereavement Alliance Available from: <https://nationalbereavementalliance.org.uk/ourpublications/care-after-caring/>

## End of Life Care Strategies for the UK Nations

- Scottish Government (2015) *Strategic framework for action on palliative and end of life care: 2016-2021*. Edinburgh: Scottish Government Available at: <https://www.gov.scot/publications/strategic-framework-action-palliative-end-life-care/>
- Welsh Government (2017) *Palliative and end of life care delivery plan*. Welsh Government Available from: <https://gov.wales/palliative-and-end-life-care-delivery-plan-2017>
- Northern Ireland Government (2010) *Living Matters Dying Matters A Palliative and End of Life Care Strategy for Adults in Northern*

*Ireland* Department of Health, Social Services and Public Safety Available at: <https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/living-matters-dying-matters-strategy-2010.pdf>

- English Government (2015) *Ambitions for Palliative and End of Life Care* The National Palliative and End of Life Care Partnership Available at: <http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf>

**eHospice** <https://ehospice.com/uk>

ehospice is an online news resource publishing the latest news, commentary and analysis on hospice, palliative and end of life care and is intended for anyone with a professional or personal interest in these subjects.

ehospice brings together the global hospice and palliative care community to share good practice and innovation, with the aim of helping to improve care around the world. It is an international collaboration between several national and regional palliative care organisations, each of which manages an edition covering their country or region. Hospice UK publishes the UK edition (<https://ehospice.com/uk>). The resource contains a number of articles on carers which can be found by searching for the word 'carers' within the website, for example:

[https://ehospice.com/uk\\_posts/phyllis-tuckwell-hospice-care-launches-carers-charter/](https://ehospice.com/uk_posts/phyllis-tuckwell-hospice-care-launches-carers-charter/)

[https://ehospice.com/uk\\_posts/hospice-launches-fundraising-campaign-to-train-local-carers/](https://ehospice.com/uk_posts/hospice-launches-fundraising-campaign-to-train-local-carers/)

[https://ehospice.com/uk\\_posts/new-report-launches-to-support-family-carers-facing-bereavement/](https://ehospice.com/uk_posts/new-report-launches-to-support-family-carers-facing-bereavement/)

[https://ehospice.com/uk\\_posts/hospice-launches-respite-service-for-carers/](https://ehospice.com/uk_posts/hospice-launches-respite-service-for-carers/)



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